



UMEÅ UNIVERSITY

COPD in primary care

Exploring conditions for implementation of
evidence-based interventions and eHealth

Sara Lundell

Department of Community Medicine and Rehabilitation,
Physiotherapy
Department of Radiation Sciences,
Radiation Physics and Biomedical Engineering
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To my beloved family



*The world cannot be understood without numbers.
But the world cannot be understood with numbers alone.*

Hans Rosling (1948-2017)

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Abstract

Chronic obstructive pulmonary disease (COPD) is a major public health problem. Symptoms and comorbidities associated with COPD affect the whole body. Clinical guidelines for COPD recommend pulmonary rehabilitation (PR) including exercise training and education promoting self-management strategies. Despite the positive effects on health status, few people with COPD have access to PR. Electronic health (eHealth) has been seen as promising for increased access to evidence-based interventions. To increase the likelihood of a successful implementation, it is important to identify enablers and barriers that might affect implementation outcomes. The aim of this thesis is to explore the experiences, interactions and contexts of the management of COPD in primary care, as well as the design, experienced relevance, effect and expected usefulness of eHealth solutions.

The thesis is based on four papers that have used qualitative, quantitative and mixed methods. Qualitative interviews (papers I, II, IV) and focus group discussions (paper IV) were analysed using qualitative content analysis (papers I, IV) and grounded theory (paper II). Quantitative data, collected using questionnaires (paper I) and in a systematic review (paper III) was analysed with descriptive statistics (paper I) and meta-analysis (paper III). The qualitative and quantitative findings in paper I and II were merged in a mixed methods design. Participants in the studies included healthcare professionals (papers I, IV), people with COPD (papers II, III, IV), their relatives (paper IV), senior managers representing primary care centres (paper I), and external researchers (paper IV).

The findings in this thesis gave insight in the complex interactions within COPD management between the healthcare organisation (e.g. resources and priority), healthcare professionals (e.g. attitudes, collaboration and competence) and people with COPD (e.g. emotions, attitudes and coping). The healthcare organisation is fragmented with few resources and COPD care takes low priority. The healthcare professionals are *Building COPD care on shaky ground* (paper I), where the shaky ground is a presentation of the non-compliant organisation and other challenging circumstances. Driven, responsible and ambitious healthcare professionals wish to provide empowering COPD interventions through interprofessional collaboration, but are inhibited by their limited knowledge of and experience with COPD. People with COPD are *(Re)acting in an ambiguous interaction* with primary care providers (paper II), have limited knowledge and struggle with stigma, while they try to accept and manage their disease. The attitudes and support of healthcare professionals' are essential for necessary interaction and self-management strategies. For people with COPD, this can take

different paths: either *enhancing confidence with empowering support* or *coping with disempowering stigma and threat*.

eHealth solutions such as telehealth, have been used to provide interventions to people with COPD through phone calls, websites or mobile phones, in combination with exercise training and/or education. They show a significant effect on physical activity level, but not on physical capacity and dyspnoea (paper III). Healthcare professionals, people with COPD and their relatives, and external researchers report that, to be useful and relevant in clinical practice, an eHealth tool should be *reinforcing existing support structures* (paper IV). Furthermore, it needs to fit in the current routines and contexts and create a sense of commitment in its users. According to the participants, information about self-management strategies, such as how-to videos are valuable, and need to help them identify themselves with the people in the videos. The participants regard eHealth as providing knowledge and support for self-management.

In conclusion, there is a need for implementation of clinical guidelines for COPD in primary care in order to improve both the management of COPD, as well as the interaction between healthcare professionals and people with COPD. Several actions are needed to facilitate this implementation. The priority and status of COPD management in primary care need to be raised. In addition, more resources (e.g. healthcare professionals) for COPD interventions is required to enhance the conditions for interprofessional collaboration and patient participation. Furthermore, it is important to include physiotherapists in COPD management, considering the focus on exercise training and physical activity. Healthcare professionals in primary care need further training and more time to educate and empower people who have COPD. The use of eHealth may lead to improvements in patient outcomes, although more research on web-based interventions is required. User involvement in the development process of an eHealth tool increases its usefulness and relevance in clinical practice and everyday life. The findings from this thesis may guide implementation processes in primary care, as well as the development of eHealth tools for people with COPD or other long-term conditions.

Abbreviations

6MWT	Six minute walk test
BMI	Body mass index
C	Comparator
CAT	COPD Assessment test
CI	Confidence interval
CMA	Comprehensive Meta-Analysis
COPD	Chronic obstructive pulmonary disease
CRQ-D	Chronic Respiratory Questionnaire, Dyspnoea subscale
eHEALTH	Electronic health
FEV ₁	Forced expiratory volume in 1 s
FGD	Focus group discussion
FVC	Forced vital capacity
GOLD	Global Initiative for Chronic Obstructive Lung Disease
ICT	Information and communication technologies
i-PARIHS	Integrated-Promoting Action on Research Implementation of Health Services
MD	Mean difference
mMRC	Modified Medical Research Council
MRC	Medical Research Council
PARIHS	Promoting Action on Research Implementation of Health Services
PR	Pulmonary rehabilitation
SD	Standard deviation
SMD	Standardised mean difference
SOBQ	Shortness of Breath Questionnaire
TH	Telehealth
WHO	World Health Organization

Enkel sammanfattning på svenska

Kroniskt obstruktiv lungsjukdom (KOL) är en av våra vanligaste folksjukdomar. Sjukdomen orsakar mycket lidande hos de drabbade och ger mycket kostnader för samhället. Det vanligaste symtomet vid KOL är andnöd, men även andra delar av kroppen blir drabbade. Nedsatt fysisk förmåga, viktnedgång och depression är några vanliga symtom. Nedsatt fysisk aktivitetsnivå är också vanligt, vilket är särdeles allvarligt eftersom det kan förutsäga risk för tidig död. Tidigare forskning har visat att lungrehabilitering ger många positiva hälsoeffekter hos personer med KOL. Lungrehabilitering innehåller fysisk träning och utbildning med syfte att lära sig hantera sin sjukdom. Lungrehabilitering rekommenderas i behandlingsriktlinjer för KOL. Men trots det är det få personer med KOL som får tillgång till detta. Därför är det viktigt att hitta sätt att nå ut till personer med KOL med effektiv behandling. Elektronisk hälsa (eHälsa) har föreslagits som en strategi. eHälsa handlar om vård på distans, till exempel att få information och stöd via internet. För att kunna implementera nya arbetssätt i hälso- och sjukvården är det viktigt att känna till vilka förutsättningar som finns i dagsläget.

Avhandlingen baseras på fyra delstudier. Syftet är att utforska upplevelser, interaktion och kontext kopplat till KOL-vården i primärvården. Dessutom, att utforska design och effekt av eHälsa-lösningar, samt hur användarna upplever dess relevans och vad de förväntar sig för nytta vid användning av ett eHälsaverktyg. Individuella intervjuer och diskussioner i fokusgrupper genomfördes med personer med KOL, anhöriga, sjukvårdspersonal samt forskare. Utskrifter från intervjuer och diskussioner analyserades med kvalitativ innehållsanalys och grundad teori. Frågeformulär besvarades av sjukvårdspersonal och verksamhetschefer i primärvården och analyserades sedan med beskrivande statistik. Tidigare forskningsstudier om eHälsa samlades ihop i en systematisk forskningssammanställning och analyserades gemensamt i en metaanalys. Resultaten från analyser av individuella intervjuer och svar från frågeformulär från två av delstudierna har dessutom sammanfogats i en mixad metod.

Resultaten i den här avhandlingen ger insikter kring komplexa interaktioner inom KOL-vården, mellan sjukvårdsorganisationen (t.ex. resurser och prioritering), sjukvårdspersonal (t.ex. attityder, samarbete och kompetens) och personer med KOL (t.ex. känslor, attityder och hantering av sjukdom). Sjukvårdsorganisationen kännetecknas av ett splittrat och otydligt ansvar mellan olika delar i organisationen samt brist på resurser. KOL-vården är dessutom lågt prioriterad och präglas av bristfälliga rutiner. Den ambitiösa och drivande sjukvårdspersonalen upplever att de bygger *KOL-vård på en ostadig grund*, där den ostadiga grunden illustrerar den svårpåverkade organisationen och andra utmanande förutsättningar. De är vana vid att styra över det dagliga arbetet med

patienter och strävar efter att erbjuda en stödjande och stärkande KOL-vård med interprofessionell samverkan, men de hindras av bristande kunskap kring och erfarenhet av KOL. Personer med KOL har bristande kunskap och insikt, hanterar känslor av skuld, skam och rädsla, samtidigt som de försöker hantera och acceptera sin sjukdom. De *(re)agerar i en mångtydig interaktion* med sjukvårdspersonal i primärvården. Sjukvårdspersonalens attityder, bemötande och stöd är mycket viktiga i interaktionen och påverkar hur personer med KOL hanterar sin sjukdom. De kan få en stärkt självtillit med hjälp av stärkande stöd, eller måsta hantera nedbrytande stigmatisering och rädslor.

Tidigare studier visar att personer med KOL som har fått stöd och råd via telefon, hemsidor eller mobiltelefon ökar sin fysiska aktivitetsnivå jämfört med dem som inte har fått det. Ingen skillnad mellan grupperna hittades för fysisk förmåga och andnöd. Åtgärden kombinerades ofta med fysisk träning och/eller utbildning. Gruppen som de jämfördes med fick antingen ordinarie KOL-vård eller fysisk träning och/eller utbildning. Sjukvårdspersonal, personer med KOL och deras anhöriga, samt forskare betonar vikten av att ett eHälsa-verktyg *förstärker den befintliga KOL-vården* om det ska vara användbart och relevant i primärvården. Det behöver passa i nuvarande rutiner och vanor för att det ska vara möjligt att tillämpa det direkt. Vidare tycker de att det är viktigt att användarna känner att informationen passar deras individuella behov och egenskaper, samt att det engagerar dem. Filmer anges som ett lämpligt sätt att presentera information om strategier för att hantera sin sjukdom i ett eHälsa-verktyg. eHälsa anses av deltagarna kunna öka kunskap och ge stöd för att hantera sin sjukdom.

Sammanfattningsvis visar avhandlingen att det finns ett stort behov av att implementera behandlingsriktlinjer för KOL i primärvården för att förbättra både KOL-vården och interaktionen mellan sjukvårdspersonal och personer med KOL. Flera insatser behövs för att underlätta implementeringen. Prioriteringen av KOL behöver höjas och ökade resurser till KOL-vården krävs för att ge förutsättningar för interprofessionell samverkan och patientmedverkan. Det är viktigt att involvera fysioterapeuter i KOL-vården med tanke på vikten av fysisk träning och fysisk aktivitet för personer med KOL. Sjukvårdspersonalen i primärvården behöver ökad kompetens och mer tid avsatt för att kunna utbilda och stärka personer med KOL. Användningen av eHälsa kan leda till förbättringar av KOL-vården, men det behövs mer forskning kring internet-baserad eHälsa. Om de framtida användarna involveras i utvecklingen av eHälsa-verktyg, ökar användbarheten och relevansen i deras vardag och sammanhang.

Resultaten från den här avhandlingen kan ge vägledning vid implementering av behandlingsriktlinjer i primärvården och vid utveckling av nya eHälsa-verktyg. Många av resultaten kan användas även vid arbete med personer med andra långvariga tillstånd, utöver KOL.

Original papers

The thesis is based on following publications, which will be referred to by their Roman numerals.

- I. Lundell S, Tistad M, Rehn B, Wiklund M, Holmner Å, Wadell K. Building COPD care on shaky ground: A mixed methods study from Swedish primary care professional perspective. *BMC Health Serv Res.* 2017;17(1):467.
- II. Lundell S, Wadell K, Wiklund M, Tistad M. Enhancing confidence or coping with stigma in an ambiguous interaction with primary care: a qualitative study of people with COPD. *Manuscript.*
- III. Lundell S, Holmner Å, Rehn B, Nyberg A, Wadell K. Telehealthcare in COPD: A systematic review and meta-analysis on physical outcomes and dyspnea. *Respir Med.* 2015;109(1):11-26.
- IV. Tistad M, Lundell S, Wiklund M, Nyberg A, Holmner Å, Wadell K. Usefulness and Relevance of an eHealth Tool in Supporting Self-Management in Chronic Obstructive Pulmonary Disease: Perspectives From a Cocreative Process. *JMIR Hum Factors.* *Accepted.*

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Preface

My first experience with people with COPD was during the undergraduate studies on my way to becoming a physiotherapist. My first clinical work placement was in the pulmonary medicine ward of a hospital. There I met several people with COPD, and I found my work with them to be very interesting. When I later got a job in primary care and the management wanted a physiotherapist to work with people who had recently been diagnosed with COPD, I volunteered. At that time, I observed that few of the other physiotherapists showed an interest in COPD.

When I was granted opportunity to become a PhD student in physiotherapy, I knew I wanted to do some qualitative research. I have always been interested in hearing people talk about what they are thinking and feeling. Furthermore, equity has always been important to me, and implementation of evidence also struck me as an important subject. Physical activity and exercise training are two of the cornerstones of evidence-based COPD interventions, or at least they should be. Interprofessional collaboration is also important, and physiotherapists should have an obvious role in the management of COPD. However, in primary care, people with COPD mainly meet nurses with special responsibility for COPD. Ensuring that the needs and wishes of people with COPD are the centre of focus, should be a responsibility shared by all healthcare professionals working as a team. This was the starting-point in my work on this thesis.

Introduction

Chronic obstructive pulmonary disease (COPD) is a major public health problem that causes suffering for individuals and has high costs for society. There is evidence of several interventions having positive effects on the health of people with COPD. However, these interventions have not been sufficiently implemented in clinical practice, with the result being that few people with COPD have access to the support they need. The primary focus of this thesis is to explore the conditions for implementation of evidence-based interventions and eHealth in primary care, in order to improve access for people with COPD. The reason for focusing on primary care is that most people with COPD in Sweden are managed there. The introduction first provides an overview of COPD and its consequences, as well as the management of COPD. It then focuses on eHealth, which has been suggested as a means of increasing access to evidence-based interventions for people with COPD. Finally, the end of the introduction deals with implementation and the rationale for the thesis.

Burden of COPD

COPD is considered a systemic disease that affects the whole individual, with dyspnoea as the most characteristic symptom.¹ The definition of COPD, according to the Global Initiative for Chronic Obstructive Lung Disease (GOLD) is:

“a common, preventable and treatable disease that is characterized by persistent respiratory symptoms and airflow limitation that is due to airway and/or alveolar abnormalities usually caused by significant exposure to noxious particles or gases”^{1, p.2}

About 251 million people worldwide are estimated to have a diagnosis of COPD, which gives it a prevalence of 3.5%.² About 65 million people are estimated to have moderate-to-severe COPD.³ However, since more than 80% of the COPD cases have been reported to be underdiagnosed,⁴ and different diagnostic criteria give variation in results,⁵ it is difficult to estimate prevalence. In 2016, 5.4% of deaths were due to COPD, making it the third leading cause of death worldwide.^{2, 6} It is predicted that deaths due to COPD will increase to 7.8% by 2030.⁷ The prevalence of and death rate due to COPD is higher among men than women.² In Sweden the prevalence of COPD has been estimated to be 7.2% (about 670,000 people).² However, a decrease in the prevalence of moderate-to-severe COPD and a smaller difference in the prevalence of COPD between men and women have been reported in northern Sweden.⁸ The death rate due to COPD in Sweden was 3.9% in 2016, and more women than men died from COPD.²

COPD is also an economic burden, in which the largest portion of the cost is related to comorbidities and a smaller portion to the disease itself.^{9, 10} Hospital care accounts for most of the healthcare costs, and the costs are directly related to the severity of the disease.⁹⁻¹¹ In Sweden, the total cost for COPD was estimated to about 1.5 billion euros (13.9 billion SEK) in 2010.¹¹

Tobacco smoking is the main risk factor for COPD,^{1, 5} though environmental exposure to noxious particles and genetic factors may contribute also to the development of COPD.¹ Airflow limitation and mucociliary dysfunction are consequences of a chronic inflammation that causes narrowing of the small airways and destruction of parenchyma (emphysema).¹ Studies have also shown that systemic inflammation is present in COPD, manifested by symptoms of the whole body.^{12, 13}

Living with COPD

Dyspnoea is the most characteristic symptom of COPD.¹ Other common symptoms are weight loss, loss of skeletal muscle mass and skeletal muscle dysfunction, which lead to decreased physical capacity and reduced quality of life.^{1, 12, 13} Several of these symptoms are associated with systemic inflammation.¹² People with COPD have a higher risk for comorbidities than the general population,¹⁴ and these are associated with poor clinical outcomes and increased mortality.¹⁵ The most common comorbidities are heart failure and other cardiovascular diseases. Other common comorbidities are osteoporosis, anxiety and/or depression, lung cancer and diabetes mellitus.^{1, 13-15} The number of comorbidities has been shown to predict mortality.^{13, 15} People with COPD experience daily variations in their symptoms of COPD. It limits their activities and can evoke emotions such as fear, loneliness, sadness and anger. Living with the disease requires planning activities and finding ways of coping with its symptoms.^{16, 17}

People with COPD are significantly more inactive than healthy controls.¹⁸ Physical activity is defined as “*any bodily movement produced by skeletal muscles that results in energy expenditure*”.^{19, p.126} Physical activity level is markedly reduced even in people with mild COPD, and decreases even more as the severity of the disease increases,^{18, 20} and over time in general.²⁰ The low physical activity level in people with COPD is alarming since one study found it to be the strongest predictor of all-cause mortality, and that reduction in physical activity level increases the relative risk for death.²¹ Physical activity among people with COPD is a protective factor for hospital admissions and respiratory mortality.²²

As the disease worsens, people with COPD often experience exacerbations. Exacerbation is an acute worsening of respiratory symptoms that have a negative

impact on health status and leads to changes in medication. The worsening is beyond the normal day-to-day-variation that people with COPD experience.¹ Experiencing an exacerbation may be frightful and can lead to avoidance of activities.¹⁶ It is important to detect and treat exacerbations early in order to decrease disability and healthcare costs.²³ More than 80% of exacerbations can be treated with medication on an outpatient basis.¹

Women seem to be more vulnerable to tobacco smoking than men, since they get COPD earlier in life and develop severe COPD to a greater extent than men with comparable exposure to smoking.²⁴⁻²⁶ Women with COPD report shortness of breath more often,^{5, 24, 25} and they tend to have more sensitive airways than men, which might be explained by their smaller airways.^{5, 24, 25} They also have a lower body mass index (BMI) and physical capacity, more exacerbations, lower quality of life and poorer self-related health.²⁵ Regarding comorbidities, osteoporosis, non-psychotic mental disorders or depressive disorders are more common in women, while ischemic heart disease, diabetes mellitus and malignant pulmonary neoplasms are more common in men.^{14, 26}

Diagnostic and disease severity

Before the diagnosis of COPD, many people blame their early symptoms on other reasons, such as aging. Consequently, their initial contact with healthcare is due to acute episodes rather than for early symptoms of COPD.¹⁶ The process of diagnosis can be prolonged for them and it can take a few visits before they get a diagnosis, and sometimes even then they do not get a clear diagnosis.^{16, 27}

According to GOLD,¹ spirometry is the most objective and reproducible measurement of airflow limitation and is required for diagnosis. Spirometry measures the volume and function of the lungs. Forced vital capacity (FVC) is the largest volume one can breathe out with a forced expiration after the intake of a full breath. Forced expiratory volume in one second (FEV₁) is the volume one can breathe out during the first second of a forced expiration.²⁸ A ratio of FEV₁/FVC <0.70 after bronchodilator confirms the presence of persistent airflow limitation and COPD. The percentage of predicted FEV₁, according to normal values, guides the severity of airflow limitation from grades 1-4 (Figure 1).¹ Spirometry is recommended for all individuals with symptoms and/or risk factors such as smoking.¹ People in Sweden first enter healthcare through primary care; hence, it is an appropriate setting for spirometry screenings. Considering that COPD is vastly underdiagnosed, it is clear that the diagnosis process has not been sufficiently implemented.

Since more than airflow limitation impacts COPD, the classification of the disease has changed over the years. According to the latest update of GOLD, the

assessment of people with COPD should include airflow limitation combined with symptom burden and risk of exacerbation (Figure 1). Airflow limitation is still important on a population level for predicting mortality and hospitalizations, while symptoms and risk of exacerbation can guide the treatment of individual patients.¹

Symptoms should be measured using the modified Medical Research Council (mMRC) dyspnoea scale or the COPD assessment test (CAT).¹ The mMRC is a five-grade scale measuring the degree of dyspnoea during different activity levels.²⁹ CAT consists of eight questions designed to evaluate subjective COPD-related health status.³⁰ The risk of exacerbation is measured using earlier experienced exacerbations. Two or more exacerbations, or one exacerbation leading to hospital care, are considered to be a high risk of future events.¹

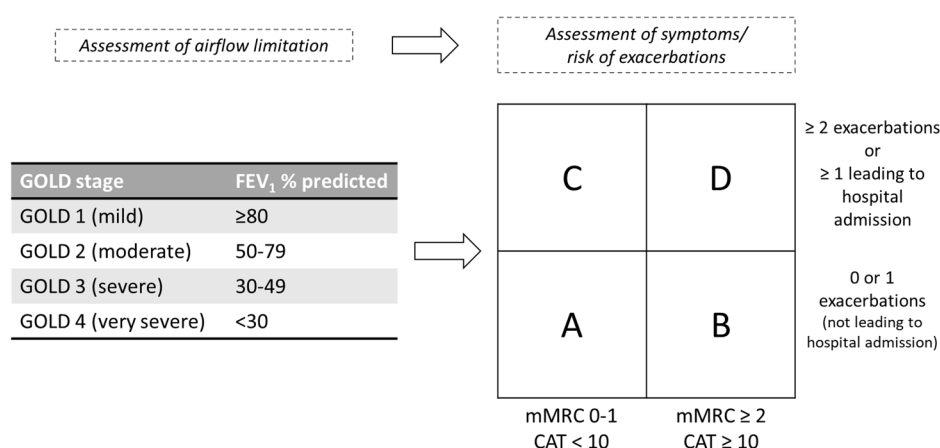


Figure 1. The GOLD assessment of disease severity. CAT = COPD Assessment test; FEV₁ = forced expiratory volume in 1 s; GOLD = Global Initiative for Chronic Obstructive Lung Disease; mMRC = modified Medical Research Council

Management of COPD

There are both international and national guidelines for the management of COPD.^{1, 31, 32} Interprofessional collaboration is emphasised, and management should be based on the individual assessment of symptoms and risk for exacerbations. The main aim of the management is to reduce symptoms and future risk of exacerbations. To expand knowledge and the ability to manage the disease among people with COPD, it is important to provide patient education and support for self-management, and to offer a written, individualised action plan to all.^{1, 31} Adherence to the clinical guidelines in clinical practice is unsatisfactory, especially for non-pharmacological management.^{33, 34} The need for implementation is evident.

Internationally, the management of people with COPD varies between hospital-based specialty care and primary care settings.^{35, 36} Previously, they in Sweden were managed in specialty clinics at the hospitals, but now most are managed in primary care. People with severe COPD and a higher rate of exacerbations are still often treated in specialty care.³⁷ Criteria for asthma/COPD management in Swedish primary care have been developed, based on the most prioritised interventions in the national clinical guidelines.³⁸ It is recommended that physiotherapists be the core of interprofessional collaboration around every person with COPD, along with COPD nurses and physicians.^{31, 38} Clinical guidelines state that there should be a physiotherapist responsible for asthma and COPD, with the right competence and time allowance, at each primary care centre.³⁸ However, even though the availability of physiotherapists in Swedish primary care is high (80-92%),^{37, 39, 40} few people with COPD meet physiotherapists in their contacts with healthcare.⁴⁰

The clinical guidelines include several health promotion interventions.^{1, 31} Health promotion is a process whereby people gain control over, and improve, their health.⁴¹ Smoking cessation is the key intervention for people with COPD, since it can influence the progression of the disease. In addition, the clinical guidelines consist of assessment of symptoms and walking distance, exercise training, regular follow-ups, nutritional interventions and pharmacologic treatment. An important part of the management of people with COPD is pulmonary rehabilitation.¹

Pulmonary rehabilitation

Pulmonary rehabilitation (PR) can be provided in primary care, hospital specialty care, community centres and in home settings, and it can be adapted for all people with COPD. It is a comprehensive, individualised intervention that includes, at the very least, exercise training, patient education and behaviour change. It is recommended to be implemented with interprofessional collaboration,⁴² and a full and individualised programme is recommended for groups B-D.¹ The aim of PR is to promote autonomy, self-management and long-term behaviour change, in order to decrease the burden of symptoms, increase exercise capacity and increase participation in everyday activities.^{42, 43} A self-management intervention for people with COPD is defined as:

“...structured but personalised and often multi-component, with goals of motivation, engaging and supporting the patients to positively adapt their health behaviour(s) and develop skills to better manage their disease.”^{43, p.50}

Internationally, PR programmes are offered in several different settings, and 61% of the PR teams include physiotherapists.³⁶ In Sweden, PR programmes exist in

both primary care and hospitals; and physiotherapists are included in all of the teams and are responsible for some of them.^{39, 44}

PR for people with COPD improves physical capacity, quality of life and dyspnoea, and is also cost-effective.⁴⁵⁻⁴⁹ The effect on physical activity level, hospital readmission after exacerbations and mortality is however inconsistent.^{47, 48, 50} Many of the positive effects on exercise capacity and dyspnoea are lost during the first year after PR, even with maintenance interventions.^{51, 52} People with COPD have expressed that PR improves their well-being and supports behaviour changes related to health promotion.⁵³

Despite evidence of the benefits of PR there is only a limited proportion of people with COPD who participate in PR programmes.^{35, 54, 55} The programmes are unequally distributed across Sweden, with the northern regions having very little access to PR. About a quarter of all the Swedish hospitals and primary care centres have reported having no access to PR at all,^{39, 44} which provides a clear picture of the need for implementation of the clinical guidelines. In addition to low referral rates, many patients also decline participation in or drop out of the programmes.^{36, 44, 54} Transportation difficulties, health issues, personal finances, family obligations, and lack of motivation or support are some of the reported barriers of participation.^{44, 56-59} In an agreement between the Swedish state and the Swedish Association of Local Authorities and Regions,⁶⁰ it has been stated that healthcare shall be equal for both men and women, regardless of where one lives. Considering that many patients in Sweden have a long distance to travel to obtain PR, the possibility of rehabilitation in their homes needs to be explored. Electronic health (eHealth) has been suggested as showing promise for increasing access to evidence-based COPD interventions such as PR.^{42, 61} Therefore, eHealth could be a strategy for facilitating implementation of the clinical guidelines.

eHealth in the management of COPD

Several definitions of eHealth are available.⁶² World Health Organization (WHO)⁶³ defines eHealth as *“the use of information and communication technologies (ICT) for health”*. eHealth can be viewed as a broad term that include monitoring of patients, interaction between healthcare provider and patient, education of patients and healthcare professionals, communication between healthcare providers, and facilitating innovations to improve the healthcare system.⁶²

Telehealth (or telehealthcare) is described as the most basic element of eHealth: *“Telehealth involves the use of telecommunications and virtual technology to deliver health care outside of traditional health-care facilities”*.⁶⁴ The effects of telehealth for people with COPD have been evaluated in two earlier systematic reviews. These presented moderate evidence for increased quality of life, and decreased hospital

admissions and emergency department visits, while the results in terms of patient satisfaction and mortality is inconsistent.^{65, 66} Additionally, healthcare costs tend to be reduced, while patients' knowledge and self-management increase with telehealth for people with chronic diseases.^{67, 68} However, the effect of telehealth on physical activity level, physical capacity or dyspnoea for people with COPD is still unknown. The design of the telehealth interventions in earlier systematic reviews has been heterogeneous.^{65, 66}

People with COPD have a positive attitude towards eHealth solutions, even if it contributes to fewer face-to-face contacts with healthcare professionals.⁶⁹⁻⁷³ They perceive that the eHealth that it is easy to learn and use, that it increases their motivation for exercise training, contributes with new knowledge about self-management, and provides feelings of security.⁷¹⁻⁷³ Interaction with other people with COPD via the internet is appreciated, as well as the convenience of receiving healthcare services in their own homes.^{69, 71, 73} Healthcare professionals instead seem to be more cautiously positive towards eHealth solutions.^{72, 74} Lack of technical skills, fear of losing control, insecurity in their new roles and lack of time have been mentioned as concerns for them.^{72, 74-76} Implementation of eHealth interventions in clinical practice is challenging.^{77, 78} Involving users in the design of eHealth intervention is important since this can lead to a better understanding of their needs and, consequently, facilitates implementation.^{77, 79-81} A lack of fit between the users' needs and the eHealth intervention can be a barrier for implementation.⁷⁸

In Sweden most of the population has access to the internet at home, which is beneficial for using eHealth to implement evidence-based interventions. More than 90% of the population use the internet each week, but the usage decreases in older age groups. Among people aged 75-85 years, 52% use the internet each week, while 33% have never have used it.⁸² The possibility of reaching the older population via the internet is still relatively strong. In Australia, which has challenges similar to those of Sweden, such as long distances between places and sparsely populated rural areas, almost half of the people attending PR indicated a willingness to use telehealth, which was associated in the survey with regular computer use.⁸³

To promote equity in health the Swedish government and the Swedish Association of Local Authorities and Regions have jointly developed an eHealth vision for 2025.⁸⁴ According to the vision, Sweden should be world leading in using the possibilities of eHealth with the aim of empowering people to become more independent and to participate more in society.⁸⁴ Also the Swedish Association of Physiotherapists has formulated a strategy for eHealth,⁸⁵ which emphasises that physiotherapists should play an obvious part in digital meetings.

The aim of the strategy is to improve participation and availability, and to facilitate knowledge dispersion and interaction with patients.⁸⁵

Interaction between people with COPD and healthcare professionals

In order to provide personalised healthcare with effective interprofessional collaboration where the person with COPD is in focus, an iterative interaction between the patient and the healthcare professional is required.^{31, 43, 86} Shared goals are important in the interaction, with the needs and wishes of the patient being in focus.^{31, 43} Decision-making, interpersonal style and communication are important aspects of the interaction. The healthcare professional needs to involve the patients in treatment decisions, and evaluate their desires and abilities to implement the recommended treatments. Interpersonal style include elements such as friendliness, respectfulness, discrimination, cultural sensitivity and emotional support. The foundation in communication is the ability to communicate with general clarity to make the other person understand. To listen and be responsive to the other persons' expectations and concerns is also essential. Empowerment is an important aspect of communication.⁸⁷ Empowerment refers to a process that has its aim to provide patients with control and influence over their health.⁸⁸ This is emphasised as a clear aim in the treatment of people with COPD.^{1, 31, 42, 43}

High-quality interactions between the patient and healthcare professional lead to increased satisfaction, trust, confidence and self-care among patients.⁸⁹⁻⁹¹ The agreement and communication between the patient and healthcare professional also improves.⁸⁹ Among people with COPD, a strong relationship between their perception of interaction and quality of care has been reported.⁹² However, during observations and evaluations of interactions between people with COPD and healthcare professionals, a traditional consultation approach with low patient-centred communication has been observed.⁹³

Implementation

As presented earlier in the introduction, the implementation of evidence-based interventions for COPD is challenging and insufficient. This leads to underdiagnoses, limited access to physiotherapists and PR programmes, and scarce interaction between healthcare professionals and people with COPD. In an official policy statement document, the implementation of PR into clinical practice has been emphasised by the American Thoracic Society and the European Respiratory Society. It provides recommendations for how the provision of PR should be expanded that include increasing the awareness and knowledge of PR, and expanding access to and improving the quality of PR

programmes.⁶¹ This could narrow the gap between the recommended provision of PR and other treatments, and actual availability for people with COPD.

The research society contributes with an enormous wealth of evidence about healthcare interventions each year. However, the adoption of the evidence into clinical practice takes a long time. The implementation process is complex and requires systematic work with good planning and preparation.⁹⁴ In a successful implementation, the evidence is embedded in clinical practice in which the involved individuals are engaged and motivated. The goals of the implementation are reached when there is little variation within the setting where the evidence has been implemented.⁹⁵ In an effort to overbridge the gap between research evidence and the interventions provided in healthcare, clinical guidelines are developed. Clinical guidelines synthesise current evidence on how to organise and deliver healthcare interventions in an effective manner, with the aim of improving quality of care.^{31, 94} Earlier research reports focused more on guideline development than guideline implementation.⁹⁶ If implementation is to be maximised, it should already be taken into account in the development process. Several factors can influence the implementation process, such as the innovation that is expected to be implemented, the people who are going to adopt it, their social setting, the healthcare organisation and the healthcare system. The impact of the implementation can be strengthened or weakened by these factors. As a support in the assessment and analysis of these factors, theories can and should be used.⁹⁴

Theoretical framework

In implementation science, there are several theories, models and frameworks available to guide, understand and evaluate implementation. Determinant implementation frameworks specify barriers and enablers that have an impact on the outcome of implementation. They can be useful when designing and executing implementation strategies.⁹⁷ For this thesis, the integrated-Promoting Action on Research Implementation of Health Services (i-PARIHS) framework⁹⁵ has been chosen to understand the conditions and to guide implementation of national COPD guidelines in primary care in a county council in Sweden.

i-PARIHS

The i-PARIHS framework is based on substantial research and development work, and is a revised version of the earlier PARIHS framework,^{95, 98} which has been well used in research.⁹⁹ The earlier version of the framework were used in the design of the study where papers I, II and IV are included, even though the analyses were inductive. In this thesis, the discussion is based on i-PARIHS, in order to join the findings and look at them from an implementation perspective.

In the i-PARIHS framework, there are four core constructs, and the interplay between these constructs is emphasised. The characteristics of the *innovation* to be implemented, the *recipients*, the *context* (including management, organisation and culture), and the *facilitation* of the implementation are highlighted as components that are important for reaching a successful implementation. Facilitation is described as an active element that activates the implementation by assessing and responding to the other concepts (Figure 2).⁹⁵

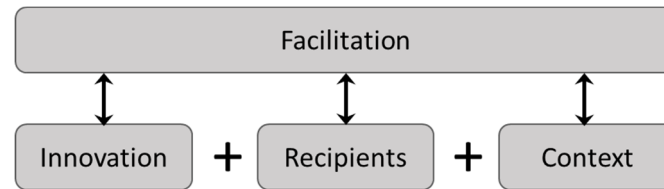


Figure 2. The interplay between the core constructs of the i-PARIHS framework.

Innovation focuses on what is supposed to be implemented. It includes available research evidence, but also how the innovation and the change it will cause fit in the local setting. Further, it determines how likely it is that the innovation will be accepted by the people who are going to implement it.⁹⁵

Recipients focuses on the attitudes of the intended targets for implementation and their existing collaboration. It is important to explore motivation and ability to change among the recipients.⁹⁵

Context includes both inner and outer contexts. *Inner context* refers to the immediate work environment for the recipients (local level) and its overall organisation, such as management support and organisational priorities (organisational level). *Outer context* refers to the whole health system, policies and political environment (such as priorities and environment).⁹⁵

Facilitation is emphasised as a core factor within i-PARIHS, but mainly as an active ingredient that is assessing and reacting to characteristics of the other constructs, and that activates implementation. This requires someone taking on the role of facilitator, and using a set of strategies and actions - a facilitation process - to enable implementation.⁹⁵

Rationale for the thesis

Even though there is evidence for the benefits of PR and other interventions recommended in clinical guidelines, only a limited number of people with COPD receive these interventions. It is important to implement these interventions in clinical practice to gain access for people with COPD. To increase the chances of a successful implementation, knowledge about the current situation is required. The focus in this thesis is on primary care, since most people with COPD are managed there. Consequently, there is a need for greater knowledge about the organisation of Swedish primary care, as well as of the healthcare system as a whole. Furthermore, more knowledge is needed about the experiences of the recipients involved in the implementation – in this case, healthcare professionals and people with COPD – and how they interact in the context of primary care.

As eHealth could be an opportunity for attaining equity in healthcare, there is a need for more knowledge about the design and effect of eHealth tools. The effects of telehealth on people with COPD have been systematically evaluated for emergency department visits, hospital admissions, quality of life, and mortality. However, no earlier systematic reviews have evaluated the effect of telehealth on physical activity level, physical capacity or dyspnoea for people with COPD.

Since access to PR and other evidence-based interventions is limited for people with COPD in Sweden, we decided to develop an eHealth tool mainly directed to people with COPD and healthcare professionals in primary care. The eHealth tool *KOLwebben* (the COPD web) is an interactive website with a twofold aim. The first is to support people with COPD in their self-management strategies. The second is to facilitate implementation of healthcare professionals' provision of healthcare and support for these patients in primary care. In order to develop an eHealth tool that is relevant and useful to its users, there is a need for greater knowledge about contextual conditions, as well as the needs and wishes of the users.

Aims

The overall aim of this thesis is to explore the conditions for implementation of evidence-based COPD interventions and the use of eHealth in primary care. This aim is twofold. The first is to explore the experiences, interactions and context of the management of COPD in primary care from the perspective of people with COPD, healthcare professionals and managers. The second is to explore the design and experienced relevance, along with the effect and expected usefulness of eHealth solutions, with the intention of making evidence-based care more available.

Specific aims

The specific aims of this thesis are:

1. To increase the understanding of what management is offered in primary care to people with COPD, and what shapes this provision from the perspective of healthcare professionals and managers (paper I).
2. To explore how people with COPD and healthcare professionals experience interactions they have in primary care (papers I and II).
3. To explore how people with COPD deal with interactions with healthcare professionals in primary care and how these interactions influence how they cope with their disease (paper II).
4. To describe how earlier telehealth interventions have been designed (paper III).
5. To investigate the effects of telehealth on physical activity level, physical capacity and dyspnoea in people with COPD (paper III).
6. To explore what aspects of an eHealth tool would make it relevant and useful in supporting COPD-related self-management strategies from the perspective of healthcare professionals, people with COPD and their relatives, as well as external researchers (paper IV).

Methods

Study design

This thesis consists of four papers. An overview of these is presented in Table 1. A combination of qualitative methods and quantitative methods are used in this thesis, including a mixed methods design.

Table 1. Overview of the papers included in the thesis.

	Paper I	Paper II	Paper III	Paper IV
Study design	Mixed methods study	Qualitative study	Systematic review	Qualitative study
Data collection	Individual interviews, questionnaires	Individual interviews	Database searches	Individual interviews, focus groups
Participants	Healthcare professionals and senior managers	People with COPD	People with COPD	Healthcare professionals, people with COPD, relatives and external researchers
Data material	Interview transcriptions (n=14), Questionnaires (n=18+26)	Interview transcriptions (n=13)	Randomised controlled trials (n=9)	Interview transcriptions (n=21), focus group transcriptions (n=9)
Data analysis	Qualitative content analysis, descriptive statistics, mixed methods merging	Grounded theory	Meta-analysis	Qualitative content analysis

COPD = Chronic obstructive pulmonary disease

Three of the papers (papers I, II and IV) were part of a larger research project aimed at developing an eHealth tool, the COPD web.¹⁰⁰ User involvement was an important part of this project, and the data collection was designed based on the implementation framework i-PARIHS.⁹⁵ The needs and wishes expressed by the participants in papers I, II and IV in this thesis were an important contribution in the development of the COPD web. Not included in this thesis was the development of a prototype of the COPD web, based on the national guidelines.³¹ Iterative tests of the prototype were performed with the users, which contributed to further development toward the first version of the COPD web. The iterative tests are also not included in this thesis.

Qualitative methods were used to explore experiences, perceptions and interactions in papers I, II and IV. A mixed methods design was used¹⁰¹ in the thesis to merge the qualitative and quantitative findings from papers I and II, which give a more comprehensive picture of the findings.¹⁰² Grounded theory, as described by Charmaz¹⁰³ guided both the data collection and data analysis, as well as the sampling in paper II. The data collection and data analysis were performed in a parallel process where the participants are recruited gradually, guided by the

emerging categories and ideas from the analysis, which enables testing and revision of the analysis. Theoretical saturation¹⁰³ was applied, which means that no more participants are recruited when new interviews do not contribute new ideas and content to the categories.



*Figure 3.
Västerbotten
county in Sweden.*

Setting

Papers I, II and IV were conducted in a primary care setting in the county council of Västerbotten in Sweden. Both inland and coastal areas, as well as private and public centres, are represented. Västerbotten county is located in northern Sweden (Figure 3) and has a population of approximately 266,000 citizens.¹⁰⁴ The coastal area of the county is home to several cities, where a majority of the population lives. The inland consists of large, sparsely populated areas. The population of Sweden is among the oldest in the world,¹⁰⁵ and in Västerbotten county the proportion of the population that is 65 years and older is slightly higher than it is nationally. The population in the inland of the county is considerably older than in the coastal area.¹⁰⁴

Swedish healthcare is organised as 20 autonomous county councils and regions, and all the healthcare services are publicly funded. Primary care consists of outpatient facilities and is where most people in Sweden first enter the healthcare system. However, Västerbotten County Councils and a few other county councils in northern Sweden, which can have great distances from to the closest healthcare facility, have community hospitals in the inland. These belong to the primary care organisation, but they are also equipped with inpatient facilities and provide emergency care and other extended services, such as x-ray imaging. All citizens in Sweden have the right to enrol with any public or private primary care centre of their choice.

Recruitment and participants

The recruitment was performed in primary care centres in Västerbotten County Council (papers I, II and IV) and in research databases (paper III).

One primary care centre in an urban area and one primary care centre in a rural, sparsely populated area were chosen for papers I and IV. For paper II two additional primary care centres were included: one urban and one rural. All four centres were chosen since they had COPD nurses (designated nurses responsible for COPD care). The COPD nurses assisted with identifying participants for recruitment according to the instructions of the researchers. For the quantitative

data collection in paper I, all primary care centres in Västerbotten County Council were chosen (Figure 4).

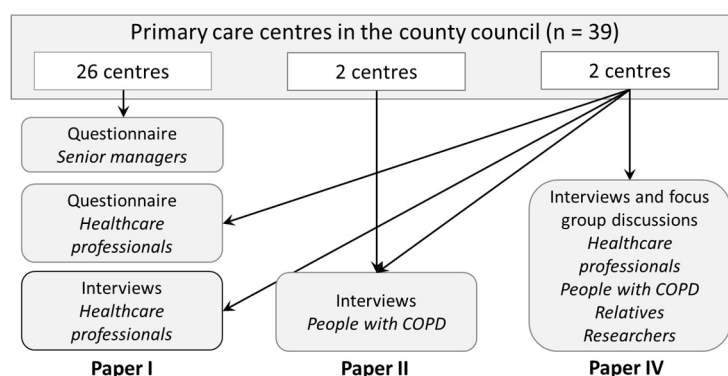


Figure 4. Flow chart of the recruitment, data collection and participants in papers I, II and IV.
COPD = Chronic obstructive pulmonary disease

Healthcare professionals and managers from two primary care centres were invited to answer questionnaires (paper I) and to participate in individual interviews (papers I and IV) and focus group discussions (paper IV). Some of them divided their time between both roles, but they are presented as healthcare professionals below since that was the main focus in their interviews. The number of participants included were partly restricted due to the number of available professionals at the primary care centres. There was some overlap between the quantitative and qualitative sample for allow comparisons of the data, as suggested by Creswell.¹⁰¹ Detailed information about the included healthcare professionals and managers is presented in Tables 2 and 3.

Table 2. Characteristics of healthcare professionals and primary care centres included in questionnaires in paper I.

Healthcare professionals from two centres, n = 18 (82% of invited)	
Age, mean (SD)	49 (12)
Professional experience in years, mean (SD)	21 (10)
Years in present position, median (range)	4.5 (1-34)
Women/men, n	12/6
Profession, n	
• Nurse	9
• Physician	4
• Physiotherapist	3
• Occupational therapist	2
Primary care centres represented by senior managers, n=26 (67% of invited)	
Enrolled patients, n, median (range)	5,808 (1,050-18,800)
Percent of enrolled patients with a COPD diagnosis, median (range)	0.65 (0-2.6)

SD = Standard deviation

The senior managers at all primary care centres in Västerbotten County Council were invited to fill out a questionnaire (paper I). Included centres are presented in Table 2.

People with COPD were invited to participate in individual interviews (papers II and IV) and focus groups (paper IV). The recruitment in paper II was guided by the emergent and flexible study design of grounded theory.¹⁰³ The participants were recruited from four primary care centres (paper II) and two primary care centres (paper IV), respectively. People with COPD included in paper IV were asked to nominate a relative who could be invited to participate in individual interviews and focus groups (paper IV). Detailed information is presented in Table 3.

Table 3. Characteristics of participants included in interviews and focus groups in papers I, II, IV.

	Healthcare professionals		People with COPD		Relatives	Researchers
	Paper I n = 14	Paper IV n = 14	Paper II n = 13	Paper IV n = 6	Paper IV n = 2	Paper IV n = 4
Age, mean (SD)	49 (10)	48 (9)	67 (11)	74 (6)		
Professional experience in years, mean (SD)	20 (10)*	20 (9)				24 (9)
Years in present position, mean (SD)	9 (6)*	9 (6)*				
Women/men, n	9/5	10/4	8/5	2/4	2/0	1/3
Profession/role, n						
• Nurse	5	5				1
• Physician	3	4				1
• Physiotherapist	2	2				1
• Occupational therapist	1	1				-
• Dietician	2	2				1
• Senior manager	1	-				-
Relation, n, child/spouse					1/1	
Living area, n, urban/rural			4/9	4/2	1/1	
Work situation, n, retired/working			9/4	6/0		
Smokers, n, current/former			6/7	2/4		
FEV ₁ % predicted, mean (SD)			54 (19)	58 (19)		

*One participant missing. COPD = Chronic obstructive pulmonary disease; FEV₁ = forced expiratory volume in one second, SD = Standard deviation

Four external researchers who were not involved in the project were invited to participate in focus group discussions (paper IV), with the aim of getting an objective expert perspective on available evidence. They were engaged in both research and clinical practice within the field of COPD (Table 3).

In paper III searches were performed on several databases, namely, the Cochrane Central Register of Controlled Trials (CENTRAL), PubMed, CINAHL, AMED, PsycINFO, Web of Science, Scopus and PEDro.

Data collection

Questionnaires (paper I)

Two questionnaires were constructed for paper I, and prior to the study they were tested for face validity in primary care and specialty care contexts.

The questionnaire *Mapping of resources and interventions* included questions regarding resources (healthcare professionals and equipment), further training and interventions for COPD, and difficulties related to COPD (Appendix 1). The questionnaire was constructed in collaboration with a committee aiming to implement COPD and asthma guidelines in the healthcare of the county council. It was based on the national guidelines³¹ and criteria for COPD management in primary care.¹⁰⁶ The senior managers at all primary care centres received the questionnaire as a web survey.

The questionnaire *Conceptual knowledge use* included questions regarding the healthcare professionals' knowledge, attitudes and readiness in delivering health promotion interventions to people with COPD (Appendix 2). Conceptual knowledge use refers to knowledge that influences how people think about certain issues.¹⁰⁷ The questionnaire was administered to healthcare professionals at two primary care centres.

Individual interviews and focus group discussions (papers I, II, IV)

Semi-structured individual interviews were performed face-to-face (papers I, II and IV). The interviews were performed at a place chosen by the participant: at home, the primary care centre, a work place, the university or a restaurant. The interviews lasted between 20 and 60 minutes, with most lasting 40 to 60 minutes. The interview guides were inspired by the i-PARIHS framework.⁹⁵ In paper I, the interview guide covered questions about the healthcare professionals' work with people with COPD, aspects that influenced COPD interventions, and routines/guidelines for COPD. In paper II, the interview guide covered questions about the experiences of people with COPD, including their health-related needs and coping with their disease, their interactions with primary care providers, and the healthcare interventions and support they received. In paper IV, healthcare professionals, people with COPD and their relatives were asked questions about what needs were not attended to by COPD interventions and how an eHealth tool could be designed and used to meet these needs. The questions were open-ended,

and attendant questions such as “Can you tell me more about that?” and “How does that affect you?” were asked to make the participants deepen their answers. Background information was collected orally, and information about pulmonary function for people with COPD was obtained from medical charts.

Focus group discussions (FGDs) in paper IV were performed with one researcher as moderator and two researchers as observers who took notes and could ask additional questions. FGDs with healthcare professionals, patients and relatives were performed at the primary care centre or the university. The FGDs with external researchers were performed at the university with some of the researchers participating via video conference. All FGDs lasted for approximately one hour. The subjects discussed in the FGDs are presented in Table 4. All interviews and FGDs were audio-recorded and transcribed verbatim by a professional transcriber.

Table 4. Subjects discussed during focus group discussions (FGDs) in paper IV.

	Healthcare professionals <i>2 focus groups</i>	People with COPD and relatives <i>2 focus groups</i>	External researchers <i>1 focus group</i>
First FGD	Touch on points from individual interviews and national guidelines		Important aspects of COPD-related self-management strategies
Second FGD	Mock-ups and pilot videos, and how the eHealth tool can be used in clinical practice		Touch on points from interviews with healthcare professionals, people with COPD and relatives

COPD = Chronic obstructive pulmonary disease, FGD = Focus group discussion

Database searches and data extraction (paper III)

Articles were searched for in the databases, by the author of this thesis, using a broad search strategy, combining several search terms related to COPD, telehealth, physical activity, physical capacity and dyspnoea. The search was made from inception to August 2013. In addition, related citations in PubMed and reference lists were reviewed, and included authors were asked for additional articles. To be included in the systematic review, articles had to be peer-reviewed RCTs in English and meet the criteria presented in Table 5. No restriction was made in terms of publication year.

Table 5. Eligibility criteria for articles included in systematic review.

Participants	Interventions	Comparator	Outcomes
≥40 years	Major part telehealth	Any kind	Any of these before and after intervention:
COPD diagnosis	Element of feedback, counselling or motivation provided to patient		Physical activity level
	≥3 contacts during first three months		Physical capacity (objectively measured)
			Dyspnoea

COPD = Chronic obstructive pulmonary disease

The author of this thesis screened all titles and, together with two additional researchers, reviewed abstracts and full texts using a standardised form that was developed based on the eligibility criteria. Articles not meeting eligibility criteria were excluded. Finally, data was extracted using a standardised form based on a recommendation from the Cochrane Handbook.¹⁰⁸ The authors of the included articles were contacted by email if additional data was needed. The author of this thesis and an additional researcher independently assessed risk of bias with the Cochrane risk of bias tool.¹⁰⁸ Several domains for each article were rated for “low risk”, “high risk” or “unclear risk” of bias. A third researcher was involved if consensus could not be reached.

Data analyses

Several different methods for data analysis, both qualitative and quantitative, as well as mixed method, were used in the papers in this thesis.

Qualitative methods for data analysis (papers I, II, IV)

An assumption underlying the qualitative analysis used in this thesis is that an interview text includes multiple meanings and realities that can be interpreted in various ways.¹⁰⁹ Even though the researchers base their analyses on the text, their own experience, competence and history influence their interpretation, which is in line with a constructivist view.¹⁰³ The qualitative parts of this thesis are reported as recommended by standards for reporting qualitative research.¹¹⁰

Qualitative content analysis (papers I, IV)

The transcripts from interviews and FGDs in papers I and IV were analysed inductively with qualitative content analysis as described by Graneheim.¹⁰⁹ Qualitative content analysis focuses on variation in the data, such as similarities within and differences between parts of the text,¹⁰⁹ which was considered relevant due to the aims of papers I and IV. To get a sense of the interviews as a whole, the transcripts were read through several times. Meaning units that covered similar content were condensed and coded. During the coding procedure, the software OpenCode 4¹¹¹ was used. Similarities and differences among the codes were analysed, and the codes were grouped into subcategories with similar content. The codes and the subcategories described the manifest content¹⁰⁹ of the interviews and focus group discussions. Thereafter, the subcategories were grouped and further abstracted to categories. Finally a theme was formulated, based on the latent meaning¹⁰⁹ of the data. In paper IV, codes, subcategories and categories were formulated for each group of participants separately, and finally they were collated into a collective analysis. In both papers, the analyses moved back and forth between the whole and parts of the interviews.

The author of this thesis and an additional researcher had a close collaboration during the analyses and were primarily responsible for the analysis in papers I and IV, respectively.

Grounded theory (paper II)

Grounded theory focuses on processes and actions¹⁰³, which were considered relevant given the aim of paper II. The analysis was inductive and conducted according to the analytical phases of grounded theory.¹⁰³ First, during the *initial coding*¹⁰³ the texts were read line by line and paragraph by paragraph, and labelled preferably with codes that illustrated actions. Second, smaller clusters of codes with similar content were created in the *focused coding*,¹⁰³ and in the *axial coding*¹⁰³ subcategories and categories were created by merging the clusters. Finally, in the *theoretical coding* a model¹¹² was constructed to illustrate the relationships between categories and subcategories, and a core category was formulated. A constant comparison approach¹⁰³ was used, which requires going back and forth between interview data and the analysis. Preliminary analytical ideas (memos¹⁰³) were written down and used in the emerging analysis. OpenCode 4¹¹¹ was used for the coding procedure and the author of this thesis was mainly responsible for the analysis. The analysis process is illustrated in Table 6.

Table 6. Examples of interview text, codes, subcategories and category in paper II.

Interview text	Code	Subcategory	Category
"Will it be like that for me too? How long will it take? There is some concerns when one does not know how it will develop."	Worries about the development of the disease	Fearing dyspnoea and death	Personal emotions and attitudes
"I try to live as usual. I'm trying to do... what I can and what I've done before."	Trying to live as usual	Accepting COPD	

COPD = Chronic obstructive pulmonary disease

Quantitative methods for data analysis (papers I, III)

The systematic review in paper I was performed and reported in accordance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA).¹¹³ It was registered in PROSPERO 2012: CRD42012003294, and at http://www.crd.york.ac.uk/PROSPEROFILES/3294_PROTOCOL_20121016.pdf a study protocol was published. We found more RCTs than expected, and therefore two changes were made from the protocol: we included only RCTs and performed a meta-analysis.

Descriptive statistics (paper I)

Descriptive analyses were performed using IBM SPSS Statistics, version 23. The Shapiro-Wilk test was used to assess normal distribution among the variables. For normally distributed variables, means and standard deviations were calculated, while median and ranges were used for non-normally distributed variables. Frequency tables were used to analyse ordinal and nominal variables.

Meta-analysis (paper III)

Comprehensive Meta-Analysis (CMA) software was used for the meta-analysis. The meta-analysis was performed as recommended by Higgins.¹⁰⁸ Heterogeneity was examined with I^2 statistics, and when $I^2 > 60\%$ the study with the most outlying result was excluded, which continued until $I^2 < 60\%$, as recommended. To decrease the impact of heterogeneity, several strategies were used, as recommended.¹⁰⁸ A random-effects model was used when $I^2 > 30\%$, and a fixed-effects model when $I^2 < 30\%$. The comparator group was divided for the study with two telehealth intervention groups and sensitivity analyses were performed. The effect measures were expressed as standardised mean difference (SMD) in analyses with different assessments, and mean difference (MD) in analyses with the same assessment, with corresponding 95% confidence intervals (CI). Egger's test was used to statistically assess publication bias and $p < 0.05$ was considered statistically significant. In the thesis, the final findings of the three meta-analyses are synthesised in a collective forest plot, along with the sensitivity analyses.

Mixed method (papers I, II)

A convergent, parallel mixed method design^{116, 127, 128} with a qualitatively driven approach¹⁰² was used in paper I. The data collection and analysis for the qualitative and quantitative data were performed in parallel, but separately. The qualitative component consisting of interviews with healthcare professionals was considered the main component. The quantitative findings from the questionnaires with healthcare professionals and senior managers was considered a complementary component that was merged into the qualitative findings in a weaving approach¹¹⁴ to give the findings an additional dimension. The merging was discussed in the research group and adjusted until satisfaction was attained. Furthermore, in the results section of this thesis the findings from paper II were compared and merged with the findings from paper I. The mixed methods parts in the thesis are reported as recommended for mixed methods studies.¹¹⁵

Ethical considerations

The Regional Ethical Board, Umeå University, Umeå, Sweden, approved the larger study, which resulted in papers I, II and IV (Dnr 2014-319-31 and 2016-380-32 M). Before the data collection, all participants received written

information about the study. In addition, oral information was given to participants in interviews and focus groups. All gave their written informed consent.

The interview guides and questionnaires used in the study did not include questions judged to be of sensitive nature. However, some people are ashamed for having COPD, which is important to consider during the interviews. The pulmonary function that was obtained from medical charts is important for describing the severity of disease to enhance judgement of validity of the findings. However, pulmonary function is not judged to be of any sensitive nature. Throughout the whole research process, including dissemination and storage of the results, confidentiality has been carefully ensured for the participants and primary care centres included in the studies.

Results

The findings in the thesis are presented in three sections. First, the findings from papers I and II are presented under the heading *COPD management in primary care: context and experiences*. This section includes findings about the management is offered in primary care to people with COPD and what influences this provision (aim 1). It also reports on experiences of interactions between healthcare professionals and people with COPD, how people with COPD deals with them and how these interactions influence how they cope with their disease (aim 2-3). Second, the findings from papers III and IV are presented under the heading *Use of eHealth for COPD interventions: design and effect*. This section includes the design of earlier telehealth interventions (aim 4), along with the users' perceptions of aspects of an eHealth tool that make it relevant (aim 6). It also includes findings about the effects of telehealth (aim 5) and the expected usefulness of an eHealth tool (aim 6). Finally, there is a short section presenting the findings as viewed from the perspective of the constructs in the i-PARIHS framework.⁹⁵

COPD care in primary care: context and experiences

In paper I, healthcare professionals and managers participated in individual interviews and questionnaires. The overarching theme of *Building COPD care on shaky ground* was formulated after a mixed methods analysis. The theme is constant through four categories: *the (un)demanding patient group*, *the non-compliant healthcare organisation*, *the challenged professionalism* and *the autonomous staff* (aims 1-2). In paper II, people with COPD participated in individual interviews. The core category, *(Re)acting in an ambiguous interaction* was formulated during the analysis. It represents a process of interaction that comprises three categories: *Healthcare priority*, *Professional attitudes* and *Personal emotions and attitudes*. Two contrasting paths *Enhancing confidence with empowering support* versus *Coping with disempowering stigma and threat* illustrate how people with COPD reacts to the ambiguity in the interaction (aims 2-3).

During the analyses of papers I and II, it became clear that the findings deal with the interaction between three entities: healthcare organisation, healthcare professionals and patients. The interaction between these three entities can affect the implementation of self-management interventions in clinical practice.^{93, 116} Thus, the findings from paper I and II are jointly analysed with a mixed methods weaving approach, in terms of these three entities (Figure 5). The entity *healthcare organisation* represents the context that provides the conditions for the work of the healthcare professionals. The entities *healthcare professionals*

and *people with COPD* represents the attitudes, behaviours and actions of the healthcare professionals and people with COPD in primary care, respectively. Notably, the findings in the entities are related and sometimes overlapping, and representative quotes are presented to illustrate the findings.

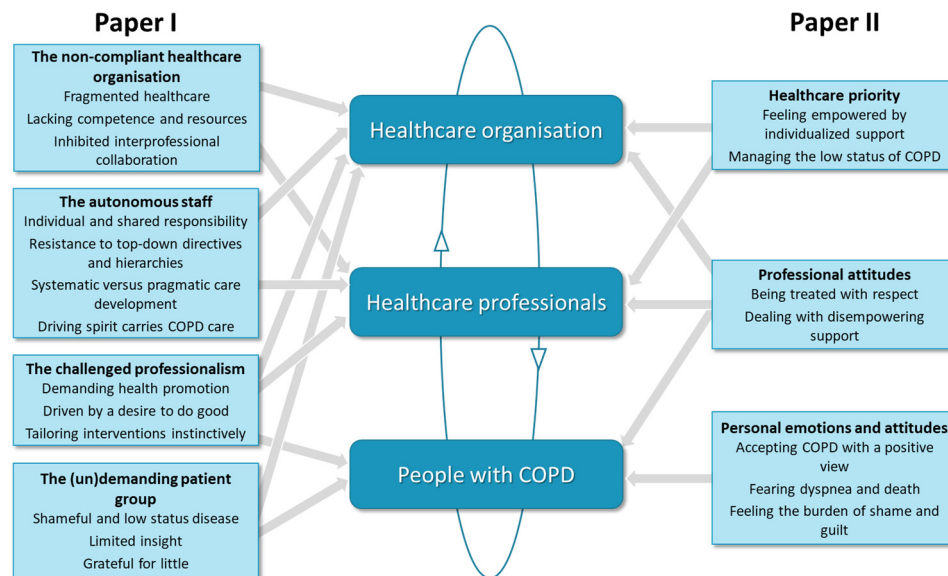


Figure 5. Findings from papers I and II analysed in terms of the entities *healthcare organisation*, *healthcare professionals* and *people with COPD*.
COPD = Chronic obstructive pulmonary disease

Healthcare organisation

The entity *healthcare organisation* comprises experiences of fragmented COPD management of and low priority, and lacking resources in primary care, even though some systematic work with care programmes was reported.

Fragmented healthcare was a concern for healthcare professionals, where the responsibility for COPD management was divided between primary care, hospital-based specialty care, the municipality and sometimes, general dentistry. The distribution of responsibility between the different levels in the healthcare system was perceived as “blurred” by the healthcare professionals. People with COPD had experiences of varying quality of care even within primary care centres. Senior managers reported there being a care programme for COPD at 77% of the healthcare centres, which was perceived as important tools for the healthcare professionals. In the interviews, it was mainly managers who described systematic work in which care programmes and routines were discussed at regular, formal meetings.

A lack of resources in primary care was experienced by all groups of participants. Healthcare professionals thought that the allocated resources in primary care were unfair considering the “constant burden of new assignments”. People with COPD questioned whether COPD received the same resources as other diseases. This lack of resources was reported as making it difficult to provide COPD interventions in 38% of the primary care centres. The economy and difficulties recruiting healthcare professionals limited work that could be done with people with COPD. Nurses, physicians and physiotherapists were the healthcare professionals who were mainly involved in COPD management (Figure 6). Only 19% of the centres included in the study reported offering patient education in which several healthcare professionals were involved. Healthcare professionals pointed out that the opportunities for interprofessional collaboration were limited or even impossible in small centres since some professionals had very limited time at these centres. Furthermore, the responsibility fell on them to establish teams, and most common physicians and nurses formed a small team that decided whether patients should meet other professionals, too.

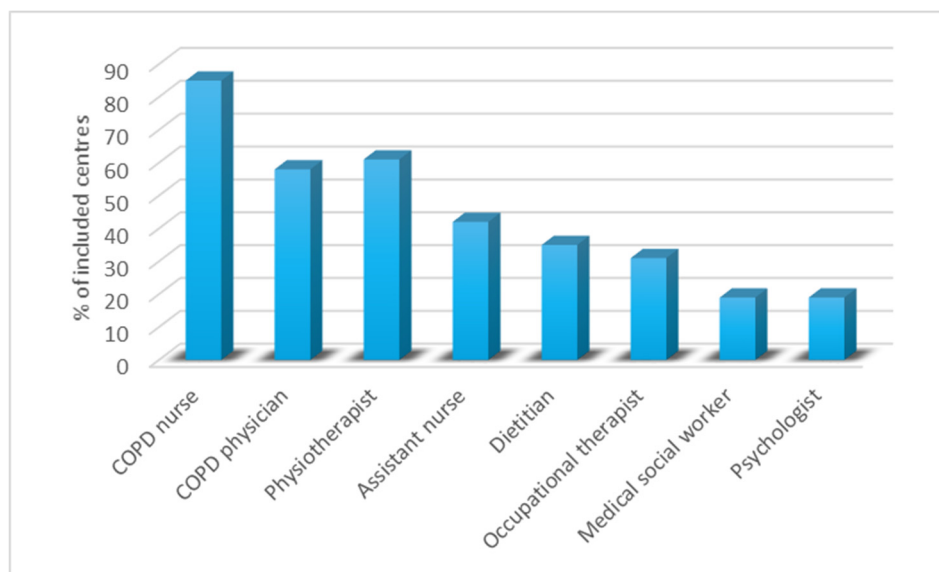


Figure 6. Healthcare professionals working with COPD at the included primary care centres.
COPD = Chronic obstructive pulmonary disease

In addition to the lack of resources, both healthcare professionals and people with COPD experienced COPD having a low status in primary care. By contrast, only two primary care centres reported people with COPD not being a prioritised group. The experience of healthcare professionals was that COPD was treated as “not as ‘special’”, and had a lower priority than other chronic conditions, such as diabetes. Seventy-seven percent of the primary care centres reported having

additional training for COPD, while healthcare professionals experienced that it was mainly pharmaceutical companies that conducted this training. Only 31% of the COPD nurses at had ≥ 7.5 university credits for COPD and asthma, which contrasted with the prioritisation of additional training for diabetes.

“So, here’s how it’s always been, Diabetes has always had a lot higher status. Diabetes nurses get training—and while they’re getting trained, they’re getting paid. That’s a huge difference. So it’s always been sort of more important than asthma - COPD.”

Healthcare professional

Even greater frustration was created when management prioritised more time for diabetes management than for COPD management. The COPD nurses used a median of 4 hours per week (ranging from 0-15) for people with COPD, which is equal to 40 minutes a week per 1,000 enrolees. Senior managers reported spirometries and treatment of exacerbations being prioritised at the primary care centres (Figure 7). On the other hand, people with COPD desired more interventions than the spirometries and medications that primary care mainly focused on.

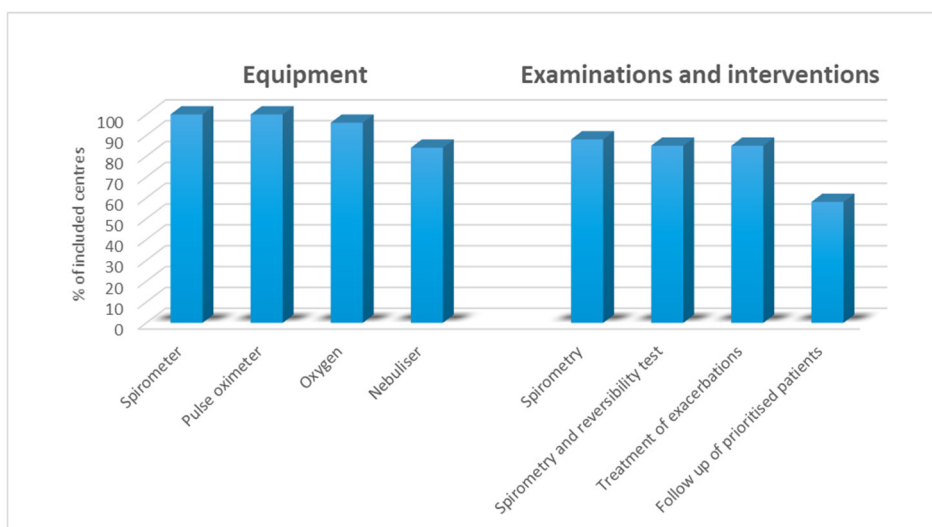


Figure 7. Equipment, examinations and interventions available at the primary care centres.

Healthcare professionals

In the entity *healthcare professionals*, there appears a picture of driven, caring, but at the same time, uncertain healthcare professionals. These professionals wish to provide empowering and health promoting interventions in collaboration with other professionals, but are inhibited by their lacking competence and by contextual factors.

The healthcare professionals were autonomous and accustomed to bear the responsibility of their own work and routines. Management retained more general control and did not directly influence the practical work at the centres. Instead, the responsibility for everyday work with patients was placed on the healthcare professionals or on each profession. If there was only one representative of a profession in the centre, this became an individual responsibility. Sometimes their roles were more pragmatic, and they helped each other.

"...[we] are pretty independent here. We get to run things pretty much how we want, just as long as we get it done. /... / We get to try different ways of doing things and really find what works best...and there's no-one who tries to tell us what to do."

Healthcare professional

Healthcare professionals mainly described a more pragmatic work with routines, since not all healthcare professionals were involved in systematic work with routines due to lack of time. Implementation of routines were the responsibility of the individuals, performed in a kind of "trial and error" manner and follow-up routines were also done pragmatically. At the same time, there were wishes of more structured follow-ups to ensure the quality of the initial work. The healthcare professionals sometimes used coffee and lunch breaks to solve problems and discuss issues, and they experienced that working at a small unit could make this kind of pragmatic work easier to do.

Some resistance to top-down directives and hierarchies was expressed by healthcare professionals. They were critical of economic incentives, and instead tried to focus on what they judged was best for people with COPD. At the same

time, they believed that it was important to monitor healthcare, but expressed frustration since the theoretical image of civil servants and politicians was not perceived as being consistent with their clinical reality. Also professional hierarchies were a concern, and some scepticism about the working methods of other professions was expressed. Physicians were sometimes seen as forming a “complicated” professional group to work with when they tried to protect their power at the top of the healthcare hierarchy. They were also described as having a clear dominance in work with routines, where it was difficult to act contrary to their opinions.

The COPD nurse was considered important by both healthcare professionals and people with COPD, and described as a competent driving spirit that carried the COPD interventions, and had time allocated for COPD. Healthcare professionals defined the COPD nurse as “a spider in the web” – an “administrative hub” that coordinated and performed a large portion of the COPD interventions. It was perceived as a security for the other healthcare professionals to be able to consult with a COPD nurse about COPD. The competence and experiences of the healthcare professionals seemed to be guiding the interventions provided to people with COPD. They only used quality registers and patient assessment when it was an advantage in their work. Similarly, only a minority of the primary care centres reported a use of symptom assessment, or assessment of physical capacity (Figure 8).

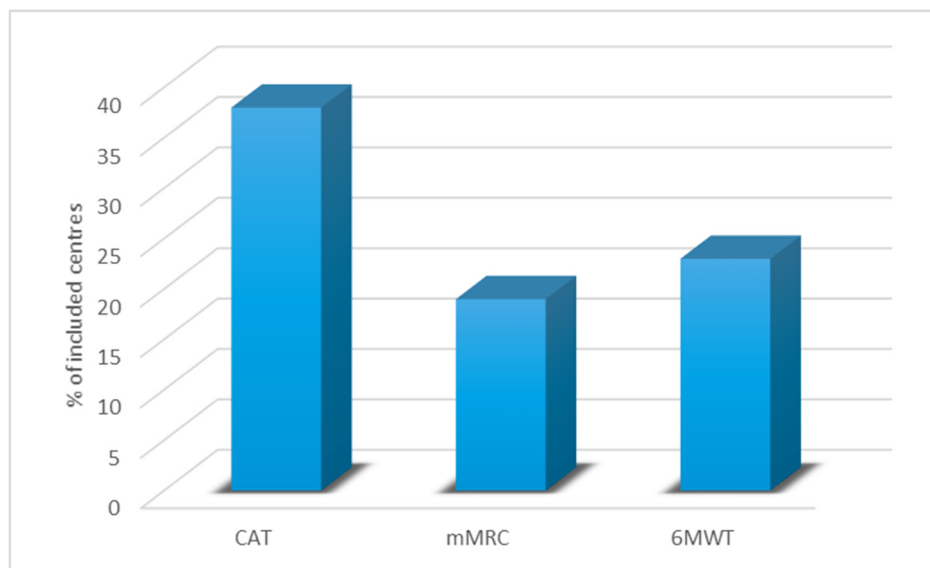
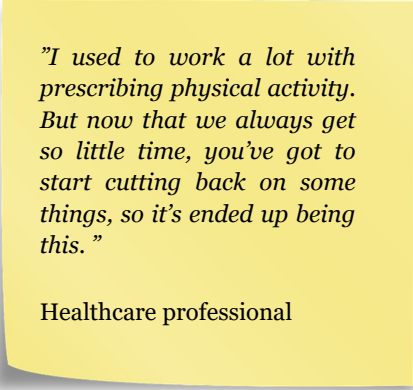


Figure 8. Use of assessments of patient-related outcomes at the included primary care centres. CAT = Chronic obstructive pulmonary disease Assessment Test; mMRC = modified Medical Research Council scale; 6MWT = six minute walk test

A majority of the healthcare professionals perceived health promotion interventions as being important to offer early in the disease to people with COPD, but only 56% of them reported doing so as being part of their work tasks. Only 38% of the primary care centres reported routinely offering health promotion interventions to people with COPD, except for tobacco cessation, which was offered by 85%. All centres reported their healthcare professionals being convinced of the positive effects of health promotion. Several barriers to providing health promotion interventions were mentioned by the healthcare professionals: meeting people with COPD only in acute situations, comorbidities, lack of knowledge, and unfamiliarity. Difficulties arranging patient education or exercise training in groups, poor economy and travel issues for the patients, as well as the society's perception of lifestyle issues could also serve as barriers. In addition, healthcare professionals expressed frustration and worries concerning the lack of resources in terms of limited time. People with COPD questioned whether the stressed healthcare professionals had sufficient competence, interest, time and routines for supporting people with COPD. Healthcare professionals admitted that they sometimes had to work with "quick fixes" and give low priority to giving advice on physical activity, support for tobacco cessation, and other important interventions to compensate for the lack of resources.

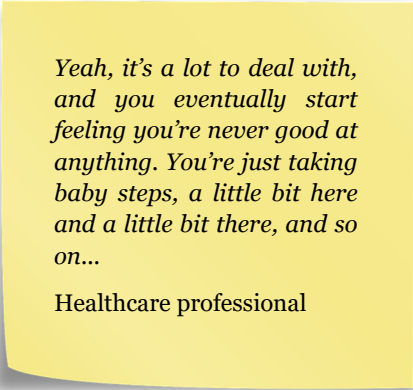


"I used to work a lot with prescribing physical activity. But now that we always get so little time, you've got to start cutting back on some things, so it's ended up being this."

Healthcare professional

People with COPD perceived that healthcare professionals were sometimes uncertain and that they needed more education on COPD. In addition, healthcare professionals reported in both interviews and questionnaires a lack of knowledge of and experience with COPD. Physiotherapists and occupational therapists mostly reported meeting with few, if any, people with COPD during an ordinary week. Physicians and COPD nurses reported meeting three to five people with COPD each week, while other nurses often met a few as well. For several health promotion interventions recommended in clinical guidelines 61-78% of the

healthcare professionals perceived not having sufficient knowledge. For preventive work for tobacco use and for giving information about COPD-related self-management, 39% and 50% of healthcare professionals, respectively, perceived that they did not have sufficient knowledge. By contrast, only 8% of the senior managers in the primary care centres reported healthcare professionals having inadequate knowledge of COPD as making it difficult to work with health promotion interventions. The healthcare professionals perceived that this lack of knowledge might inhibit interprofessional collaboration. They yearned greater competence in the subject, but perceived that they were given responsibility for their own professional development due to limited opportunities for further training. Staying up-to-date on the wide range of conditions that was covered by primary care was perceived as difficult:



Yeah, it's a lot to deal with, and you eventually start feeling you're never good at anything. You're just taking baby steps, a little bit here and a little bit there, and so on...

Healthcare professional

Despite the challenges in primary care, healthcare professionals were being driven by a desire to do good, which also was perceived by people with COPD. It was important for the healthcare professionals to be proud of their work and know that their patients were getting equal healthcare. They wanted to be available and supportive, and to work toward prevention, which were also important aspects for people with COPD. Developing a “primary care relationship” was important for both healthcare professionals and people with COPD, meaning that they get to know each other and meet regularly and over time. Doing so made it easier for healthcare professionals to be efficient and to introduce health promoting interventions more naturally, while for people with COPD this was a security and facilitated contacting and getting help more quickly. People with COPD expressed placing value in the social part of the interaction, and healthcare professionals also appreciated continuous relationship.

Interprofessional collaboration was desirable to healthcare professionals, was experienced to give an opportunity to work towards prevention. It was considered to be an opportunity for acquiring deeper knowledge of COPD, obtaining an

overview of the area and gaining insight into the work of other professions. Furthermore, they wanted to be flexible in interactions and wanted to get people with COPD involved in their healthcare, and to support them in coping with their disease. By contrast, a written treatment plan was only offered in 15% of the primary care centres. Healthcare professionals were tailoring interventions for people with COPD instinctively. Follow-up visits were planned based on the needs, expectations and life situations of the patients. Smokers and patients with recurrent exacerbations were planned for regular visits, while others had the responsibility of calling when needs arose. People with COPD experienced regular follow-ups and available healthcare professionals as reassuring and as assistance in managing their disease.

Being treated with respect was expressed as being important for people with COPD during interaction with healthcare professionals. In general, people with COPD perceived that the healthcare professionals were nice, cared for them, encouraged them, and included them in decision-making. It was important for them to be taken seriously and to be respected, as well as to feel welcome and listened to, and these feelings made it easier for them to contact primary care when it was necessary to do so. However, there were also experiences dealing with disempowering support and feeling abandoned by healthcare professionals. Too few follow-ups, not being taken seriously or not feeling like they were believed could make them wait unnecessarily long before seeking the healthcare they needed. Frustration arose when they did not get interventions for exacerbation according to the instructions they had got and instead were made to wait until the situation became more acute. Finally, talking about smoking was a tricky issue for both healthcare professionals and people with COPD. It was a balancing act where the healthcare professionals had to “go on instinct” to avoid nagging and imposing guilt, since doing so could make people with COPD turn a deaf ear due to a feeling that they were being “pigeonholed” because of their disease.

People with COPD

The entity *people with COPD* points to a grateful group of patients with limited knowledge and insight, and thus little impact on their healthcare. They experience shame, guilt and fear associated with their disease and its symptoms, which can be difficult to reach an understanding of in interaction with primary care.

People with COPD expressed feeling a burden of shame and guilt since COPD was perceived as a self-inflicted disease caused by smoking. Healthcare professionals expressed having to be aware of this in their work. When people with COPD did not manage to stop smoking despite professional support, they experienced even more shame. Overall, feelings of shame made them hesitate contacting primary

care because of a feeling of “troubling” the healthcare professionals. They were also concerned about what other people would think about them and how others should react when they were prioritised in primary care. Furthermore, feelings of loneliness were expressed, since they were inclined to avoid telling others about their COPD diagnosis.

“No-one talks about mental illness which is the most common illness in Sweden. No-one really gets how common it is. People don’t bring it up. It’s probably the same with COPD. It’s this shameful thing...so nobody really knows how many have it.”

Person with COPD

In addition to experiencing shame and guilt, symptoms caused by COPD made people with COPD fear dyspnoea and death. Successive worsening, exacerbation and dyspnoea could lead to insecurity, anxiety or even panic and fear of dying. Some difficulty in arriving an understanding of their symptoms in primary care made them avoid some situations and activities since they could trigger dyspnoea and exacerbations. They were missing information from primary care about the progression of COPD and speculated that their future did not look especially bright.

People with COPD were seen, by healthcare professionals, as members of an undemanding group with limited insight and knowledge, who were grateful for little. The dominant view was that people with COPD had too little knowledge about their disease, and that they were not always aware that they had COPD. When an exacerbation came, it was perceived that they had made contact with primary care too late, even if some expressed that they had done a lot of interventions at home on their own. In 27% of the primary care centres, people with COPD were reported as having no interest in participating in health promotion interventions. In addition, they had little influence on their healthcare since they rarely had any requests or opinions. Instead, they were experienced as a group that appreciated the interventions they received. This was confirmed by people with COPD who expressed a general satisfaction with the healthcare in primary care. They also attempted to accept COPD and not worry so much, and they focused on how they could improve their health status in interaction with

primary care. After all, it was perceived to be important that they also take responsibility in their interaction with primary care. A social network with helpful friends and family was also important, in addition to interaction with primary care.

Use of eHealth for COPD interventions: design and effect

For paper III, a systematic review of the effect of telehealth interventions was performed. The search strategy resulted in 9,930 articles. Of these, 597 abstracts and 132 full texts were assessed for eligibility, with a total of 9 articles remaining for analysis.¹¹⁷⁻¹²⁵ A total of 971 patients (44% women) were analysed in the included articles, and they had moderate-to-severe COPD. All articles were judged as having a high risk of bias in at least two domains, where no blinding of participants and personnel were the most common reason. The articles had a low risk of bias in zero to five (median three) of seven domains.¹¹⁷⁻¹²⁵ In paper IV, healthcare professionals, people with COPD and their relatives, as well as external researchers, participated in individual interviews and focus group discussions. The overarching theme *Reinforcing existing support structures* was formulated in the analysis. The theme runs through the two categories *supportive and non-interfering* and *meaningful and urgent*.

The findings from papers III and IV are presented in two sections (Figure 9). The first section presents the design of earlier telehealth interventions (aim 4) and the participants' view on what would make an eHealth tool relevant to them (aim 6). The second section presents the effects of telehealth interventions (aim 5) and the participants' perceived expected usability (aim 6). To illustrate, representative quotes from the findings of paper IV are also presented.

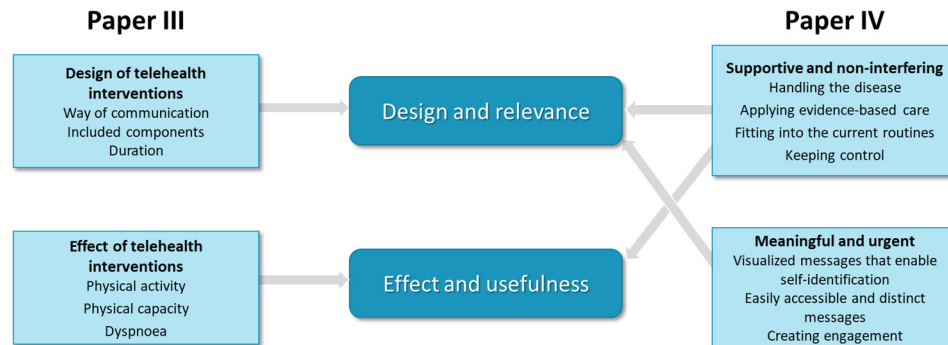


Figure 9. Findings from papers III and IV presented in the sections design and effect.

Design and relevance

Most of the articles included in the systematic review in paper III used interventions that were telephone-based with regular phone calls.^{117-119, 123-125} One study used short text messages through mobile phones,¹²⁰ while two studies had internet-based interventions with a website¹²¹ and video calls.¹²² The telehealth interventions consisted of regular contacts with the reporting of symptoms and compliance by people with COPD, as well as education, feedback and support by healthcare professionals. The interventions were combined also with education about self-management,^{117, 119, 121, 123} self-management plans^{120, 121} and/or exercise training.^{117, 118, 120, 121, 123, 124} There was a wide range in the duration of the interventions, from four weeks to 18 months.¹¹⁷⁻¹²⁵

The comparators in the included articles were ordinary care (optimised medication and ordinary healthcare contacts),^{117, 119, 125} education,¹²¹⁻¹²³ or exercise training.^{118, 120, 124} Some comparators also received telephone calls,^{118, 120, 121, 124} although not enough to reach the defined criteria for telehealth interventions. In three articles, the participants had received exercise training and/or self-management education before baseline assessment.^{118, 124, 125}

Healthcare professionals and researchers in paper IV experienced that an eHealth tool like the COPD web would be relevant if it supported healthcare professionals in applying evidence-based interventions in clinical practice. Healthcare professionals suggested that it should provide information and support for self-management strategies to meet their needs for knowledge. They presented a great variability in their present COPD-related knowledge and need for knowledge. For example, the physiotherapists needed additional knowledge about breathing techniques and appropriate intensity of exercise.

“...it’s basically the same kind of training for heart failure and COPD as I understand it. As far as using resistance bands goes at least. But then the thing is... how much I should be pushing them? You know, so they’re at a reasonable level to have some effect.”

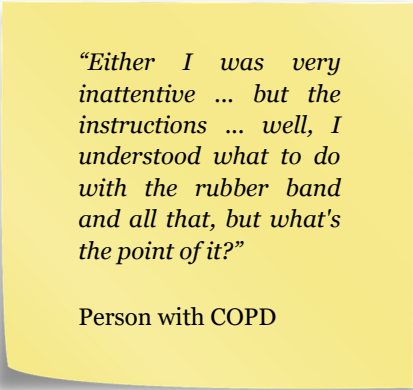
Healthcare professional

Easy access to materials such as screening tools, materials for patient education, and information about exercise groups was also perceived as having value by the

healthcare professionals. In addition, the researchers' discussions often concerned how guidelines and other evidence should be applied in primary care. Concrete advice could be provided by the eHealth tool on self-management for people with COPD and on how healthcare professionals could use the recommended screening tools. Finally, they also requested descriptions on how the guideline recommendations could be adapted to clinical practice, and how interprofessional collaboration and evidence based-practice could be organised.

In order to enhance use of the eHealth tool by people with COPD, healthcare professionals emphasised the importance of being able to individualise the tool. They wanted to be able to choose relevant information for each individual with COPD, and adapt to different stages of the disease and different comorbidities. Even though the desire to strengthen patients was prominent for both healthcare professionals and researchers, the eHealth tool was perceived as a potential threat to the hierarchy between healthcare professional and patient. Healthcare professionals expressed a desire to regain control, and patients having too much knowledge might result in the healthcare professionals being questioned. Hence, the researchers and healthcare professionals agreed that not all information on the eHealth tool was appropriate for people with COPD to read, such as the organisation of interprofessional collaboration, national guidelines and alternative interpretations of symptoms.

Easily accessible information and the possibility for self-identification were important aspects of the eHealth tool for all groups of participants. They found it important that the information was presented in a brief and clear manner, and was illustrated with pictures. A possibility of listening to the information was also suggested, to grant availability to more people. Both healthcare professionals and people with COPD emphasised that it was important to specify the purpose and benefits of the self-management strategies presented in videos.



"Either I was very inattentive ... but the instructions ... well, I understood what to do with the rubber band and all that, but what's the point of it?"

Person with COPD

Furthermore, another important aspect was that the eHealth tool was easy to find on the internet. If registration and login could be voluntary or avoided, the healthcare professionals believed it would be used to a greater extent. All groups of participants suggested using videos that enabled self-identification as a tool to reach the users with information about how to handle the disease. To make the information meaningful, it was important for people with COPD to identify themselves with people in the videos. Therefore, they suggested using real people with COPD of all ages, colours and disabilities as role models. Healthcare professionals further suggested that different stages of the disease, as well as various experiences of using self-management strategies, should be represented in the videos. Furthermore, people with COPD suggested short videos on handling specific situations, such as talking about the disease with friends, to help deal with the self-blame and shame connected to COPD.

It was important to all groups of participants that the eHealth tool promoted engagement among its potential users. The researcher pointed out that word choice was crucial to the engagement of all groups of healthcare professionals. Pulmonary rehabilitation was perceived as too much physiotherapy, and health promotion was suggested as an alternative. The introduction of the eHealth tool was also an important part of creating engagement. People with COPD preferred a face-to-face introduction to the eHealth tool by a health professional. They were annoyed by leaflets, but thought some kind of card with the address of the website was unavoidable. Healthcare professionals, on the other hand, preferred written information about the eHealth tool to hand to people with COPD, as well as to their relatives, as a way of getting them involved.

Effect and usefulness

The effect of telehealth on physical activity was analysed using a meta-analysis for each of the outcomes.

Physical activity level was measured in three studies using questionnaires^{119, 121} and an accelerometer.¹²⁰ Two studies were excluded from the meta-analysis due to the use of a dichotomized scale¹¹⁹ and heterogeneity,¹²⁰ leaving only one study with two telehealth groups.¹²¹ The mean difference was 64.7 minutes (95% CI, 54.4 to 74.9; $p < 0.001$), which favoured telehealth (Figure 10). Due to there being too few studies, Egger's test was not applicable. A sensitivity analysis was performed to explore how the exclusion due to heterogeneity affected the results (Figure 10).

Physical capacity was measured in eight studies using several tests.^{117, 118, 120-125} The six-minute walk test was the most common^{117, 118, 120-124} and was selected for the meta-analysis. Two studies were excluded due to heterogeneity,^{121, 123} leaving

five studies.^{117, 118, 120, 122, 124} There was no difference found between telehealth and comparator (MD, -1.3 m; 95% CI, -8.1 to 5.5; $p=0.708$) (Figure 10). Egger's test showed no evidence of publication bias ($p=0.813$). A sensitivity analysis was performed, and the result is shown in Figure 10.

Dyspnoea was measured in seven studies using several questionnaires and scales.^{118, 119, 121-125} The Chronic Respiratory Questionnaire, Dyspnoea subscale (CRQ-D),^{118, 121, 123-125} Shortness of Breath Questionnaire (SOBQ)¹²² and Medical Research Council (MRC) Dyspnoea scale¹¹⁹ were selected to be included in the meta-analysis, since they are validated and frequently used for measuring dyspnoea in daily life. There was no significant difference found between telehealth and comparator (SMD, 0.088; 95% CI -0.056 to 0.233; $p=0.232$) (Figure 10). Egger's test showed no evidence of publication bias ($p=0.412$).

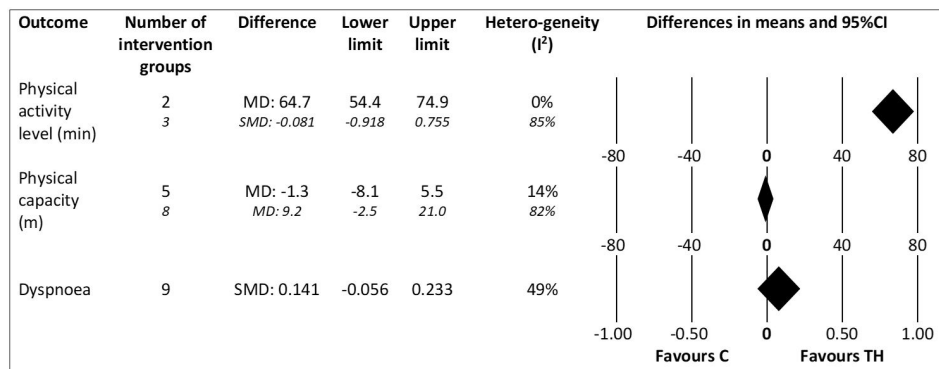


Figure 10. Forest plot of the effect of telehealth on physical activity level, physical capacity and dyspnoea. Numbers in italics show the result of the sensitivity analysis. Abbreviations: C = comparator; CI = confidence, MD = mean difference, SMD = standard mean difference, TH = Telehealth

All groups of participants considered the eHealth tool as contributing improved knowledge and support for self-management strategies for people with COPD. The relatives perceived that the eHealth tool could be a support for them to acquire deeper understanding about COPD. The support from the eHealth tool was important for people with COPD, since they experienced pressure handling the disease themselves, and that physicians and the healthcare system ignored COPD. At the same time, people with COPD had limited knowledge about the disease, self-management and the healthcare services that were available. Further, they did not want to “bother” busy healthcare professionals with non-medical issues, such as support for exercise training, except for smoking cessation. The responsibility for their disease was their own to carry, since COPD was not always something that they talked to their relatives about. The

importance of empowering people with COPD with the eHealth tool was especially emphasised by the healthcare professionals and researchers. They perceived people with COPD as being a stigmatised and low-powered group that might have difficulty asking for services.

“How easy can it be for the patient who is weak, stigmatized, devalued and feels bad? That’s not so simple.”

Researcher

It was important for the healthcare professionals and the people with COPD that the eHealth tool fit into current routines and contexts of primary care, and was also of interest to people with COPD. Not all rooms at the primary care centres had computers, and there was a need to use the eHealth tool in a flexible way, e.g. with a tablet. Longer time for visits was also of concern in using an eHealth tool. People with COPD presented variation in computer skills, and interest in and motivation for using the eHealth tool, which was seen as a challenge. Using the eHealth tool to perform exercise training at home was commonly perceived as less fun and motivational than doing exercise training in a group with other people with COPD.

The findings based on i-PARIHS

In this thesis, the findings can be related to the four constructs of i-PARIHS.⁹⁵

The *innovation* is represented by the clinical guidelines and the use of eHealth. Senior managers report that guidelines for COPD are used in the primary care centres, while the healthcare professionals experience trouble with keeping up-to-date on all guidelines. Telehealth interventions show a positive effect on physical activity level, but no effect for physical capacity and dyspnoea. The intended users experience that an eHealth tool is relevant if it provides information and advices, is easy accessible and possible to individualise.

The *recipients* is represented by healthcare professionals and people with COPD in primary care, and their ambiguous interactions. The healthcare professionals

are ambitious, are used to taking responsibility, and have a desire for interprofessional collaboration and provide high-quality interventions. Meanwhile, they struggle with limited competence and with context barriers. People with COPD are characterised by shame and guilt, limited knowledge and impact, as well as fears. On the other hand, they have a positive view of life and wish to live a normal one.

The *context* is represented by the primary care centres and the healthcare system. The responsibility distribution in the healthcare system is perceived as fragmented and unclear, while COPD is experienced as a low priority resulting in limited resources in primary care.

The *facilitation* is represented by the perceptions of how an eHealth tool can support improved access to self-management strategies for people with COPD. It can be accessible, and improve knowledge, awareness and engagement among its users.

Discussion

The overall aim of this thesis is to explore the conditions for implementation in primary care. The conditions were explored in two parts, the first being the experiences, interactions and context of the management of COPD in primary care. In addition, the design and perceived relevance, as well as the effect and experienced usefulness of eHealth solutions were also investigated. The findings show several enablers and barriers at the organisational, professional and patient levels. The organisation is illustrated as being shaky ground that results in challenging circumstances and work conditions for the healthcare professionals. They are driven and wish to build an empowering healthcare for their patients, but they are inhibited by having a limited competence in COPD. People with COPD form a group of patients that are generally satisfied with the interventions they receive, but they struggle with shame, guilt and fear. Their interaction with healthcare professionals is ambiguous and influenced by prioritisation of COPD in primary care, attitudes and support from healthcare professionals, as well as their own emotions and attitudes. eHealth may increase physical activity level in people with COPD and is expected by the users to improve the knowledge of healthcare professionals and people with COPD. In order to provide support for self-management, eHealth tools need to be easy to use and understand, and should offer the possibility of individualisation. Furthermore, it must fit into the current routines and daily lives of the users, and promote engagement in order to enhance its use.

In the following sections, some of the findings are discussed based on the four constructs of the i-PARIHS framework: *innovation*, *recipients*, *context* and *facilitation*.⁹⁵

Innovation: clinical guidelines and eHealth for COPD

The innovation construct in the i-PARIHS framework⁹⁵ refers to the evidence that is supposed to be implemented, and its fit in clinical practice. In this thesis, the innovation is represented by the clinical guidelines for COPD that are based on available evidence and eHealth, which promotes self-management strategies.

The clinical guidelines for COPD^{1, 31, 32} are based on available evidence. The findings in this thesis show that there is a gap between the recommendations and the healthcare that is offered to people with COPD, such as low availability to PR, physiotherapists and exercise training. Criteria for asthma/COPD receptions in Swedish primary care³⁸ are based on the most prioritised interventions in the national guidelines. People with COPD have been reported to experience fewer exacerbations and require less healthcare contacts if they are enrolled in primary care centres that meet the criteria for asthma/COPD management. Consequently,

the annual costs of medication and healthcare utilisation was considerably lower for these people.¹²⁶

It has been suggested that eHealth solutions can be used to increase the access to evidence-based interventions for people with COPD.^{53, 75} One aim of this thesis is to describe the design of earlier telehealth interventions where some kind of motivational or advisory interaction with healthcare professionals had occurred. Our findings show that very few studies have used internet-based interventions. Internet access is expanding in Sweden, even in the older population.⁸² The need for more research about internet-based interventions is therefore required. Since the systematic review (paper III) was conducted, some new studies have been published. Four different internet-based telehealth interventions that included patient education, monitoring and/or exercise training were compared with usual care. The interventions lasted for 8 weeks to 12 months.¹²⁷⁻¹³⁰ No between-group difference was found for physical activity.^{127, 128} Most studies found no between-group difference for physical capacity^{127, 128, 130} and dyspnoea,^{127, 128, 130} while some found that the intervention group had improved in dyspnoea¹²⁹ and physical capacity^{128, 129} compared to the usual care group.

Several of the intervention and comparator groups in paper III had similar interventions, with the difference being that the comparators' interventions were face-to-face instead of by phone/mobile/internet. This might explain why several studies found within-group changes, but no between-group changes. A meta-review of telehealth interventions for people with COPD and other chronic diseases included 53 systematic reviews (e.g. paper III). The results varied between the reviews, but no review reported any negative effects of telehealth.¹³¹ When active interventions are compared, Gotzsche¹³² notes that even small between-group differences can be important because of the small difference between the interventions. If PR is as effective by telehealth as face-to-face, it can be an important tool for making PR more available to people with COPD, especially for those who are a long distance from healthcare facilities, or have transportation difficulties.

A low use of internet-based intervention has been reported as being a barrier for implementation of eHealth solutions for people with COPD, where problems with usability was one suggested reason.¹³³ It is important to assess the fit and usability of an innovation in clinical practice, according to i-PARIHS,⁹⁵ if it is to be successfully implemented. Thus, user involvement in the development phase is important for improving usability in the healthcare system.¹³⁴ In paper IV, the participants pointed out the importance of the eHealth tool being meaningful and *fitting into the current routines*. The importance of eHealth solutions being easy to use and fitting into the everyday lives of people with COPD and the workflow of healthcare professionals have also been stated in earlier studies.^{78, 135}

Recipients: interaction and knowledge

In the i-PARIHS framework, the construct recipients can be explored from two angles. First, the change commitment concerns the motivation, values and beliefs of the recipients regarding issues necessary for the implementation,⁹⁵ such as interactions between healthcare professionals and people with COPD. Second, the change efficacy concerns whether the recipients have the ability to change, in terms of knowledge, skills, time, resources and support.⁹⁵ In the following sections, the main focus is on interaction and knowledge.

The *interactions* between healthcare professionals and people with COPD is an important part of the management of COPD. Thus, it is important that the recipients value shared decision-making, a respectful interpersonal style and empowering communication. Wouters⁸⁶ concludes that patients need to be involved if healthcare professionals are going to be able to provide individualised COPD management. According to Swedish law, patients should be involved in the design of interventions, and their wishes and prerequisites should influence the interventions.¹³⁶ Patient empowerment and self-management have been determined as the most important factors for a successful implementation of eHealth interventions for patients.¹³⁷ Similar to the findings from paper I, people with COPD have been described as having a low engagement in their healthcare.¹³⁸ A lack of knowledge, along with anxiety, and feelings of helplessness and hopelessness, associated with dyspnoea and death, have been reported as barriers for people with COPD to engage in self-management and other healthcare interventions.^{58, 139-141} People with COPD find shared decision-making with healthcare professionals to be important.¹³⁹ Involving and supporting people with COPD in the referral-process might facilitate their participation in PR.^{56, 57} In addition, eHealth interventions that enable interactions between healthcare professionals and patients are suggested as ways to facilitate behavioural change.¹³⁵ Despite this, the healthcare professionals and researchers in paper IV of this thesis expressed conflicting thoughts about involving and empowering people with COPD. Similar to our findings, Nilsson⁷⁶ and Stoilkova-Hartmann¹⁴² reported that involving patients in healthcare decisions and using eHealth solutions can challenge professional identity and the hierarchy between healthcare professionals and patients. Healthcare professionals are not always willing to change their work routines to adapt to new situations.⁷⁶

The interpersonal style of the healthcare professional is an aspect of the interaction that is important for how people with COPD adhere to self-management strategies. People with COPD in paper II emphasised the importance of being seen, understood and taken seriously in interactions with healthcare professionals. These findings are similar to those reported in earlier

studies with people with COPD¹⁴³ and other long-term conditions.^{144, 145} A close and regular relationship with a healthcare professional, in which people with COPD could share their thoughts and feelings, was also important for their motivation.¹⁴³ Common patient complaints concerning interactions in healthcare encounters relate to several aspects that were mentioned in the findings of this thesis, such as not being treated with respect, not being involved in decision-making, and not feeling welcome and being seen as an important person.¹⁴⁶ These aspects have also been mentioned by primary care nurses important in having a good encounter.¹⁴⁷

The *knowledge* of the recipients influence their ability to change according to i-PARIHS.⁹⁵ The findings in this thesis show that both healthcare professionals and people with COPD lack knowledge about COPD. A lack of knowledge about COPD among healthcare professionals has also been reported elsewhere.^{69, 148} The concepts health promotion and self-management can be difficult for healthcare professionals to grasp.¹⁴⁹ This may be an explanation for why the healthcare professionals in this thesis, and other studies¹⁴¹ consider them to be outside their daily practice. Altogether, healthcare professionals' lack of COPD knowledge leads to a lack of adherence to guidelines, such as referring people with COPD to PR.^{55, 57, 148} As found in this thesis, several studies have reported that people with COPD also lack in knowledge and insight.^{17, 54, 141, 150-152} Implementation of self-management interventions and eHealth solutions require awareness of the health literacy and eHealth literacy of patients.^{43, 150}

Health literacy is defined as an individual's motivation and ability to gain access to, understand and act upon healthcare information to promote and maintain a good health.¹⁵³ In addition, eHealth literacy also includes the ability to find healthcare information from electronic sources.¹⁵⁴ In earlier studies, about a third of people with COPD had low health literacy, and mean eHealth literacy was moderate.^{155, 156} High eHealth literacy is associated with greater COPD knowledge and can positively influence the ability of patients to benefit from self-management support from eHealth.^{135, 156} People with COPD in this thesis perceived that they had to compensate for insufficient support from primary care. Likewise, to compensate for the lack of knowledge among healthcare professionals, people with COPD have expressed a wish for greater availability sources of information about COPD.⁶⁹ However, they recognise difficulties in distinguishing between high- and low-quality resources, as well as in using the information to make health decisions.¹⁵⁶

The competence of healthcare professionals is emphasised in the criteria for asthma/COPD management in Swedish primary care. For the asthma/COPD nurses and the physiotherapists additional training in COPD at a level corresponding to a ten-week and five-week university course, respectively, is

required. Physicians responsible for asthma/COPD were reported to need at least two additional days of training each year.³⁸ However, a conflict was shown in the findings in this thesis where healthcare professionals wanted greater knowledge about COPD, whereas senior managers found the same healthcare professionals knowledgeable enough. This might, of course, have a bearing on possibility of additional training. Finally, it is important to identify people with COPD with low health literacy in order to adapt the information, for example by using pictorial aids or films,¹⁵⁷ just as the participants in this thesis suggested.

Context: stigma and resources

Change commitment and change efficacy among the recipients are influenced by their context. In i-PARIHS, context is divided into inner and outer context.⁹⁵ In this thesis, the inner context is represented by the primary care centre, which is the immediate work environment for the recipients (local level) and the organisational priorities and culture of the whole primary care (organisational level). The outer context is represented by the entire health system. In the following sections the focus will be on the inner context, more specifically on stigma at local level and resources at organisational level.

Stigma related to COPD is part of the culture at the primary care centres (local level). An important aspect of the culture is whether the healthcare professionals and patients feel valued.⁹⁵ Emotions of shame and guilt were found to be prevalent among people with COPD in this thesis and in several other studies with people with COPD.^{69, 140, 141, 158-160} Shame is an emotion experienced in social interaction when people see themselves through the eyes of others and fail to live up to their own standards. Shame leads to a desire to hide or disappear.¹⁶¹ The findings that the participants did not want to tell others about their disease (paper II) could be a response to shame. Similarly, others have found that people with COPD have a desire to hide their COPD diagnoses and its symptoms from others, even from their closest family members,^{141, 151, 160} leading to a decrease in social interactions.^{141, 160} Guilt arises after a personal failure that is associated with one defined aspect of the self. The response to guilt is to make restitution towards others.¹⁶¹ The reluctance of people with COPD in paper II to be prioritised before other patients is comparable to earlier findings where people with COPD did not find themselves worthy of healthcare,^{140, 159, 160, 162} which might be because of the guilt due to their self-inflicted disease. Consequently, shame among people with COPD has been shown to delay seeking healthcare support, as well as being a barrier for self-management and patient education.^{27, 93, 141, 163} Shame and guilt have been shown to be associated with depression, lower quality of life, symptoms and absence from work for people with COPD.¹⁵⁸ The shame and guilt, in combination with perceptions that COPD is a low priority in primary care, as expressed in this thesis, create a culture in the local context that can be a barrier

for implementation. Thus, it is important for the facilitator to take this into account.

The *resources* in the primary care organisation (organisational level) have an influence on whether the recipients are given the necessary time and opportunities to implement an innovation.⁹⁵ To be able to offer the most prioritised interventions in accordance with the national guidelines, healthcare professionals need to have time set aside for people with asthma and COPD. A physiotherapist needs 1.3 hours/week per 1,000 enrollees and the COPD nurse needs 4.8 hours/week per 1,000 enrollees.³⁸ In this thesis, many of the physiotherapists did not meet people with COPD at all. The COPD nurses worked only 1.4 hours/week per 1,000 enrollees, which also corresponds to an earlier Swedish study.³⁷ Lack of time and increased workload have been reported as barriers in implementing interprofessional PR programmes for COPD¹⁵⁰ and eHealth interventions.¹³⁷ The resources available during the implementation process may determine whether the implementation is successful or not, as well as the quality of the interventions.^{137, 164}

Facilitation: eHealth as a strategy

The role of the facilitator and the facilitation process can be very complex. It requires an understanding of the nature of the innovation, the recipients and the context, as well ideas of how the implementation should be supported. A team that work towards the same goals preferably take the role of facilitator. Several strategies and actions are required to enable implementation.⁹⁵ In the following section the main focus will be on using eHealth as an implementation strategy.

eHealth can be a strategy to support implementation of interventions recommended in clinical guidelines, such as PR. In guidelines for developing eHealth solutions with the aim of empowering patients, user involvement is emphasised.⁷⁹ Papers I, II and IV were part of the user involvement process in the development of the eHealth tool, the COPD web. The COPD web has been developed to enhance implementation of the national guidelines in Swedish primary care. User involvement can facilitate implementation of eHealth into clinical practice by motivating healthcare professionals to use the tool and to show the patients that eHealth aims to improve their health.⁷⁹ The COPD web has been evaluated in a pilot study in primary care,¹⁰⁰ showing that the use was modest, but still increased perceived knowledge and self-reported physical activity level in people with COPD (submitted manuscript, Nyberg 2018). The participants in paper IV mentioned both increased knowledge and support for self-management as expected and desired effects.

Implications for physiotherapy

Physiotherapists have an obvious and important role in the management of COPD, to help people with COPD enhance their health behaviours. However, even though primary care centres in Sweden have good access to physiotherapists,^{37, 39, 40} this thesis shows that people with COPD mainly interact with COPD nurses in primary care. The physiotherapists in our study mainly met people with musculoskeletal problems and had rarely met people with COPD in clinical practice. This agrees with another study in Swedish primary care where only 7% of people with COPD had met a physiotherapist.⁴⁰ Physiotherapists have an important core role in interprofessional collaboration in primary care, together with nurses and physicians.³⁸ In centres with PR programmes this also seems to be the case⁴⁰, but the access to PR programmes across Sweden is too limited.^{39, 44} To reach more people with COPD, eHealth can be an appropriate tool for physiotherapists. This is supported by the Swedish Association of Physiotherapists, which has formulated an eHealth strategy to improve availability, knowledge and interaction with patients.⁸⁵

Exercise training and physical activity level, which are part of the expertise of physiotherapists, are some of the cornerstones in the management of COPD. Assessment of physical capacity with 6MWT and exercise training are highly prioritised in clinical guidelines for COPD.^{1, 31, 42} In particular, 6MWT could be an important assessment tool for physiotherapists, since a reduced walking distance is correlated with physical inactivity in people with COPD.¹⁶⁵ It could also be a useful tool for identifying patients with a high risk for mortality and hospitalisations due to exacerbations.¹⁶⁶ Since a low physical activity level is a predictor for mortality, it is also important for physiotherapists to work with behaviour change techniques to improve or maintain physical activity level.¹⁶⁷ However, in order for physiotherapists in primary care to implement this way of working they need further training in COPD and more time allocated for people with COPD.³⁸ The findings in this thesis may contribute to an increase in the knowledge of physiotherapists.

Methodological considerations

The use of qualitative, quantitative, and mixed methods is a strength of this thesis. Used together, the different methods can provide a more comprehensive picture of the conditions for implementation of evidence-based interventions and eHealth for people with COPD in primary care. The combination increases the strengths of and decreases the weaknesses of each method.¹⁶⁸ Another strength is that the findings from the included studies have been assessed and discussed based on the implementation framework i-PARIHS.⁹⁵

Trustworthiness^{103, 109} has been striven for in the design, data collection, data analysis and description of the papers included in this thesis. First, to ensure *credibility*,¹⁰⁹ the participants included in papers I, II and IV represented healthcare professionals, people with COPD, relatives and external researchers with variation considering sex/gender, age, and urban/rural primary care centres. People with COPD varied in perceived symptoms and work situations, while healthcare professionals and external researchers varied in their professions. A limitation is that variation in ethnicity was not reached. A larger number of people with COPD and their relatives in paper IV, as well as a greater representation of different professionals in the FGDs, would have been preferable. In paper III, a broad search strategy was constructed to make sure that no relevant article was lost since a pre-search showed that few articles met our criteria. However, a limitation is that the interventions and comparators in the included articles have a high risk of bias and are heterogeneous, which makes it difficult to draw any stable conclusions. The choice of performing a meta-analysis despite such heterogeneity can be questioned, but several strategies were used to decrease this heterogeneity and provide the reader assistance in judging the findings. Triangulation¹⁶⁹ between the researchers was used as a method to strengthen credibility in all four papers. Even though most of the researchers were registered physiotherapists, they represented various sex/gender, as well as a broad range of competencies, methodological backgrounds and perspectives, which strengthens the studies. Finally, peer-debriefing was applied to three of the papers, at seminars consisting mainly of PhD students (papers I, II and III), and qualitative researchers (paper II).

To ensure *dependability*,¹⁰⁹ the data collection with individual interviews, FGDs and questionnaires (papers I, IV) were conducted during a limited period of time. The database search (paper III) was updated right before the data analysis was completed. To ease the readers judgement of *transferability*,¹⁰⁹ thorough descriptions of the setting, the participants, and the methods used for data collection and data analysis have been presented, based on recommendations for how to report qualitative research,¹¹⁰ mixed methods¹¹⁵ and systematic reviews.¹¹³ The low availability of PR programmes and challenges with implementation of clinical guidelines and eHealth is not only present in Sweden.^{4, 33-35, 54, 55, 77, 78} The findings in this thesis also have several similarities with studies that have explored the conditions for people with other long-term conditions in Swedish primary care.^{144, 145, 170} Since the findings in the thesis are based on user involvement with several methods, groups of participants and materials, they could be transferable to healthcare organisations with similar contexts. The findings offer information that could be used in implementation processes in primary care where the aim is to narrow the gap between evidence and clinical practice, e.g. with eHealth solutions, for people with COPD or other long-term conditions.

Clinical and research implications

This thesis has explored the conditions for implementation of evidence-based interventions and eHealth in primary care. Several enablers and barriers have been found. The findings can be useful information for a facilitator preparing for the implementation of an innovation in primary care. It is important for the facilitator to be aware of the enablers and barriers that exist for the innovation, recipients and context to be able to manage them during the implementation process. Some of the findings that the facilitator has to focus on and find ways to handle in particular include how the context will be influenced by the implementation of clinical guidelines, and the shame and guilt that is associated with COPD.

Healthcare professionals in primary care need further training to be able to support self-management strategies for people with COPD. Furthermore, they also need more technical competence to facilitate use of eHealth solutions.⁷⁶ The Swedish National Board of Health and Welfare has established that in addition to further training of healthcare professionals, Swedish primary care also needs to develop structures that enable interprofessional collaboration, patient education and collaboration with specialty care. The costs are estimated to increase initially due to more follow-up visits and more involved healthcare professionals, in order to decrease later because of decreased hospital care and sick-leave.³¹

Since stigma-related experiences such as shame and guilt have been reported also for people with other non-communicable diseases,^{27, 158} psoriasis,¹⁷¹ and persistent pain,^{145, 172} healthcare professionals probably meet these issues regularly in primary care. Finding an approach that could mitigate emotions like shame and guilt could therefore be useful for people with several conditions. People with COPD in paper II experienced negative attitudes from healthcare professionals and society that made them feel like a burden and that they had no one to talk to about worries related to their disease, which was also confirmed elsewhere.^{69, 159} Social support from fellow patients was expressed as being important, especially for people with COPD, who often are confronted with stigma and misunderstanding.⁵⁶ Lazare¹⁶¹ presents several suggestions on how to manage shame in clinical practice, such as creating a respectful atmosphere where patients feel welcome; supporting and praising patients who are seeking help and trying to manage their disease; and getting patients involved by asking for their perspective. For people with persistent pain a multi-professional rehabilitation programme began an emotional process that took patients from shame to respecting themselves. The process involved increased knowledge and awareness, and improved self-image.¹⁷² Future studies need to establish if PR could have the same effect on shame among people with COPD.

This thesis had a lack of variation in ethnicity among healthcare professionals and people with COPD. Immigrants with COPD have been shown to have low adherence to COPD-related interventions.¹⁷³ In addition, minorities in the population have been shown to have less experience using computers and the internet.¹⁷⁴ Further, this thesis did not analyse gender aspects. Women with COPD are more affected by their disease than men, which also leads to a higher use of healthcare resources.¹⁷⁵ They also experience trouble reaching their healthcare contacts and then receiving enough time with them.²⁶ Consequently, future studies should focus more on how ethnicity and gender may influence the interaction between healthcare professionals and people with COPD, and the use of eHealth solutions.

The COPD web needs to be further evaluated when it comes to its effects on people with COPD. For that reason, a larger RCT is planned to evaluate the effect on physical activity level, quality of life, symptoms, health economics, as well as experienced enablers and barriers for the use in order to change behaviour. Furthermore, the COPD web might also be useful for supporting implementation of clinical guidelines in other settings of the health system. User involvement has been employed to further develop the COPD web for use in home healthcare, where an evaluation is in progress.

Conclusions

This thesis, based on qualitative, quantitative and mixed methods, explore the conditions for implementation of evidence-based COPD interventions and the use of eHealth in primary care. There is a gap between clinical guidelines for COPD and the interventions provided in primary care. The complex interaction between the healthcare organisation, healthcare professionals and people with COPD show several barriers and enablers for implementation. The healthcare organisation have inadequate resources and routines for COPD and inadequate access to different professionals such as physiotherapists. Healthcare professionals are ambitious and driven but have limited competence for COPD. People with COPD try to cope with their disease with limited knowledge. The interaction between healthcare professionals and people with COPD is experienced as ambiguous, which for people with COPD can be empowering and facilitate self-management strategies, but can also be disempowering due to the stigma and low status of COPD.

eHealth can be used to facilitate the provision of evidence-based intervention for people with COPD. Earlier telehealth interventions have mainly been telephone-based and have included education and/or exercise training. They show improvements in physical activity level, while no effect is found for physical capacity and dyspnoea. Since the interventions are heterogeneous and the comparators often have similar interventions, the findings should be considered with caution. Intended users consider eHealth relevant if it fits in existing routines and contexts and provides information presented in an accessible way, which can be adapted to individual needs. It is expected to increase the users' knowledge and provide support for self-management, even though, at the same time, the users are concerned about the practical use.

Several actions are required to enhance implementation in primary care setting. The status and priority of COPD need to be raised and high quality interactions between healthcare professionals and people with COPD, where stigma is acknowledged, are desirable. Increased access to several kinds of professionals, such as physiotherapists, and further training of healthcare professionals is also required to improve COPD management. Future studies are required to determine how eHealth can be used to facilitate implementation of COPD guidelines, and how ethnicity and gender may influence the interaction between people with COPD and healthcare professionals.

The findings in this thesis may be valuable for facilitators in the preparation of implementation processes in primary care.

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Appendix 1

Compressed questionnaire “Mapping of resources and interventions”

1. Enter the name of the primary care centre. (Free text)
2. How many patients are enrolled at the primary care centre? (Free text)
3. How many of the patients enrolled at the primary care centre have been diagnosed with COPD (diagnosis code J44)? (Free text)
4. Does the primary care centre have a physician medically responsible specifically for patients with asthma and COPD? (Yes, No)
5. Is there an asthma/COPD nurse at the primary care centre? (Yes, No, Other, Free text)
Asthma/COPD nurse refers to a nurse specifically tasked with responsibility for patients diagnosed with asthma and COPD. If there is other staff with a specialised function in the area of asthma and COPD at the primary care centre, please describe this at “Other”.
6. What supplementary training does the asthma/COPD nurse have? (No advanced training, 7.5 credits, 15 credits, 30 credits, Other, Free text)
If you chose “Other” in the preceding question, please specify the supplementary training of that person.
7. How many hours of the asthma/COPD nurse's working time each week are designated for work with asthma patients? (Free text)
If the asthma/COPD nurse also works with general smoking cessation support, i.e. smoking cessation support not targeting individuals with asthma, then these hours should not be included.
8. How many hours of the asthma/COPD nurse's working time each week are designated for work with COPD patients? (Free text)
If the asthma/COPD nurse also works with general smoking cessation support, i.e. smoking cessation support not targeting individuals with COPD, then these hours should not be included.
9. How many actual hours of the asthma/COPD nurse's working time each week are used for work with asthma patients? (Free text)
10. How many actual hours of the asthma/COPD nurse's working time each week are used for work with COPD patients? (Free text)
11. How many full-time positions of the professional categories below are found at the primary care centre? (0, 0.1-0.5, 0.6-0.9, 1, 2, 3, 4, >4 for the professionals in question 12)
12. Which staff category/categories work with patients with COPD? (Physician, Nurse/district nurse (including asthma/COPD nurse), Assistant nurse, Physiotherapist, Occupational therapist, Dietitian, Medical social worker, Psychologist)
13. How many working hours per week are designated for working with patients with COPD for the different professional categories? (0, 1-2, 3-4,

5-8, 9-12, 13-16, 17-20, 21-24, 25-28, 29-32, 33-36, 37-40, >40 for the professionals in question 12)

If multiple people in the same professional category have time designated for working with patients with COPD, add together their hours.

14. How many actual working hours per week are used for working with patients with COPD for the different professional categories? ? (0, 1-2, 3-4, 5-8, 9-12, 13-16, 17-20, 21-24, 25-28, 29-32, 33-36, 37-40, >40 for the professionals in question 12)
If multiple people in the same professional category have time designated for working with patients with COPD, add together their hours.
15. Is there any further/supplementary training in COPD available to the staff? (Yes, No)
16. Please provide a brief description of the COPD further/supplementary training available. (Free text)
17. In relation to interventions for patients with COPD, is a defined care program applied at the primary care centre? (Yes, No)
18. Who developed the care program for COPD? (Free text)
19. Which of the following measures does the primary care centre offer to patients with COPD?
 - a. Spirometry
 - b. Structured investigations with spirometry and reversibility testing
 - c. Treatment of exacerbations
 - d. Follow-up of prioritised patients in accordance with the National Board of Health and Welfare's guidelines
 - e. Symptom assessment with CAT
 - f. Symptom assessment with mMRC
 - g. Patient education/PR program (in addition to individual consultation)
 - h. Written treatment plan
 - i. Smoking cessation support
 - j. Designated time for patient counselling with the asthma/COPD nurse in person or by phone
 - k. 6-minute walk test
 - l. Physical exercise/activity as part of the treatment (with physiotherapist)
 - m. Consultative discussions about physical exercise/activity
 - n. Physical activity on prescription (FaR)
 - o. Consultative discussions about diet and energy needs
 - p. Consultative discussions about energy-saving measures and assistive devices
 - q. Instruction and follow-up of inhalation techniques
 - r. Other, please specify: _____

20. Please provide a brief description of the structure and content in the patient education. (Free text)
21. Please indicate which professional categories are involved in the patient education. (Same as in question 12, Other, Free text)
22. Which of the following equipment is available at the primary care centre? (Spirometer, Pulse Oximeter, Oxygen, Nebuliser)
23. Are there routines at the primary care centre for asking patients about their tobacco habits? (Yes, No)
24. Please provide a brief description of the routines for asking patients about their tobacco habits. (Free text)
25. Does the primary care centre offer smoking cessation support? (Yes, No)
26. What professional categories offer smoking cessation support? (Free text)
27. What percentage of patients who are or were previously smokers are offered a spirometry examination? (0-25%, 25-50%, 50-75%, 75-100%, Not routinely offered)
28. Research shows that health promotion interventions have positive effects on people with COPD, but only a small number have access to such interventions. Are people with COPD routinely offered health promotion interventions at the primary care centre? (Yes, No, Other, Free text)
In this context, health promotion interventions refers to physical exercise/activity or consultative discussions about physical exercise/activity, information about self-care strategies and breathing techniques.
29. What difficulties have you encountered when it comes to offering patients with COPD health promotion interventions (as described in question 28)?
 - a. No resources for this purpose
 - b. The patient group is not prioritised
 - c. The patients are not interested in participating in health promotion interventions
 - d. The patients feel that they do not have the energy to travel to the health centre to participate in health promotion interventions
 - e. The staff do not have adequate knowledge to be able to provide health promotion interventions
 - f. The staff are doubtful about the effect of health promotion interventions
 - g. We have not encountered any difficulties
 - h. Other, please specify: _____
30. Additional comments or viewpoints:
 We welcome any comments you may have about the questions or other viewpoints you have regarding interventions in primary care for patients with COPD. (Free text)

Appendix 2

Compressed questionnaire “Conceptual knowledge use”

1. How many patients with COPD do you meet during a regular working week?
(0, 1-2, 3-5, 6-10, 11-15, >15)
2. Offering to people with COPD is an important task in primary care (Disagree, Agree to some extent, Largely agree, Agree completely)
3. Do you feel like you have sufficient knowledge to offer to people with COPD? (Yes, No)
4. Do your work tasks include providing to people with COPD? (Yes, No)
5. If your work tasks include providing to people with COPD, have you encountered any difficulties in providing these interventions/activities? (Yes, No)
6. If yes, please describe. (Free text)
7. Are there any interventions/activities not mentioned in this survey that you would like to offer people with COPD? (Yes, No)
8. If yes, please describe (Free text)
9. If you entered any interventions/activities at question 10a, have you experienced any difficulties in providing these interventions/activities to people with COPD? (Yes, No)
10. If yes, please describe. (Free text)

Questions 2-6 were asked about:

- Health promotion interventions
- Tobacco prevention
- Disease-specific instruction
- Information on strategies for COPD-related self-care (e.g. information on for which symptoms an individual should seek healthcare)
- Consultative discussions about physical activity/exercise training
- Physical activity on prescription
- Instruction and training in breathing techniques
- Consultative discussions about nutrition and energy needs
- Information on energy conservation techniques and assistive devices

Dissertations written by physiotherapists, Umeå University 1989–2018

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