

UiT

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## Managing exacerbations of chronic obstructive pulmonary disease

### *An investigation of treatment decisions from a primary care perspective*

—  
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“Alone we can do so little;  
together we can do so much.”

– *Helen Keller*

Illustration on front page: Mount Cook, New Zealand. By Johanna Laue



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## **Foreword and acknowledgements**

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# Summary

## English summary

Exacerbations of chronic obstructive pulmonary disease (COPD) compose a considerable burden for both patients and health care systems. Optimal management in primary care, including self-treatment of COPD exacerbations with antibiotics and oral corticosteroids, is considered to be one key for providing good care for patients at reasonable costs. This thesis aimed to explore treatment of COPD exacerbations with antibiotics and/or oral corticosteroids and hospitalization from different primary care perspectives, e.g. guidelines, general practitioners and patients.

A systematic review of treatment criteria for antibiotics and oral corticosteroids in national and international COPD guidelines, and an assessment of the underlying evidence for these recommendations composed the first part of the project. The results showed that the recommended treatment criteria were mostly based on respiratory symptoms, and that the studies the recommendations are based on are often conducted with patients that are not representative for a primary care setting. The second study explored COPD patients' perspective on self-treatment with antibiotics and oral corticosteroids through a thematic analysis of 12 semi-structured in-depths interviews. We found that concerns with the medications' adverse effects play a key role in COPD patients' decisions to initiate self-treatment with antibiotics and/or oral corticosteroids. The nature of the patient-physician relationship including the patients' understanding of legitimacy to seek help is important to their help seeking behaviour when feeling insecure about the need for treatment or in case of treatment failure. The third study investigated GPs' accounts of their decision-making regarding treatment with antibiotics and oral corticosteroids and hospitalization through a thematic analysis of seven focus group discussions. The results show that one main driver of GPs' decision-making are worries about having overlooked a severe underlying illness. GPs consider a holistic understanding of illness and the patients' own experiential knowledge important to make reasonable decisions for the individual patient under medical uncertainty. Moreover, GPs' decisions depend on the availability and reliability of other formal and informal carers, and the healthcare systems' organization and sociocultural 'code of conduct'.

Overall, the findings of this thesis support an integrative and collaborative approach to management of COPD exacerbations. The heterogeneous, versatile and often individualized nature of COPD exacerbations requires a flexible framework to decision-making that integrates both medical knowledge and other types of knowledge that are grounded in human experience and relationships. Such an integrative understanding of knowledge may guide future clinical research and guideline development in considering primary care evidence and expertise from primary care stakeholders and patients to a larger extent, and may also facilitate collaborative management of COPD exacerbations that allows for sharing expertise and responsibility between patients and the involved carers.

## **Norsk sammendrag**

Forverringar av kronisk obstruktiv lungesykdom (KOLS) er en betydelig byrde for pasienter og helsesystemer. Optimal behandling av KOLS forverringar i primærhelsetjenesten, inkludert egenbehandling med antibiotika og orale kortikosteroider, ansees som meget viktig for å sikre god behandling og samtidig redusere den økonomiske byrden. Denne avhandlingen ønsker å øke kunnskapen om behandling av KOLS pasienter med eksaserbasjoner i primærhelsetjenesten ved å utforske tre forskjellige perspektiver (retningslinjer, pasienter og allmennleger) på dette fenomenet.

Denne avhandlingen er basert på tre studier. Første studie er en systematisk review av behandlingsskriterier for antibiotika og orale kortikosteroider i nasjonale og internasjonale KOLS retningslinjer og en kritisk evaluering av evidensen som anbefalingene er basert på. Resultatene viser at behandlingsskriteriene er hovedsakelig basert på respiratoriske symptomer og at evidensen er i lite grad overførbar til en primærhelsetjenestekontekst. I den andre studien ble KOLS pasienters erfaringer med egenbehandling utforsket ved tematisk analyse av 12 semi-strukturerte dybde-intervjuer. Hovedfunnene viser at bekymringer for medisinenes bivirkninger spiller en viktig rolle i pasientens beslutninger angående behandlingsstart, og at lege-pasient forholdet inkludert pasientens forståelse av eget ansvar for behandlingen kan påvirke i stor grad om og når pasienter søker hjelp ved usikkerhet eller når behandlingen ikke virker. Målet for den tredje studien var å utforske allmennlegers beslutninger på behandling

av KOLS eksaserbasjoner med antibiotika og orale kortikosteroider, og innleggelser, ved tematisk analyse av 7 fokusgruppeintervjuer fra forskjellige europeiske land og Hongkong. Hovedfunnene viser at usikkerhet og redsel for å ha oversett alvorlig sykdom er sterke pådrivere i allmennlegers beslutninger. Allmennlegene syntes at en holistisk forståelse av sykdommen og å involvere pasienters erfaringsbasert kunnskap i beslutningene er viktig for adekvat behandling av den enkelte pasienten.

Samlet støtter resultatene av de tre studiene integrativ og samhandlingsbasert behandling av KOLS pasienter med eksaserbasjoner. De heterogene, komplekse og ofte individualiserte KOLS eksaserbasjoner krever en fleksibel ramme for beslutninger som integrerer både biomedisinsk kunnskap og andre typer kunnskap som er basert på menneskers erfaring og relasjoner. En slik integrativ forståelse av kunnskap vil kunne guide fremtidig klinisk forskning og utvikling av retningslinjer i å ta større hensyn til medisinsk kunnskap og ekspertise fra primærhelsetjenesten og pasienter, og vil også kunne fremme samhandling basert på deling av kunnskap og ansvar mellom pasienter og helsepersonell, og helsepersonell imellom.

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## List of papers

### Paper I Guideline study

***“When should acute exacerbations of COPD be treated with systemic corticosteroids and antibiotics in primary care: a systematic review of current COPD guidelines”***

Laue J, Reierth E, Melbye H. NPJ Prim Care Respir Med. 2015;25:15002.

### Paper II Patient study

***“Self-treatment of acute exacerbations of chronic obstructive pulmonary disease requires more than symptom recognition – A qualitative study of COPD patients’ perspectives on self-treatment”***

Laue J, Melbye H, Risør MB. BMC Fam Pract. (currently under review)

### Paper III GP study

***“How do general practitioners implement decision-making regarding COPD patients with exacerbations? An international focus group study”***

Laue J, Melbye H, Halvorsen PA, Andreeva EA, Godycki-Cwirko M, Wollny A, Francis NA, Spigt M, Kung K, Risør MB. Int J Chron Obstruct Pulmon Dis. 2016;11:3109-3119.

## **Abbreviations**

AGREE: Appraisal of Guidelines for Research and Evaluation

CRP: C-reactive protein

COPD: Chronic obstructive pulmonary disease

EBM: Evidence-based medicine

e.g.: *exempli gratia*/for example

FEV<sub>1</sub>: Forced expiratory volume in 1 second

FGD: Focus group discussions

FVC: Forced vital capacity

GP: General practitioner

GOLD: Global Initiative for Chronic Obstructive Lung Disease

GRACE: Genomics to combat Resistance against Antibiotics in Community-acquired low respiratory tract infections in Europe

GRIN: General Practice Research on Infections Network

i.e.: *id est*/that is

PEXACO: Caring for adult patients with acute exacerbations of asthma or COPD in general practice

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

UNN: University Hospital of North Norway

# 1 Background

## 1.1 Personal and professional background

According to a skilled Norwegian qualitative researcher and professor of family medicine, Kirsti Malterud, engaging in a research project can be compared to going on a journey<sup>1</sup>. She wrote that the baggage we carry mirrors our assumptions and understandings that influence the way we proceed on our journey - e.g. how we collect and read our data<sup>1</sup>. In addition to personal and professional experiences, we carry a certain worldview and understanding of knowledge in our 'baggage', which will inevitably influence our motivations and our choices along the way. Being aware of this 'baggage' and making it transparent for the reader is therefore a key to producing and sharing research in a credible, valid and responsible way<sup>1</sup>. Hence, I will first introduce the reader to my personal and professional background and my theoretical approach to this research project.

I started to engage in research in April 2012 as a research assistant in the General Practice Research Unit at UiT The Arctic University of Norway after having finished my medical studies in Germany. During my time as a research assistant, I translated transcripts of focus group discussions (FGD) (not knowing that they would later on become part of my own project), which gave me a first taste of qualitative methods as well as on research on chronic obstructive pulmonary disease (COPD). Furthermore, I collected information about the healthcare systems in which the FGDs had taken place. I was not particularly interested in COPD, but had quite some experience (at least from the point of view of a doctor just having finished medical school) with this patient group from my internships at a pulmonology department in Germany. During a calmer period at work, I started to read more about COPD and issues that may complicate the management of exacerbations. I felt sort of honoured when I was then asked to start a PhD project. The PhD project was and is part of the international research project "Caring for adult patients with acute exacerbations of asthma or COPD in general practice" (PEXACO), which was initiated by Hasse Melbye and conducted in collaboration with research groups from six European countries and Hong Kong. PEXACO consists of both epidemiological studies and qualitative interview studies, the latter projects being led by Mette Bech Risør.

The opportunity to combine research with clinical work as general practitioner (GP) trainee was important to me to not lose contact with patients and clinical practice. Throughout the years, I learned to enjoy the reflective nature of research as counterbalance to rather hectic days in general practice. When starting working as a GP, I realized that practicing medicine was different from studying medicine in medical school. Instead of dealing with diseases, I had to deal with people. Instead of solving cases in classrooms and typically coming up with a conclusion on how to solve the problem, I needed to learn to deal with the uncertainty of 'real world' clinical practice. I recognized quickly that medical theoretical knowledge was worth little without the ability to use it in a specific context.

These experiences have truly influenced the way I approached this research project. Particularly, I carried with me the experienced gap between theoretical, 'textbook' medicine and how medicine is practiced in a 'real world' setting. I found my own experiences reflected in literature addressing problems in COPD care and in criticisms of evidence-based medicine (EBM). As a result, my interest in what *else* than evidence and guidelines is relevant to a person's decision-making grew.

## **1.2 Literature review**

### **1.2.1 Chronic obstructive pulmonary disease - an overview**

COPD is a chronic lung disease characterized by persistent, typically progressive, airflow limitation. COPD is associated with an enhanced chronic inflammatory response in the airways to noxious particles or gases. Typical symptoms of COPD include dyspnoea, chronic cough and chronic sputum production, but spirometry detected persistent airflow limitation (post-bronchodilator forced expiratory volume in 1 second (FEV<sub>1</sub>)/forced vital capacity (FVC) < 0.7) is required to establish the clinical diagnosis<sup>2</sup>. COPD has been, and will be, a considerable public health problem worldwide. Globally, about 328 Million people are estimated to suffer from COPD, which is 4.77% of the world population<sup>3</sup>. It is one of the major leading causes of death worldwide<sup>4</sup>. The major risk factor is tobacco smoking, but occupational exposure, air pollution and individual predisposition also play an important role<sup>3</sup>. There is a geographic variety of risk factors, prevalence, mortality and burden of illness<sup>5</sup>. In Europe and North America, people with COPD now live longer than two decades



ago, however, the quality of life during these years may be diminished due to the illnesses impact on daily living<sup>3,4,6,7</sup>. COPD is associated with high comorbidity from all organ systems, including anxiety and depression<sup>8</sup>. Yet, respiratory illnesses such as asthma and pulmonary vascular disease, and cardiovascular illnesses such as ischemic heart disease, congestive heart failure and arrhythmias, are the most prevalent comorbidities<sup>9</sup>. In addition to negative impact on patients' quality of life, COPD accounts for a high societal burden with a considerable economic impact on health care systems. Costs increase with COPD severity, prevalence of comorbidity and with inpatient treatment. Exacerbations of COPD are the major cause of hospitalizations and driver for inpatient treatment expenditure<sup>10,11</sup>.

### **1.2.2 Exacerbations of COPD**

COPD exacerbations are defined by the Global Initiative for Chronic Obstructive Lung disease<sup>2</sup> as “an acute event characterized by a worsening of the patient’s respiratory symptoms that is beyond normal day-to-day variations and leads to a change in medication”<sup>2</sup>. Another consensus definition is slightly broader and acknowledges associated non-respiratory clinical descriptors (such as increased heart rate, or fatigue): e.g., a COPD exacerbation is “a sustained worsening of the patient's condition, from the stable state and beyond normal day-to-day variations, necessitating a change in regular medication in a patient with underlying COPD”<sup>12</sup>. COPD patients experience approximately one or two exacerbations per year, with increasing frequency in the later stages of the illness. Yet, epidemiological data indicate that a subgroup of patients, the “frequent exacerbators”, may be particularly susceptible to exacerbations regardless of disease severity<sup>13,14</sup>. In the long-term, COPD exacerbations have been found associated with accelerated decline in lung function and progressive decline of the overall health status<sup>15,16</sup>. Exacerbations have a negative impact on the personal and societal level, both short-term and long-term. The symptoms’ impact on the patients’ daily living impair their health related quality of life and exercise capacity. In severe cases, reduced exercise capacity may mean being housebound or being in need of assistance with daily tasks, which again may reduce the patients’ feeling of well-being<sup>15-18</sup>. At the societal level, COPD exacerbations stand for a great economic burden. In addition to direct costs from inpatient treatment, loss of workdays and long-term impact on the patients’ health status compose a considerable burden for a country’s health care system<sup>10,11</sup>.

COPD exacerbations are heterogeneous in terms of aetiology, clinical manifestation and treatment requirements. Their main cause are assumed to be bacterial and viral infections, but non-infectious factors, such as air pollution and meteorological effects also play a role. The overall cause, however, may be multifactorial, and especially the role of systemic inflammation and of comorbidities is not yet fully understood<sup>15,16</sup>. The clinical manifestation is typically characterised by increased cough, dyspnoea and sputum volume and purulence, but systemic responses such as fatigue and simultaneous exacerbation of comorbidities such as heart failure are common<sup>12</sup>. COPD exacerbations may require different kinds of treatments on all levels of the healthcare system<sup>12</sup>.

### **1.2.3 Management of COPD exacerbations: treatment options and guidelines**

COPD exacerbations may be treated in a primary or secondary care setting, depending for instance on the exacerbation's severity, frequency of exacerbations and comorbidity<sup>12</sup>. The goal of managing a COPD exacerbation has been summarized to “minimize the impact of the current exacerbation and prevent the development of subsequent exacerbations”<sup>19</sup>. Based on previous literature<sup>13,20,21</sup>, the GOLD committee estimated that 80% of exacerbations can be managed in an outpatient setting<sup>2</sup>. There are three principle pharmacological treatment options, short-acting bronchodilators, antibiotics and oral corticosteroids<sup>2</sup>. Short-acting bronchodilators, such as beta-agonists or anticholinergic agents are the first line treatment of airflow obstruction and symptoms during exacerbations. Antibiotics and/or oral corticosteroids should be added when there is an expected benefit for the patient<sup>2</sup>. The expected benefit, however, is apparently greater for patients with severe exacerbations treated in a hospital setting. Patients treated in primary care have mainly mild to moderate exacerbations, for which the effect of antibiotics and oral corticosteroids remains controversial<sup>2,19,22,23</sup>. Due to potential disadvantages of either treatment, particularly side effects of oral corticosteroids<sup>23</sup> and the risk of bacterial resistance development from unnecessary antibiotic use<sup>24</sup>, patients should be carefully assessed before initiating treatment.

In the latest GOLD guidelines, it is stated that “the assessment of an exacerbation is based on the patient's medical history and clinical signs of severity and some laboratory tests, if available”, specifying that “spirometry is not recommended during an exacerbation because it can be difficult to perform and measurements are not accurate enough”<sup>2</sup>. Symptoms such as

increased dyspnoea and clinical signs such as changes in sputum play a major role in the assessment of COPD exacerbations since Anthonisen's landmark trial published in 1987<sup>25</sup>. Since then, increased dyspnoea, increased amount of sputum, and increased purulence of sputum are regarded as the cardinal symptoms of COPD exacerbations. Anthonisen et al. recommended that antibiotic treatment was only justified in the presence of more than one of these symptoms<sup>25</sup>. Still today, in the current GOLD guidelines, recommendations on antibiotic treatment for COPD exacerbations are based on the presence of these symptoms, yet with emphasis on sputum purulence<sup>2</sup>. Even though studies have shown the usefulness of CRP testing to reduce antibiotic prescribing<sup>26,27</sup>, it is not recommended in the GOLD guidelines - as opposed to, for instance, the Norwegian COPD guidelines<sup>2,28</sup>. The Dutch guidelines do not only base their recommendations on sputum changes, but reserve antibiotic treatment for patients with poor lung function and other risk factors for a severe disease course<sup>29</sup>. Recommended diagnostic tests for the assessment of COPD exacerbations in the GOLD guidelines include pulse oximetry, chest radiography, electrocardiogram and several blood tests, and recommendations for hospitalizations are solely based on clinical signs that indicate severe respiratory problems (e.g. cyanosis, resting dyspnoea) and on signs for high vulnerability (older age, frequent exacerbations, severe underlying COPD, insufficient home support)<sup>2</sup>. We do not know exactly to which degree COPD guidelines are followed in primary care, but concerns about implementation of COPD guidelines indicate that primary care physicians may not follow guidelines very closely<sup>30,31</sup>. Perceived inapplicability is one of many possible barriers to adherence, which can also vary largely within and between guidelines<sup>30,32-34</sup>.

#### **1.2.4 Management of COPD exacerbations in clinical practice**

Studies from various countries on management of COPD exacerbations show high hospitalization rates and great variations in prescribing antibiotics and/or oral corticosteroids<sup>26,35-41</sup>. In terms of assessment and decision-making for treatment, several predictors for prescribing have been identified in clinical studies. Especially purulent sputum and raised CRP values seem strongly associated with the decision to prescribe antibiotics, but also chest findings or decreased oxygen for both antibiotics and oral corticosteroids<sup>26,41</sup>. Studies on antibiotic prescribing for cough, respiratory infections and lower respiratory tract infections show comparable results<sup>42-44</sup>. Overall, it seems as if CRP testing decreases the

emphasis laid on symptoms and clinical findings for prescribing antibiotics in COPD exacerbations and other respiratory illnesses, and that CRP testing is protective against antibiotic use. Predictors for prescribing oral corticosteroids for COPD exacerbations are not investigated to a comparable extent. Al-Ani et al. described that, similar to antibiotics, abnormal chest findings, raised CRP values and decreased oxygen saturation were the strongest predictors for prescribing<sup>41</sup>.

Prescribing behaviour, however, is complex and a variety of interrelated intrinsic and extrinsic factors influence prescribing. A considerable body of evidence exists that addresses GPs' prescribing practices, mostly regarding antibiotic prescribing for a variety of conditions. Signs and symptoms present at the time of prescribing seem indeed important factors, as well as comorbidity and allergies. Factors relating to clinicians' themselves - such as complacency, fear of complications, the relationship with the patient, problems with communication and peer influence – as well as healthcare system-related factors - such as time pressure, organizational models and lack of resources – also play a role in clinicians' management decisions<sup>45-50</sup>.

### **1.2.5 Self-treatment of COPD exacerbations**

In addition to choosing the right treatment, initiating it early is important to prevent a severe disease course and to minimize its burden<sup>51</sup>. Therefore, it is of concern that COPD patients may delay help seeking or not seek help at all<sup>52-55</sup>. Self-treatment of COPD exacerbations has emerged during the last decade as a new concept to tackle the high burden of COPD exacerbations for patients and society as a result from delay in treatment onset<sup>56</sup>. The underlying idea is that patients receive 'standby' antibiotics and/or oral corticosteroids to promptly start treatment when certain symptom changes occur. Self-treatment of exacerbations is often central part of the much more comprehensive care concept 'self-management'. The latter is based on the chronic care model of disease management, which draws on self-regulation theories and the concept of 'self-efficacy'<sup>57,58</sup>. Cornerstones for self-management programs or interventions are pulmonary rehabilitation, approaches targeting knowledge development, social support, web-based interventions and knowledge and attitudes of healthcare professionals, all of which should empower patients to confidently manage their illness and engage in collaboration with healthcare professionals<sup>59</sup>. More

specifically, self-management in COPD encompasses smoking cessation, physical activity, nutrition, medication adherence, and coping skills in addition to self-treatment of exacerbations<sup>60</sup>. As Nici stated in 2014, self-management and self-treatment of COPD and its exacerbations composes “a splendid concept”<sup>61</sup> to help patients gaining knowledge and skills that are necessary to achieve optimal outcomes. However, so far, the efficacy of self-management interventions are not convincing. One issue concerning research on efficacy is that self-management interventions vary in design, and trials in methodology<sup>58</sup>, another is that results of these trials are contradictory. In 2000, Gallefoss found that giving COPD patients with inhaled corticosteroids oral corticosteroids on standby reduced the number of GP visits the following year and increased the patients’ health-related quality of life<sup>62</sup>. Bourbeau’s and Rice’s trials in 2003 and 2010, respectively, showed reduced COPD-related and all-cause hospitalization rates and emergency room visits and increased health statuses in the intervention groups<sup>63,64</sup>. Four studies between 2007 and 2012 could not confirm these findings. Beaulieu-Genest observed increased use of both antibiotics and oral corticosteroids but no reduction in unplanned medical visits<sup>65</sup>. Bucknall et al. reported no differences in admission and death rates<sup>66</sup> and Bischoff no improved health related quality of life in the intervention groups<sup>67</sup>. Moreover, Fan’s trial had to be stopped prematurely due to increased mortality rates in the self-management group<sup>68</sup>. The reasons for these undesired courses remain unknown. It might be that not all participants were able to decide whether antibiotics and/or steroids were the right type of treatment for their symptoms, and, as Nici argued, some may have needed an assessment by a physician<sup>61</sup>. Bischoff’s analysis would fit such a hypothesis. He found that patients who actually use the medication and successfully treat themselves may in fact achieve benefits, but that, at least in his trials, only 40% actually adhered to the self-treatment plans as intended by the researchers<sup>67,69</sup>.

Both healthcare professionals’ and patients’ opinion about the idea of self-treatment of exacerbations seems predominantly positive<sup>70,71</sup>. Yet, healthcare professionals may be concerned that self-treatment does not fit all patients, that patients should be carefully chosen (by disease severity and previous behaviour), and that giving sufficient education may be difficult due to time constraints<sup>70,71</sup>.

## **1.3 Challenges and gaps of knowledge**

Considering the body of evidence and state of knowledge so far, I will point to three main – though interrelated - aspects that emerge as challenges and/or gaps of knowledge.

### **1.3.1 Challenges regarding primary care of COPD exacerbations**

#### **1.3.1.1 The complexity of diagnosing and decision-making**

The first aspect relates to the fact that the debate about the management of COPD exacerbations is not uniform, i.e. that it starts at different points in the diagnostic process and that it varies in the degree to which the complexity of decision-making and health and illness behaviour is taken into account. Care policies and guidelines are, for instance, concerned with the management of a diagnosis, the ‘disease’ COPD exacerbation. Also, observational studies that aim to identify predictors for treatment, calculate their results on the basis of the diagnosis ‘COPD exacerbation’. However, this *disease*-oriented approach to management does not consider that, for patients and GPs, decision-making about self-treatment, help seeking, prescribing and hospitalization rather starts with experiencing symptoms/symptom changes and the patients’ story, respectively. Particularly management decisions in primary care are often based on symptom patterns instead of a diagnosis<sup>72</sup>. Moreover, due to the complex etiological and pathophysiological pathways and mechanism underlying COPD exacerbations, it may often be impossible to make a clear diagnosis. As Beghé wrote in the European Respiratory Journal in 2013: “Exacerbations of respiratory symptoms in COPD patients may not be exacerbations of COPD”<sup>73</sup>, but can express different underlying diseases<sup>74</sup>. Overall, however, even though when making a clear diagnosis is possible, we know that medical decision-making and patients’ health and illness behaviour, respectively, are complex. These processes can be influenced by a variety of contextual, cognitive and emotional factors and may take place on both a conscious and subconscious level<sup>75-78</sup>.

#### **1.3.1.2 Self-treatment behaviour as response to illness experience**

The second aspect relates to a comparable issue, yet concerning self-treatment. Even though based on symptom recognition and not on a clinical diagnosis as such, self-treatment plans as described in the literature do not acknowledge that symptoms may not present ‘textbook’ like, but can be diffuse and slowly developing over a couple of days<sup>79,80</sup>. Even though these

symptoms may in fact indicate a COPD exacerbation and the need for treatment, the slow development of symptoms may hamper the determination of the adequate point of time for starting treatment. In this regard, it is useful to refer to the important distinction between ‘disease’ and ‘illness’ and the implications for patients’ self-treatment behaviour. While ‘disease’ refers to abnormalities of the structure and function of body organs and systems, ‘illness’ refers to a person’s experience of ill-health and the meaning given to that experience<sup>81</sup>. From this perspective, when COPD patients respond to symptoms, they do not respond to the biomedical, pathophysiological changes causing the symptoms, but to how their body and mind react to these changes. Therefore, as Helman wrote in 1981, “the disease/illness model (...) provides a useful perspective on the treatment of ill-health in general practice and on such phenomena as non-compliance, self-medication and dissatisfaction with medical care. (...)”<sup>81</sup>. Self-regulatory models, such as Leventhal’s Common Sense Model of Illness Representation<sup>82</sup> are based on this distinction, which is in fact brought up as theoretical framework in the self-management literature<sup>83</sup>. The Common Sense Model of Illness Representation<sup>82</sup> proposes that a person’s response to ill health is based on cognitive representations of the particular health threat, informed by concrete or abstract information, beliefs and experiences. As Nici writes: “It’s one thing to have an action plan and to convey this information to the patient; it’s another matter to have the patient actually put it into practice.”<sup>61</sup>. In other words, it would be naïve to believe that a patient’s initiation of self-treatment is solely based on an objective evaluation of symptoms according to medical knowledge. In addition to education<sup>58,84,85</sup>, motivation, believe in treatment, self-efficacy, psychological health and the patient-provider relationship may COPD patients’ self-management behaviour<sup>86-89</sup>.

### **1.3.1.3 Organizational and relational aspects of healthcare**

The third aspect relates to care on the interface of different sectors and levels of healthcare systems, particularly in terms of sharing care between involved actors, role identification, the scope of responsibility and power relations. Healthcare can be divided into different levels, such as primary care, secondary and tertiary care<sup>90</sup>, as well as into the type of healthcare provided. In Kleinman’s model of health care sectors, for instance, healthcare systems consist of three sectors, a popular, professional and folk sector<sup>91</sup>. All of these can be found within the primary care level, where they overlap and interconnect. I would regard the phenomenon of

‘self-treatment of COPD exacerbations’ to take place in between the popular and the professional sector. GPs are principally part of the professional sector in primary care, but their practice touches both the popular and folk sectors as well as they collaborate with professionals on the secondary care level. Understanding the mechanisms and factors that influence the social actors’ behaviour and decision-making on the boundaries of these sectors and levels seems highly relevant to understanding how COPD exacerbations are managed in primary care, especially hospitalization and self-treatment as alternative/supplement to traditional health seeking. Moreover, the relationship, including power relations, between actors in different sectors may play a role to decisions made at the boundaries, or even within, sectors and levels of healthcare organization. For instance, the overall relationship between patients and physicians/healthcare professionals can be assumed to have undergone changes during the last decades, from an overweight of a paternalistic relation to more patient empowerment and patient involvement<sup>92</sup>.

### **1.3.2 Gaps of knowledge**

As described above (see *Literature review*), the overall care goals for COPD exacerbations are to reduce mortality, morbidity and health costs and to improve patients’ self-management abilities and quality of life. Much focus is, and has been, on the prevention of exacerbations to reduce hospitalization rates through pulmonary rehabilitation and self-management under stable state. This is of course positive, but similarly important is to improve management of exacerbations when actually happening. So far, research has mainly focused on the effects of medical treatments and of self-treatment interventions on disease progression, morbidity and mortality rates, healthcare utilization, health related quality of life and cost-effectiveness and on symptoms, clinical signs and diagnostic tests as predictors for treatment (see *Literature review*). There are a number of studies addressing COPD patients’ perspectives on COPD exacerbations<sup>79,80,93,94</sup>, how they experience helplessness under an exacerbations<sup>95</sup> and their attitudes towards self-treatment<sup>70</sup>. None of these studies, however, explicitly focus on self-treatment as such, and only some patients in Williams et al.’s study seem to have used stand-by medications<sup>94</sup>. There is one qualitative study investigating the patients’ perspective of a comprehensive self-management program including self-treatment of exacerbations<sup>89</sup>. Findings show that most patients appreciated the opportunity for self-treatment, particularly for the possibility to start early, for autonomy and for not having to call a doctor. Moreover,



the frequent follow-up visits and 24 hours access to the hospital seemed important to create a feeling of safety among the participants. Overall, the authors reported increased self-confidence and coping behaviour among the participants of the self-management programme<sup>89</sup>. Despite these rather positive findings, it is questionable whether they are transferrable to COPD patients who receive self-treatment medications in regular care, with no trial programs providing close follow-ups. We do not know to which extent COPD patients receive antibiotics and/or oral corticosteroids for self-treatment, and how they are instructed in using the medications. Yet, it is indicated in for instance Davies' et al.'s study that there is a wide variation in reported use of self-treatment and that GPs carefully select patients for self-treatment<sup>71</sup>. A Canadian survey found that only 34% of COPD patients had received a written action plan<sup>96</sup>. We do not know what the respective patients think about their self-treatment opportunity and how they make use of it. Regarding help seeking of COPD patients, there is some evidence showing that not only symptom severity, but also access to care, nature and quality of the patient-provider relationship and the perception of stigmatization during prior healthcare encounters influence patients' decision to consult a healthcare professional<sup>79,97</sup>. Even though these studies are probably to a certain extent transferable to the group of COPD patients who have received antibiotics and/or oral corticosteroids in routine care, we do not know how the self-treatment possibility relates to these patients' help seeking.

Regarding GPs' management decisions for COPD patients with exacerbations, the study of Risør et al. from the PEXACO group gives some insight. The authors found that the clinical complexity of multimorbidity and the various contextual elements related to patients' social circumstances made decision-making complicated. The authors concluded that "GPs and respiratory physicians balance these concerns with medical knowledge and practical, situational knowledge, trying to encompass the complexity of a medical condition."<sup>98</sup>. Yet, from this study, it remains unclear what in particular GPs consider relevant to their decisions to prescribe antibiotics and/or oral corticosteroids and to hospitalize patients.

## **2 Research questions**

The overall aim of this project was to investigate the management of COPD exacerbations in primary care and to hopefully discover aspects that may further develop primary care for

COPD patients with exacerbations. The project has particular interest in how the key actors of managing COPD exacerbations, i.e. GPs and COPD patients, assess symptoms and make decisions regarding treatment with antibiotics, oral corticosteroids, hospitalization and help seeking.

The specific aims of the three studies were

- To assess how COPD exacerbations should be treated according to national and international COPD guidelines, and to assess the underlying evidence of the recommendations in terms of applicability to a primary care setting.
- To get insight into the patients' perspective on self-treatment of COPD exacerbations, focusing specifically on how patients decide for the right moment to start treatment with antibiotics and/or oral corticosteroids, what they consider important when making this decision and what aspects might interfere with successful implementation.
- To explore GPs' accounts of their decision-making about treatment with antibiotics and/or oral corticosteroids and hospitalization for COPD patients with exacerbations.

### **3 Design, methods and procedures**

#### **3.1 Theoretical and methodological considerations**

A principal part of designing a research project is to make explicit the ontological and epistemological assumptions of the researcher. Ontology refers to assumptions about the nature of reality. Epistemology makes assumptions on how it is possible to know something about reality, asking: "What is the relationship between the knower and what is known?", "How can we know what we know?" and "What counts as knowledge?"<sup>99</sup>. In other words, these concepts relate to the researcher's position regarding which social phenomena exist, how they are related, how they can be investigated, and how it is possible to know something about them<sup>100</sup>.

Medical science can be regarded as both a natural and humanistic science. In this sense, it may be situated within both a relativist and a realist tradition. Predominantly, I would situate my research in relativist tradition, which rejects the idea of one true reality but acknowledges multiple realities<sup>100</sup>. Yet, the main aspect for me is not to determine the existence of multiple, constructed realities, but how these influence social action and interaction. This is described in what Blaikie refers to as being a “Depth realist”. Accordingly, reality consist of natural and social structures, of which the latter depend on the social actors’ activities and their conception of their activities<sup>100</sup>. Such conceptions are influenced by social forces, such as politics and institutions, but also through direct interaction between persons<sup>101,102</sup>. Behaviour, or action, is contextually dependent, e.g. it depends on the meaning people pose on their experiences, objects, events and others’ behaviour. The symbolic interactionist perspective offers a socio-psychological approach to understanding human behaviour through emphasis on the “importance of symbols and interpretative processes that undergird interactions”<sup>103</sup>. Action, interaction and symbolic understanding are informing each other, and are dynamic in nature<sup>104</sup>. Moreover, referring to Blumer, Charmaz and Belgrave stress that “social interaction forms human conduct instead of being merely a means of expressing or releasing it”<sup>104</sup>. They note that, even though social structures and traditions exist, they rather shape than determine behaviour, which is why individuals’ reaction to social, contextual or historical structures can vary<sup>104</sup>. Symbolic interaction can therefore be regarded as a counter position to “behaviorism and mechanical stimulus-response psychology”<sup>103</sup>, and may therefore be a useful theoretical concept to get insight into how peoples’ understanding of their social world shape their actions. Through such an understanding, it may for instance be possible to gain knowledge on “what is most important to people, what will be most resistant to change, and what will be necessary to change” when institutional structures, programs or organizations develop<sup>103</sup>. Referring to Herbert Blumer, one of the founders of Symbolic interactionism, Patton notes that one way of getting insight into human behaviour that is based on interaction and interpretation, is to interview ‘experts’, i.e. key informants, who can “take the researcher into the phenomenon of interest”<sup>103</sup>.

Further, Mishler’s concept of the two voices - the “voice of the lifeworld and voice of medicine”<sup>105</sup> - gives a sense of what the humanistic and natural view on medicine means for clinical practice. He applied Habermas’s Theory of Communicative Action, according to

which there are two dialectic types of rationality underlying clinical practice, e.g. the “voice of the lifeworld” and the “voice of medicine”:

*“The voice of the lifeworld refers to the patient's contextually-grounded experiences of events and problems in her life. These are reports and descriptions of the world of everyday life expressed from the perspective of a “natural attitude”. The timing of events and their significance are dependent on the patient's biographical situation and position in the social world. In contrast, the voice of medicine reflects a technical interest and expresses a “scientific attitude”. The meaning of events is provided through abstract rules that serve to decontextualize events, to remove them from particular personal and social contexts.”<sup>105</sup>*

The relevant aspect here is that there can be fundamental differences in the principles on which medical ‘actions’, e.g. treatment decisions and help seeking decisions, are based. There can be different motivations for actions, and actions can be judged within varying frames of reference - it depends on the context, or the ‘worlds’, in which the phenomenon, in this case the “assessment and treatment of COPD exacerbations” takes place. Furthermore, I wish to mention Leder’s understanding of clinical medicine as interpretative activity<sup>106</sup>. He argues that

*“(…) clinical medicine can best be understood not as a purified science but as a hermeneutical enterprise: that is, as involved with the interpretation of texts. (...). (...) I suggest that the hermeneutics of medicine is rendered uniquely complex by its wide variety of textual forms. I discuss four in turn: the "experiential text" of illness as lived out by the patient; the "narrative text" constituted during history-taking; the "physical text" of the patient's body as objectively examined; the "instrumental text" constructed by diagnostic technologies. (...)”<sup>106</sup>*

According to this understanding, measurable outcomes such as prescribing and hospitalization rates are always the result of an interpretative activity from the patients’ and the physicians’ side, including interpretation of symptoms and their meanings, the physical examination and diagnostic tests. Both the “voice of medicine” and the “voice of the lifeworld” are represented here. In terms of patients’ decision-making for self-treatment and help seeking, one could say that behaviour in a situation of ill health is not simply a direct

reaction to physical symptoms resulting from a biological process, but rather results from interpretative processes through which persons give meaning to their experiences (e.g. of symptoms) and social encounters. GPs, who encounter a COPD patient with deteriorating symptoms, can only assess and evaluate symptoms and signs through interpretation of the patients' history, of bodily signs and test results.

This thesis aims to explore the management of COPD exacerbations in primary care, and sees both the “voice of medicine” and the “voice of the lifeworld” as relevant to clinical practice and health and illness behaviour. The “voice of medicine” may best be represented in for instance EBM standards or guidelines. The “voice of the lifeworld” may reside in the perspectives of those who indeed practice and behave on a daily basis, who act upon interpretations of experiences and social encounters, thereby creating the social phenomenon of ‘COPD care’. The main part of this thesis addresses aspects of ‘COPD care’ within a conceptual framework that emphasizes the primacy of social context, relations and interaction. To produce scientific knowledge of this, there are different approaches, or methodologies, and one may differentiate between quantitative and qualitative methods<sup>1</sup>. While quantitative methodology is traditionally grounded in a realist tradition, qualitative methodology is grounded in a relativist tradition. Both have their strengths and weaknesses. Simply put, while quantitative methods can be more suitable to answer questions on “numerical matter such as extent, distribution, or differences”, qualitative methods can be used to study, among other things, “human and social experiences”<sup>107</sup>. Choosing a method means also to make a choice regarding the type of knowledge that this method is able to produce. This thesis is primarily a qualitative research project using interviewing as method. Qualitative interviewing draws on conversations and language. Referring to Gadamer, Kvale and Brinkmann write that “we are conversational beings for whom language is reality”<sup>108</sup>. Knowledge about managing COPD exacerbations gained through interviewing is, from this perspective, useful to tell us something about the reality and the meaning-making processes of the social actors, e.g. COPD patients and GPs.

## **3.2 Methods**

In this section, I will describe the methods used for the three studies, including the designs of the studies, preparations for data collection, data collection, data analysis and reporting of

findings. I will focus mainly on the ‘procedural’ aspects of the methods and on describing the steps undertaken during the research process. The discussion of the methods will be found in the ‘Discussion of methods’.

### **3.2.1 Systematic review and assessment of guidelines**

Getting an overview over COPD guidelines and what is recommended regarding the management of COPD exacerbations was useful for two reasons. First, it served as a good starting point for learning critical assessment of scientific literature, including systematic identification of relevant literature for a specific research question, and comparison of scientific papers. Second, it would give me information about the ‘gold standard’ of managing COPD exacerbations, especially treatment criteria for antibiotics and oral corticosteroids. At this point, I thought such an overview could serve as a reference when investigating how treatment decisions were made by GPs and patients, respectively.

In terms of method, I chose to orient this first part of my thesis on systematic reviews. Due to their methodological rigour, they compose the reference standard for synthesizing evidence<sup>109</sup>. The purpose of a systematic review is to identify single studies with results that can be synthesised after a critical appraisal to inform guideline development and clinical decision-making<sup>109</sup>. Ideally, systematic reviews should follow a pre-defined approach and protocol in order to provide methodological transparency and comparability. My aim was somewhat different from a ‘classical’ systematic review, as I aimed for reviewing guidelines instead of single studies, but found the steps provided in tools for conducting systematic reviews useful also in my case. I chose the PRISMA statement and check-list (Preferred Reporting Items for Systematic Reviews and Meta-Analysis)<sup>110</sup> and AGREE II tool (Appraisal of Guidelines for Research and Evaluation)<sup>111</sup> to guide the development of my protocol on.

The PRISMA statement is a guideline that recommends which items to include in a systematic review protocol, and provides an approach to the search strategy and eligibility assessment of the literature<sup>110</sup>. The AGREE tool is an instrument which “evaluates the process of practice guideline development and the quality”<sup>111</sup>.

The main aim of the search strategy should ensure that all documents published in English or Scandinavian language within the last ten years, containing recommendations for treating COPD exacerbations with antibiotics and/or oral corticosteroids would be identified.

Therefore, we used the rather less specific search term “*Chronic Obstructive Pulmonary Disease AND (Guideline OR Recommendation)*”, accepting the relatively high number of matches in the first place. As the main interest was in the applicability of guidelines to a primary care population, I focused the appraisal of guideline development on transparency in reporting guideline development, stakeholder involvement and editorial independence. For the same reason, focus for appraising the underlying evidence was on study setting, study design and inclusion and exclusion criteria. Figure 1 shows the systematic database search and the eligibility assessment. After the search and eligibility assessment, I assessed the 19 COPD guidelines according to the aims of the study, and organized the findings in tables. Furthermore, we extracted recommendations about patient assessment for treatment with systemic corticosteroids and antibiotics. If recommendations were given separately for inpatients and outpatients, only those for outpatients were considered (Guideline study<sup>112</sup>). The publication process was relatively ‘easy’, but it was interesting to me that particularly one reviewer was very critical to how I discussed the usefulness of spirometry in the assessment of COPD exacerbations. In the end, I had to moderate my, and my supervisor’s stance to satisfy the reviewer and to get the paper accepted.

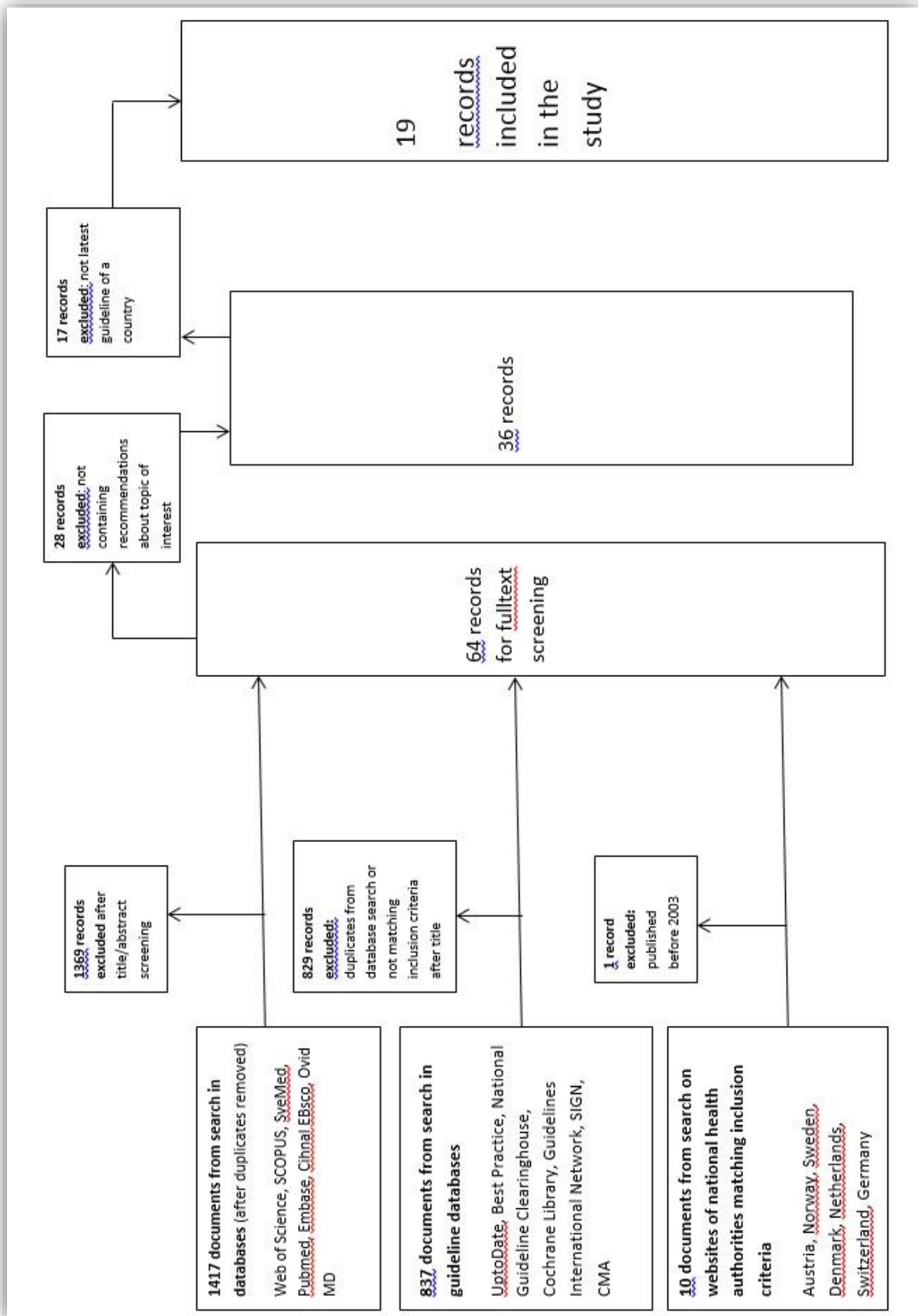


Figure 1 Flowchart describing the systematic search and eligibility assessment (Guideline study<sup>112</sup>)



### **3.2.2 Interview studies**

The Patient study and the GP study were interview studies. Kvale and Brinkmann<sup>108</sup> have described seven phases an interview design and study ideally consists of:

- 1) *Thematising: formulate the purpose of the study and conception of theme*
- 2) *Designing: design study in regard to obtaining the intended knowledge and moral implications*
- 3) *Interviewing: based on an interview guide, reflective approach about knowledge sought and interpersonal relation of interview situation*
- 4) *Transcribing: preparing the material for analysis*
- 5) *Analysing: decide upon the modes of analysis*
- 6) *Verifying: ascertain validity, reliability and generalizability*
- 7) *Reporting: report results according to scientific standards, considering ethical aspects of reporting*

As a novice researcher, I appreciated such a stepwise protocol. However, I did not strictly follow these phases as ‘steps’ for my two studies, particularly not in the GP study as the data was already collected by the PEXACO group. I experienced that conducting an interview study encompasses, as Kvale and Brinkmann state, “surprises, design changes, and reformulation of concepts and hypothesis”<sup>108</sup>, which may require a continuous adaption to new circumstances. In the following, I will use these seven ‘steps’ as a heuristic structure to describe, among other things, ‘surprises’ I encountered, the ‘design changes’ I had to make and the ‘reformulation of concepts’ I was choosing. Even though Kvale and Brinkmann’s phases are originally related to individual interviews, they are also relevant for a focus group design. Focus group interview, however, also encompass other important phases, such as sampling and composing the focus groups. Importantly, the sixth phase ‘Verifying’ will mainly be discussed in the ‘Discussion of methods’.

#### **3.2.2.1 Patient study using semi-structured interviews**

##### *Thematising and designing*

Initially, the aim of this study was quite broad and explorative, i.e. to get an insight into how COPD patients self-manage worsening symptoms. This included, but did not require that the participants had received or used antibiotics and oral corticosteroids for self-treatment. The

first round of recruiting participants started on this basis. Since the overall interest was in investigating practice of routine care, we wanted to recruit via GPs, outpatient based pulmonologists or hospital based pulmonologist - whom we knew would occasionally instruct COPD patients in self-treatment. Recruiting via the pulmonology department of the University Hospital of North Norway (UNN) seemed attractive due to the 'high concentration' of COPD patients, yet we were concerned that the sample would be too narrow and specific in terms of disease severity, use of health care services and residential area. Moreover, the hospital's will to collaborate did not seem great at that point. Recruiting via general practices would have been a feasible alternative, yet would probably be long-winded. There are certainly COPD patients on GPs' patient lists, but it seemed difficult for the GPs to remember which patients had self-treatment medications. In the end, we recruited via the responsible physician at Skibotn Rehabilitation Centre, a heart and lung rehabilitation institution in North Norway. Recruitment was done by sending out invitation letters including consent forms to 74 COPD patients who had participated in the rehabilitation program in 2012/2013, and asked to return written consent and a note about age, occupation, civil status and whether they had received medications for self-treatment of worsening symptoms. I considered that the advantages with this sampling strategy, i.e. high geographical variation in residence, age, occupation and level of care where they had received self-treatment plans from, would outweigh the disadvantages, i.e. that all had gone through a lung rehabilitation program. We assumed that there would be a certain homogeneity regarding education about COPD and COPD management the potential participants would have received. The recruitment process was smooth to begin with and there was a great willingness to participate. We received (in total) 45 consent forms and one email with written consent. In this first round of recruiting, we contacted 15 respondents, chosen purposefully to include COPD patients from rural and urban areas, both sexes and with different working and civil status, and made appointments for the interviews. I ended up with 15 participants, of which 8 had received, and 7 had not received self-treatment medications (see Table 1). Yet, during the interviewing phase, I needed to reconsider my strategy (see Figure 2 for the whole recruitment process).

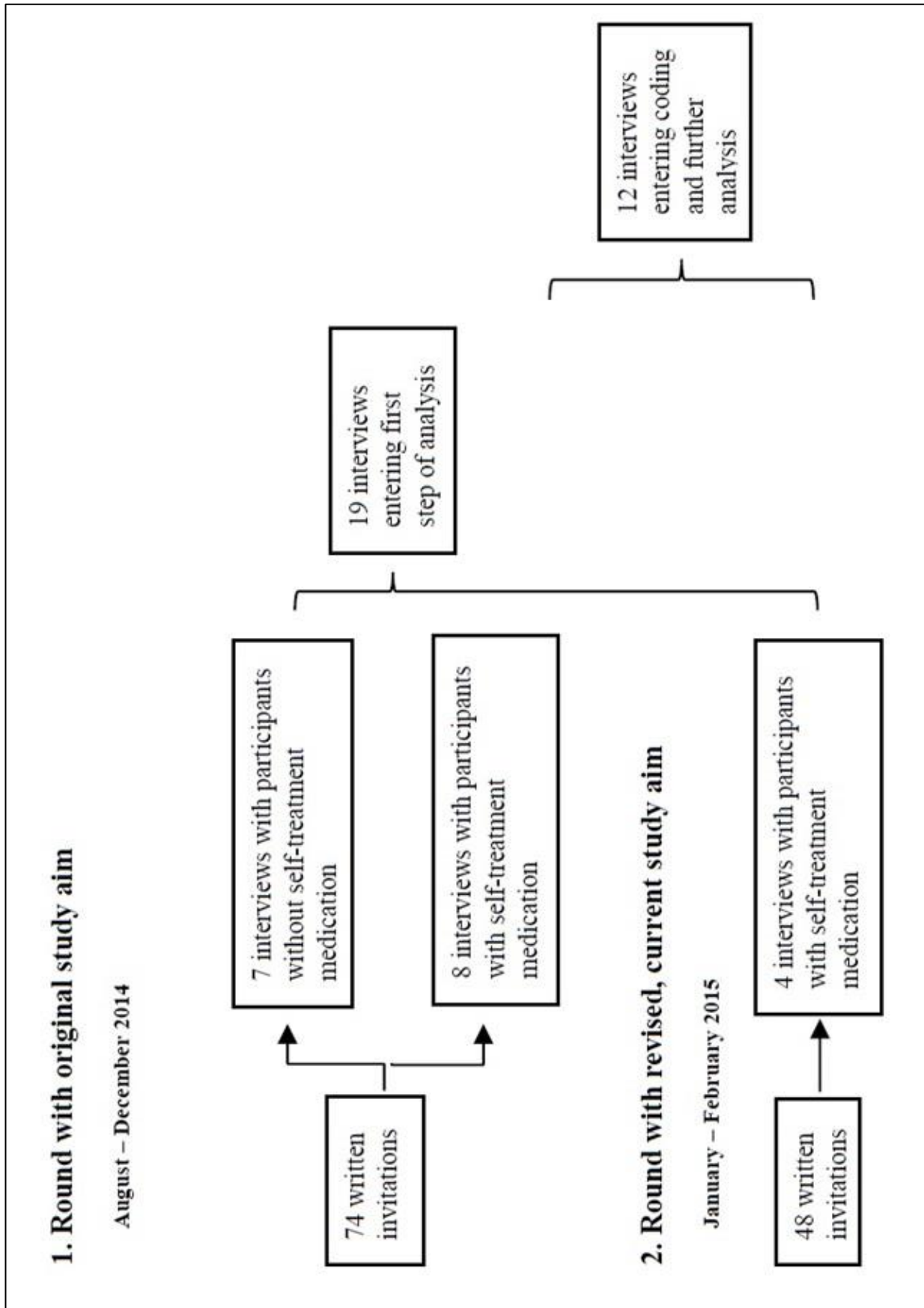


Figure 2 Flowchart showing the recruitment and sampling process (Patient study<sup>113</sup>)

### *Interviewing and transcribing*

Semi-structured interviews are usually conducted based on an interview guide, which is a collection of question or main themes the researcher wants to cover during the interview<sup>108</sup>. It is not necessary to strictly follow these questions, but the guide can help the researcher to keep track of his agenda. We developed the interview guide (see *Appendix*) based on earlier research in the field, focusing on recognition of COPD exacerbations, experiences with and reasons for using antibiotics and/or oral corticosteroids, attitudes towards being a ‘self-treating’ person and experiences and perspectives on seeking help from health professionals when experiencing worsening COPD symptoms. The formulation of the questions required a careful consideration about the use of terms. For instance, we chose not to use the term ‘COPD exacerbation’, as we did not know what the participants would associate with this term. In order to find out about exactly this, one of the first questions was whether they knew the term ‘KOLS forverring’ (which is like ‘COPD worsening’) and what this meant for them.

In autumn 2014, I travelled through Northern Norway to conduct the interviews – at least the first eight ones. All eight participants, except two who preferred to meet me at UiT The Arctic University of Norway, agreed on being interviewed in their homes. Interviewing the participants in their homes had several advantages. Obviously, it was easier for me to travel than it was for the participants. More importantly, however, being able to see where and how the participants lived would provide contextual background information for adapting the interview guide to the individual and for data interpretation.

During the first interviews, I recognized that I had been quite naïve in terms of assuming that having self-treatment medications available automatically meant to use them. Moreover, it seemed as if there were quite big variations regarding the way and the purpose the participants had received antibiotics and/or oral corticosteroids for, and regarding the self-treatment instructions they had been given. For many participants, self-treatment was a supplement and not an alternative to contacting a doctor. Moreover, I realized that recruiting both patients who had and who had not received self-treatment medication could be problematic, as I would end up with self-treatment stories that would on the one hand be based on real experiences with self-treatment and on the other hand on hypothetical self-treatment scenarios. I considered this a disadvantageous mixture of theoretical and experiential knowledge. Therefore, after thorough reflection, we narrowed down the study

aim to now focusing on self-treatment with antibiotics and oral corticosteroids and on help seeking. Subsequently, we started a second round with invitation letters to include more participants who had actually received self-treatment medications (see Figure 2). I used the same interview guide (see *Appendix*), but left out certain questions that did not correspond to the changed study aim. In this second round, I included four more COPD patients with self-treatment plans and finally ended up with 19 interviews (see Table 1).

In retrospective, I would say that we could have avoided this ‘detour’ - and the critical questions by reviewers on the matter in the publishing phase - by more thorough reflection before the recruitment.

Table 1 Participant demographics (Patient study<sup>113</sup>)

Participant	Sex	Age	Civil status	Working status	Residence	FEV <sub>1</sub> /FVC
1*	m	60	married	partly disabled	urban	32%
2*	m	73	married	retired	rural	98%
3*	f	77	widow	disabled	rural	34%
4*	f	70	married	housewife	rural	39%
5*	m	64	partner	disabled	urban	37%
6*	m	65	married	disabled	urban	45%
7*	f	62	divorced	disabled	rural	59%
8*	m	65	single	employed	urban	63%
9	m	64	married	disabled	rural	n.a.
10	m	72	married	retired	urban	47%
11	f	65	divorced	disabled	rural	39%
12	f	75	married	retired	urban	91%
13	f	55	single	disabled	rural	84%
14	m	58	single	disabled	rural	n.a.
15	m	65	married	self-employed	urban	45%
16*	f	74	married	housewife	urban	n.a.
17*	m	64	partner	disabled	urban	20%
18*	m	71	widow	retired	rural	22%
19*	m	60	single	disabled	urban	64%

*m=*male, *f=*female; FEV<sub>1</sub>/FVC=*forced expiratory volume in one second/forced vital capacity*;  
*n.a.* = not available

\* *participants who have received antibiotics and/or oral corticosteroids for AECOPD self-treatment and whose interviews were coded in detail.*

### *Analysing, verifying and reporting*

I used thematic analysis as described by Braun and Clarke<sup>114</sup> for both the Patient study and the GP study. In this section, I will give an introduction to this analysis method and how I applied it in the Patient study (below, I will describe relevant aspects of analysing the FGDs).

Thematic analysis has a less strong tradition in qualitative research than for example Grounded Theory, yet it is popular and widely used within health disciplines<sup>115</sup> (B&C 2014). It is regarded as a “comparatively easy to learn qualitative analytic approach, without deep theoretical commitments” and it is considered that “it works well for research teams where some are more and some are less qualitatively experienced”<sup>115</sup>. Therefore, thematic analysis appeared as an attractive method to use in my case, and I followed the recommendation of my supervisor Mette Bech Risør to choose this method. Braun and Clarke described thematic analysis as a “robust, systematic framework for coding qualitative data, and for then using that coding to identify patterns across the dataset in relation to the research question”<sup>115</sup>, yet emphasize its variability and flexibility in terms of analytic depths and theoretical frameworks. Flexibility requires the researcher to make choices including the epistemological stance (e.g. realist or constructionist thematic analysis), the type of analysis (broad description of the dataset or detailed account of one or more particular aspects), how to identify patterns (inductive or deductive analysis) and the types of themes (semantic or latent themes)<sup>114</sup>. For this study, my particular interest was in the patients’ perspective on self-treatment of COPD exacerbations. Therefore, I applied an initial inductive approach to data analysis – i.e. that theme development was steered by the data and not by a pre-determined theoretical interest or coding framework<sup>114</sup>. My analysis aimed at developing semantic themes, based directly on what was said, on the surface of meanings. Thematic analysis as described by Braun and Clarke follows six phases, which are described in Table 2.

Table 2 Phases of thematic analysis as described by Braun and Clarke<sup>114</sup>

Phase	Description of process
<b>1. Familiarizing yourself with the data</b>	Transcribing data (if necessary), reading and reading the data, noting down initial ideas
<b>2. Generating initial codes</b>	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code
<b>3. Searching for themes</b>	Collating codes into potential themes, gathering all data relevant to each potential theme
<b>4. Reviewing themes</b>	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic ‘map’ of the analysis
<b>5. Defining and naming themes</b>	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells; generating clear definitions and names for each theme
<b>6. Producing the report</b>	The final opportunity for analysis: Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis

Similar to Braun and Clarke’s description of data analysis as a “recursive” rather than “linear” process<sup>114</sup>, I experienced that all phases were overlapping and that it was necessary to move back and forth between the phases to find a balance between keeping closeness to the



data and reflective distance. Such ‘moving’ between phases means also to move between the data set, the analytic categories, and literature. Writing and visualization of my thoughts, as well as periods with literature readings were very important for me to keep track of my ideas, potential themes and choices. The Figures 3 and 4 give an example of how I visualized my thoughts during the analysis process.



Figure 3 Simplified MindMap created during the development of final themes (Patient study<sup>113</sup>)

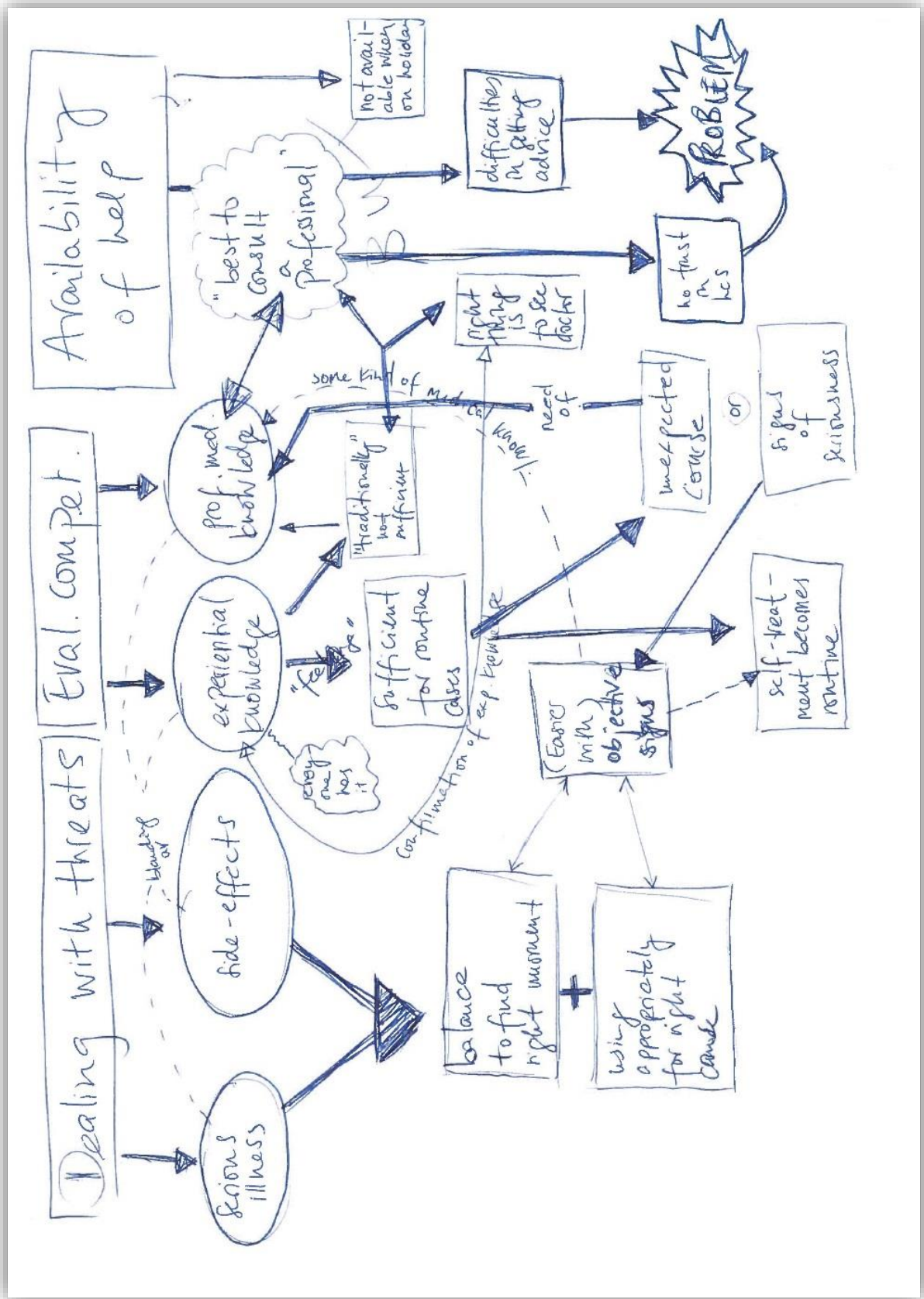


Figure 4 Visualization of ideas and potential themes in the analytic process (Patient study<sup>113</sup>)

Having a reflexive relationship to the data, going back and forth between analytic categories and the data, and contextualizing the data is important to verifying that the reported results express the participants' concerns and a way of ensuring the trustworthiness of the results<sup>116</sup>. To achieve this, I used mind maps to create a visible link between the data and potential analytic themes, discussed codes and categories with my supervisors and peers with other personal and professional backgrounds, and engaged with existing literature in the field as well as theoretical concepts (see *Discussion of methods*). Overall, taking the step from initial coding to the final themes required a lot of curiosity, creativity and patience to let ideas emerge, and to develop them during reading, thinking and discussions. Using existing theory or theoretical concepts is also a form of validation<sup>117</sup>. Particularly theoretical concepts from sociology and psychology, e.g. the health belief model<sup>118</sup>, the Common Sense Model of Illness Representation<sup>82</sup>, Attachment Theory<sup>119</sup> and the Necessity-Concerns-Framework<sup>120</sup>, which I finally use in the Patient study, appeared relevant and suitable to use in my analytic work. Using theoretical concepts as a tin opener<sup>117</sup> to 'open up' my findings was indeed 'eye-opening'. I experienced the writing up of my results and discussing them in the light of existing literature and theory as part of the analytic process rather than separated from the analysis. Overall, reporting is a sum of the leads made in the design process, and writing a condensation of presumptions concerning data. The researcher needs to ask how to convey the content of the data and how to align it with the media it is possible and relevant to publish in. First of all, however, I had to choose the journal I wanted to publish the results in. I chose a journal with a rather broad scope (BMC Family Practice) that addresses a large audience, since I regarded my findings both interesting for the COPD management debate, but particularly the self-management and help seeking aspects very relevant to other primary care contexts. I experienced the process of article writing, and the feedback from supervisors, editors and reviewers during the writing and publishing process as helpful to further refine themes and bring even more forward the 'essence' of meanings in the data.

### **3.2.2.2 GP study using focus group discussions**

#### *Thematising and designing*

In contrary to the Patient study, the data for the GP study was already collected as part of the PEXACO project when I engaged in the research project. Therefore, I had to approach 'Thematising and designing' differently. The PEXACO protocol had several aims, one of which was:

*“- How do European GPs and pulmonologists think exacerbations of asthma and COPD in adults should be assessed and treated, and in particular what role do the Anthonisen criteria play in the decision on antibiotic treatment?”*

The data I was to use was based on 21 FGDs discussions (7 countries, 3 FGDs per country). It was collected to cover several research projects and studies within the overall PEXACO project, aiming for instance to understand overall concerns of GPs and pulmonologists about primary care management of COPD exacerbations<sup>98</sup>, or to explore these healthcare professionals' perspectives on self-treatment<sup>71</sup>. From my time as a research assistant, during which I translated the Norwegian FGDs into English, I had already an idea about the content of the (at least Norwegian) FGDs. As my main interest for the GP study was in the GPs' perspective, I chose to include only the FGDs with GPs - contrary to the study of Risør et al.<sup>98</sup>. Another reason was that the results of their study indicated that there are differences in how GPs and pulmonologists approach decision-making. Moreover, one can argue that GPs typically deal with less severely ill patients than pulmonologists, and treatment with antibiotics and/or oral corticosteroids may often be less necessary for COPD patients in primary care<sup>22,23</sup>, which is why we considered it important to explore the GPs' perspective in particular. I further developed the original research question (see above) and the analytic approach. Early considerations for the research question included 'gatekeeping' and 'collaboration' (with specialists) and 'role of diagnostic tests and clinical examination'. Overall, I experienced this as a rather challenging process, as I felt that having the data already complete limited the spectrum of research questions that were adequate according to the nature of the data, i.e. cross-cultural FGDs. I tried to get as much information as possible about the thoughts and ideas from early phases of the project I was not involved in, as I felt that being able to follow the others' strings of thought eased my further decisions, and helped me to distinguish my research question from the analysis of Risør et al.<sup>98</sup>. I had many discussions at different occasions about the analytic focus for FGDs, and went back and forth reading the data and relevant literature. Moreover, I thought quite a lot about the cross-cultural dimension of the data. A teacher in a focus group course once pointed out that there was a considerable risk that my interpretations of the GPs' stories would be “influenced by prejudices rather than systematic knowledge about the preconditions of healthcare systems and cultures”. Other peers I discussed this with were not that worried about the healthcare

systems differences, as long as I was careful and reflective in my interpretations. Keeping these thoughts and the impressions from first readings in mind, I finally decided to focus on aspects of decision-making concerning treatment with antibiotics and oral corticosteroids and hospitalization, and what GPs consider relevant when deciding upon managing COPD patients with deteriorating symptoms.

### *Sampling, interviewing and transcribing*

The FGDs had been conducted in 2011, and were transcribed as well as translated into English before I started my PhD project. The PEXACO researchers designed a study of 21 (3x7) FGDs. Six of the seven participating countries (Netherlands, Poland, Russia, Germany, Wales and Norway) were selected from earlier research collaboration networks (General Practice Research on Infections Network (GRIN) and Genomics to combat Resistance against Antibiotics in Community-acquired LRTI in Europe (GRACE)). Hong Kong joined later - originally meant to serve comparative purposes to the European countries. There were three rounds of FGDs in each country with new participants each time, i.e. FGD1 with GPs only, FGD2 with pulmonologists, and FGD3 with both GPs and pulmonologists. In order to align the data collection method in each country, all researchers involved in the data collection joined a three-day workshop including instructions on the FGD method, qualitative research and an exercise. Participants for FGD1, the sample for my study, were sampled purposefully through personal contacts and professional networks. The sample covered GPs from both urban and rural practices and included GPs with both long and short experience in general practice (see Table 3) (for more details on the sampling of FGD2 and FGD3, see ref Risør et al.<sup>98</sup>).

Table 3 Overview over recruitment process and participants (GP study<sup>121</sup>)

Country	Methods of recruitment	No. invited	No. responded	No. participating	Practice organization	Practice setting
Norway	announcement at a meeting	12	7	7	group practices only	rural
Germany	written invitation	29	8	8	both single and group practices	both urban and rural
The Netherlands	announcement at a meeting, personal contacts	59	27	6	group practices only	both urban and rural
Wales	postal invitation letter send in two rounds and followed up with telephone calls	136	18	10	group practices only	both urban and rural
Poland	personal contacts	8	8	8	both single and group practices	urban
Russia	announcement at a meeting, telephone invitations, personal contact	9	8	8	both single and group practices	both urban and rural
Hong Kong	email invitations, announcement at meetings	12	6	6	group practices only	urban

Before conducting FGD1, the first topic guide was developed by Mette Bech Risør and Hasse Melbye with input from collaborating countries. A pilot interview was conducted in Tromsø in order to adjust for formulations, phrases and questions. The development of the interview guides for FGD2 and FGD3 is described comprehensively in Risør et al.'s article<sup>98</sup>. The final interview guide for FGD1 contained the following topics:

- *assessment and medication, hospitalization, self-treatment, use of guidelines, challenging or difficult situations, most important problem, and improvement of clinical practice.*

Even though I was involved in translating the Norwegian FGDs into English, and had therefore an idea about what they were about, I did not feel as 'close' to this dataset as to the semi-structured interviews I conducted myself for the Patient study. Moreover, by translating, the transcripts had already gone through a process of interpretation. Some sentences and passages in the translated transcripts were hard to make sense of because of the translations' quality. I tried to resolve unclear passages mostly by asking the researchers in the respective countries, or discussing them with my supervisors. Overall, I believe I managed to account for these obstacles and not let them negatively influence the data analysis and the validity of my results (see *Discussion of methods*).

#### *Analysing, verifying and reporting*

I also used thematic analysis for the analysis of the FGDs, and will not repeat the general aspects on this method. My initial aim for analysis was to explore the decision-making process in terms of cognitive processes, yet realized very early (and was in fact warned that this would be very difficult) while reading the interviews in the first analytic phase, that this was impossible given the nature of the data. That is, the data contained GPs' narratives that are based on their own reflections about decisions they made in the past, and can therefore not give insight into cognitive processes that occur during an actual decision-making. In the end, my actual aim was much more convenient: what the data could offer was knowledge about what GPs consider important to their management decisions. Table 4 gives some examples of the analytic process and the abstraction of meaning of the data material to a final theme.

Table 4 Examples of the interpretation and abstraction process from data to final themes (GP study<sup>121</sup>)

Data extract	Initial code	Preliminary category	Final theme
<p>“I think it’s difficult because a lot of these patients do have chronic, their sputum is chronically um there is all sorts of bacteria it is difficult to be guided by things such as sputum culture because it’s often going to come back as positive whether or not it’s acute .... ”</p>	<p>Cannot rely on validity of information</p>	<p>Dealing with uncertainty</p>	<p>Making medical decisions account for medical uncertainty</p>
<p>“It’s different patients, there are some patients that play there symptoms up and others that play them down but I mean if you went initially on symptoms you would be giving them antibiotics every month so when they perhaps don’t need it.”</p>	<p>Cannot rely on the validity of information Knowing the patient as a person Interpreting information relevant to the person</p>	<p>Knowing the patient</p>	<p>Knowing the patient</p>
<p>“If she is a worried lady and self wants to be in a hospital I would set the threshold even lower I suppose.”</p>	<p>Patient makes final decision about hospitalization</p>	<p>Listening to the patient</p>	<p>Balancing the patients’ perspective</p>
<p>“...sometimes we try...we don’t write: “for hospitalization”, but only “for diagnostic evaluation in the Admission Room”. Sometimes they ‘buy’ such things...!</p>	<p>Using hospital for diagnostic testing</p>	<p>External framework</p>	<p>The value of outpatient support and collaboration/Support from other sources of care</p>



As mentioned earlier, the FGDs covered more topics than were relevant for my study, which is why I did not code the whole FGD material and skipped certain passages when the topics were clearly not relevant for my research questions (such as discussions about self-treatment and smoking). However, I found the data could be too broad and too superficial at times. Semi-structured interviews might have provided more in-depths insight into the phenomenon<sup>1</sup>. Compared to the Patient study, where I was involved from the beginning, having a readily collected and transcribed dataset available made the conduction of the GP study less time consuming. The analysis of the FGDs differed in several ways from analysing the semi-structured patient interviews. For instance, the dynamic nature of FGDs made the context in which something was said more important to the interpretation. Analysing the FGDs from different countries, was, compared to the patient interviews, more challenging since I was not very much familiar with the healthcare systems in the countries other than Norway and Germany. Yet, since I had collected information about the other healthcare systems of the other five countries during my time as a research assistant, I knew about the overall organization of the systems. The translated interviews were in some cases difficult to understand, and it could be necessary to ask the researcher of the respective country about the meaning of a certain term or the context of a participant's narration. This ongoing dialogue within the research network was a useful way to verify my own understanding of these passages. As in the Patient study, I used mind maps and drawings to visualize my data and preliminary themes, and shared codes and further development to themes with my supervisors and other peers. We could resolve disagreements about the meaning of data units through discussions and further reading of literature and theory. For the GP study, I read particularly about medical uncertainty, different theoretical approaches to decision-making (such as 'gut feelings'<sup>122</sup> and 'mindlines'<sup>123</sup> and about patient-involvement<sup>124</sup>. Theory and literature served, as in the Patient study, as tin opener to data interpretation. In the end, I organized my results in four final themes that we reported in a scientific article. For the GP study, I choose a journal with a scope on COPD research (The International Journal of COPD), primarily because I considered my findings most relevant in the context of ongoing discussions on managing COPD exacerbations, but also because this journal had a good reputation in terms of an easy and fast review process. For more reflection and discussion of methods and use of the methods, see the 'Discussion of methods'.

### **3.3 Ethical formalities**

I followed general ethical principles as described by The Norwegian National Committees for Research Ethics<sup>125</sup> and the Helsinki Declaration<sup>126</sup>, which draw on respect, good consequences, fairness and integrity. However, all rules and guidelines have to be understood contextually and applied according to the nature of the research project, and should be reflected on continuously<sup>108</sup> (see also ‘Discussion of methods’).

Formal requirements were met in the same way in both the Patient study and the GP study. They were presented to the Regional Ethical Committee, which found that their purposes did not belong under their jurisdiction according to the Norwegian Health Research Act. Therefore, both studies were exempted from their approval. The studies were reported to the Norwegian Social Science Data Services, including changes that were made during the Patient study. Written informed consent on participation was obtained from all the participants in both studies. Letters to potential participants were sent out with general information about the study and a consent form. The persons who returned a signed consent form were contacted by me (Patient study<sup>113</sup>), or the researcher responsible for data collection in the respective country (GP study<sup>121</sup>). For the Patient study, I informed the potential participants orally about the details for the interviews and the possibility to quit the study at any point. I contacted also those who we chose to not include in the first place, thanked them for their interest and explained why they could not be included at this point. I obtained oral consent from all participants to contact them again if necessary. All participants were informed orally that their stories would comprise the raw data for this study and gave oral consent to outsourcing of the interviews’ transcription, to publication of the analysed data and citations after removal of personal information. The participants received a gift coupon of 500 Norwegian crowns as compensation for their participation. Confidentiality was ensured by secure separate storage of documents containing information that could identify the participants for both studies. The person hired to transcribe the patient interviews was carefully informed regarding confidentiality and signed a special contract on discretion. For the GP study, the participants were informed about how the researchers would proceed with the data, e.g. transcription, analysis and article writing. The transcription of the anonymized data and translation into English was conducted by the moderators, the project leaders or a language assistant in the respective countries. Also the participants of the FGDs

received a financial compensation for their participation according to national standards for compensating physicians.

## 4 Results

This thesis on the management of COPD exacerbations in primary care regarding treatment with antibiotics, oral corticosteroids and hospitalization resulted in three studies with the following titles:

1. *“When should acute exacerbations of COPD be treated with systemic corticosteroids and antibiotics in primary care: a systematic review of current COPD guidelines”* (Guideline study)<sup>112</sup>
2. *“Self-treatment of acute exacerbations of chronic obstructive pulmonary disease requires more than symptom recognition – A qualitative study of COPD patients’ perspectives on self-treatment”* (Patient study<sup>113</sup> - currently under review)
3. *“How do general practitioners implement decision-making regarding COPD patients with exacerbations? An international focus group study”* (GP study<sup>121</sup>)

Here follows the summary of the results

### *Guideline study*

The results showed that treatment recommendations were mostly symptom-based. For oral corticosteroids, criteria were often recommended universally for all patients with an exacerbation, with patients with (severe) dyspnoea or all patients with an underlying moderate to severe COPD. For antibiotics, recommended criteria were mostly based on the Anthonisen criteria from 1987<sup>25</sup> (increased dyspnoea, increased amount of sputum, and increased purulence of sputum), with emphasis on sputum purulence. The use of diagnostic tests was only recommended in a few guidelines. The patients in the trials on which the recommendations were based were a rather selected group of COPD patients, i.e. that most trials were conducted with hospitalised patients, that the exclusion rates before randomisation were high in many trials, and that the patients were often characterised by severely reduced lung function and low prevalence of cardiovascular comorbidities or diabetes. Owing to the small number of GPs in the guideline development committees, we found that there was an

imbalance between the expertise distribution in guideline development and the percentage of care that is actually provided in primary care. Overall, there was a considerable lack of transparency, as the literature review was often not documented comprehensively. A number of guidelines were financed by pharmaceutical companies, or did not report their funding sources.

### *Patient study*

The findings showed that, overall, the participants considered the opportunity for self-treatment as a practical alternative to help seeking, and that having medications on standby gave an extra feeling of safety. Many participants did not remember when or with what instructions they got the standby medications for the first time, and most of them would not talk about these medications with their doctors. When experiencing worsening symptoms, the participants used their experiential and lay-medical knowledge to weigh up risks and benefits of the illness and the medications side effects before starting treatment or seeking help. Concerns about the medications' potential side effects emerged as highly relevant to their assessment on whether to start treatment or to 'wait-and-see'. Some participants would principally contact a healthcare professional before starting treatment. Having regular exacerbations with repeating symptom patterns and positive experiences with treatment seemed important to their feeling of confidence in self-treatment. Yet, also these participants could have difficulties with interpreting symptoms in terms of finding the right time to start treatment, especially those who had strong concerns regarding side effects. Another problem reported by some participants was treatment failure. In both cases, they could appreciate assistance by a health care professional, but seeking help, however, was not natural to all participants. Some, even though appearing confident enough to deciding alone, consulted a healthcare professional as a rule before starting treatment. Others, mostly those who also reported negative experiences with having received help previously, would stick to self-treatment as long as possible in order to avoid unpleasant or 'useless' consultations with doctors. Another pattern of help seeking was characterized by a desire for assistance but, at the same time, insecurity regarding the legitimacy of seeking help, as participants could feel obliged to succeed with *self*-treatment without help from a healthcare professional.

### *GP study*

The results showed that the GPs' wish to make medically appropriate decisions could be challenged by medical uncertainty and worries regarding potentially severe outcomes if having left a serious condition untreated. Knowledge about the patients, a holistic understanding of illness and the patients' own experiential knowledge emerged as a valuable supplemental framework for GPs to interpret the often diffuse clinical picture, and to make reasonable decisions under medical uncertainty. Moreover, we found that decisions were not merely the GPs' 'brain-child', but would rather emerge from a process of interpretation, communication and negotiation between the involved actors, including patients, patients' peers and healthcare professionals. Moreover, GPs' decisions were shaped by opportunities and limitations resulting from the healthcare system's organizational structure and cultural code of conduct.

## **5 Discussion**

### **5.1 General discussion**

This thesis aimed to explore the management of COPD exacerbations in primary care, focusing on treatment with antibiotics and/or oral corticosteroids, help seeking and hospitalization. We have conducted three studies using different methodologies and methods, all of which illuminate different parts of the overall phenomenon. The results of each study are discussed in the three articles<sup>112,113,121</sup>. For this general discussion, I will try to integrate the different perspectives to draw a comprehensive picture of how COPD exacerbations are managed in primary care, and to highlight aspects that I consider overall relevant to improve current and future care of COPD exacerbations.

#### **5.1.1 A multidimensional framework for interpreting worsening symptoms**

One common aim of all the three studies was to get insight into which criteria should be applied when deciding about treatment with antibiotics and oral corticosteroids in primary care (Guideline study<sup>112</sup>), and what is relevant to making these treatment decisions in 'real life' (GP study<sup>121</sup> and Patient study<sup>113</sup>), respectively. The treatment criteria in COPD guidelines were mainly symptom-based. For antibiotics, criteria were comparable to the

Anthonisen criteria (increased sputum purulence and volume and increased dyspnoea)<sup>25</sup>, yet with more weight on sputum purulence. The criteria for oral corticosteroids rested largely on the severity of dyspnoea but were otherwise often recommended universally for all patients with exacerbations. In the Guideline study, we argued that these recommendations are probably of little help to target treatment for COPD exacerbations, as for instance cardiovascular comorbidities can present with similar symptoms<sup>12,127</sup>. Moreover, we concluded that the applicability of the recommendations to a primary care setting is probably low (Guideline study<sup>112</sup>). In primary care, patients have typically less severe underlying COPD, but more comorbidities than the patients in the trials the recommendations are based on<sup>128</sup>. The findings from the GP study and the Patient study support the limited usefulness of symptom-based criteria to making treatment decisions. One of the main findings from both studies was that basing treatment decisions on clinical criteria may be difficult due to slowly developing, diffuse symptoms that do not clearly indicate the need for treatment. Both patients and GPs seemed aware of the challenges related to comorbidity and the potentially multiple underlying causes of symptoms.

Clinical examination, diagnostic tests and biomarkers played a minor role or no role in the assessed COPD guidelines (Guideline study<sup>112</sup>). According to the GPs in the GP study, many seemed to routinely conduct a clinical examination, and could consider findings, for instance wheezing or a combination of different clinical signs, as relevant to their decision-making. Pulse oximetry, specifically a drop in oxygen saturation, seemed ‘popular’ among the GPs to assess overall disease severity, at least among GPs who had access to this test (GP study<sup>121</sup>). Only the Swedish guidelines recommended pulse oximetry for patient assessment/treatment (Guideline study<sup>112</sup>). In terms of biomarkers, CRP was only recommended in the Norwegian guidelines<sup>28</sup>, even though it is presented as a promising biomarker to target antibiotic treatment<sup>26,27</sup>. According to the GPs in the GP study, CRP could be very useful if significantly high or low, yet they stressed that this may not very often be the case in COPD patients. This finding mirrors that acute bacterial infections play a minor role in COPD exacerbations<sup>16</sup>. Diagnostic markers for viral infections or systemic inflammation may be more useful, yet such markers seem far from becoming a realistic diagnostic alternative for GPs.

Overall, it seems as if a clinical examination, diagnostic tests such as pulse oximetry, and also biomarkers can assist the otherwise symptom-based assessment when findings are deemed significant. The perceived relevance of clinical/medical information from the assessment varied across countries. It seemed as if the GPs from Poland and Russia were, at least in the beginning of the discussions, more concerned with the clinical/biomedical assessment compared to the GPs from, for instance the Netherlands, who were to a larger extent stressing the importance of the social and psychological aspects from the start. Differences between European countries regarding disease-centeredness/patient-centeredness have been previously reported<sup>129</sup>. The GP study showed also that there were variations among the GPs to which extent they considered patient contact important for assessment. Some GPs insisted that ‘seeing’ the patient was important to their assessment, others seemed positive to prescribing treatment over the phone if the patients’ story was ‘convincing’ that treatment was necessary. These variations in patient assessment are mirrored in a study of Melbye et al., showing that only 59% of patients with severe COPD and asthma underwent a clinical examination before hospitalization (many were hospitalized after telephone contact)<sup>130</sup>. Both these and our findings suggest that, given the lack of overall useful clinical criteria and diagnostic tests, GPs apply different assessment strategies to patient assessment and decision-making. Indeed, GPs certainly deal with medical uncertainty in a variety of ways<sup>131</sup>.

The Guideline study suggested that following the recommended treatment criteria for antibiotics and oral corticosteroids is likely to result in treatment for the majority of COPD patients with worsening symptoms, even though this may not be medically appropriate (Guideline study<sup>112</sup>). I found that such rather categorical approach to treatment, i.e. for all COPD patients with exacerbations, was also present in the GPs’ narrations in the GP study. Yet, the GPs’ reasoning showed that their categorical treatment was not due to following guidelines but as a strategy to deal with medical uncertainty (GP study<sup>121</sup>). In the GP study, being ‘categorical’ with treatment was rather the result of a ‘better safe than sorry’ approach to managing ‘high risk’ COPD patients (GP study<sup>121</sup>). We argued in the GP study that the underlying problem leading to this categorical/precautionary decision-making could be an attempt to apply a biomedical interpretative framework to a clinical picture that is difficult to make sense of with biomedical knowledge, often lacking an identifiable biomedical cause (GP study<sup>121</sup>). As a possible solution, the GPs described another strategy that seemed to enable them to make more tailored management decisions for the individual patient. This

approach was based on an extended interpretative framework and application of different types of knowledge to make sense of the often diffuse clinical picture (GP study<sup>121</sup>). One main finding from the GP study was that the GPs' clinical and personal knowledge about patients, including medical history, social circumstances but also "behaviour and cognition"<sup>132</sup>, was a valuable supplement to medical knowledge. Such knowledge seemed, for instance, to enable GPs to add a time perspective to patient assessment, i.e. evaluate symptom *changes* and to evaluate the role of social and psychological aspects to a patient's illness. The latter is, in my view, particularly important given that anxiety and depression are common comorbidities in COPD patients<sup>8</sup>, and since anxiety may aggravate the experience of dyspnoea<sup>133</sup>. A continuous, long term relationship to patients, which is one of the cornerstones of primary care<sup>134</sup>, may be the key to GPs' knowing their patients. Unfortunately, not all GPs have such knowledge about their patients<sup>135</sup>. However, as we argued in the GP study, with more awareness about the importance of contextual aspects to patient care, GPs may to a larger extent be able to recognize "contextual red flags"<sup>136</sup> during the patient consultation.

In addition to GPs' knowledge about their patients, also the patients' own experiential knowledge emerged as a valuable resource to making treatment decisions. The GPs seemed to consider the patients' own opinion about the need for treatment as helpful, especially when feeling uncertain themselves (GP study<sup>121</sup>). Given the little usefulness of clinical criteria for making treatment decisions, the patients' experience may indeed be a valuable resource. The reliability of diagnosis based on patients' reporting has actually been validated<sup>137</sup> and from the Patient study, we know that patients can in fact have considerable experiential knowledge from previous exacerbations to recognize symptom changes (Patient study<sup>113</sup>). The participants seemed able to judge whether symptom deterioration was related to, for instance, external circumstances (weather changes, smoke from candles) or whether 'something was really going on'. In line with Willams's study<sup>94</sup>, we found that experiential knowledge can have many faces, e.g. being an embodied feeling or consisting of more 'visible' clinical criteria such as coloured sputum or fever. Overall, the patients' experiential knowledge seemed most valuable - both for self-treatment and for the GPs' assessment - for patients with recurrent exacerbations that present with similar symptom-patterns and who have previously perceived an effect of treatment. Indeed, the Patient study and other qualitative studies<sup>79,138</sup> suggest that, even though the clinical presentation of COPD exacerbations can vary



considerably between patients, there seems to be a group of patients whose exacerbations are more or less predictable in their symptom presentation. This ‘subgroup’ of patients, which may fall under the “frequent exacerbator phenotype” of COPD<sup>139</sup>, may be most eligible to become confident ‘self-treaters’. Interestingly, the development of this phenotype was based on patients’ experiences, e.g. on clinical records or patient recall, and not on biomedical research/aetiological/pathophysiological classifications in the first place<sup>139</sup>.

Overall, our findings suggest that the patients’ expertise and other types of knowledge that are grounded in experience and relations is a valuable epistemological extension to the biomedical understanding of symptoms. A combination of and flexible use of different knowledge types and knowledge sources may be particularly relevant for the management of complex conditions such as COPD exacerbations, which are both acute and chronic in nature, and heterogeneous in terms of aetiology, pathophysiology, symptom presentation and severity. The question arises how to integrate the different types of knowledge in for instance clinical practice guidelines and treatment recommendations, which, to date, primarily rest on the expertise of pulmonologists and other specialists (Guideline study<sup>112</sup>). It would be particularly interesting for a primary care setting to get more insight into if, and how, biomedical/aetiological and pathophysiological patterns correlate with the patients’ experience of symptoms and/or with findings from a clinical examination. Such knowledge could be useful to better predict the effect of antibiotics and oral corticosteroids without the use of advanced diagnostic technology and could inform both guidelines for primary care physicians and the development of individually tailored self-treatment plans.

### **5.1.2 Perceptions of risk**

As described in the above section, slowly developing and diffuse symptoms as well as comorbidity can challenge ‘medically appropriate’ treatment decisions for both GPs and patients. However, one could argue that medical uncertainty is a common phenomenon in general practice, and just the fact that decisions are difficult may not fully explain for instance high hospitalization rates and apparent high use of antibiotics and oral corticosteroids. Indeed, the findings from the patient and the GP study uncover, in my view, that it is not the experience of uncertainty itself, i.e. the ‘lack of information’, but the worries/concerns about

possible severe consequences of ‘wrong’ decisions that are the biggest problem (Patient study<sup>113</sup> and GP study<sup>121</sup>).

In the GP study, we applied a psychological explanatory framework that understands “action rather than inaction”<sup>140</sup> as strategy to deal with uncertainty through avoiding unpleasant feeling and pondering after the decision is made<sup>141,142</sup>. Overall, we know from several qualitative studies on GPs’ work that their treatment decisions are, among other things, influenced by a desire to “minimize risk”<sup>143,144</sup>, and a feeling that they have to “protect their backs”<sup>145</sup>. In terms of hospitalization, our findings support other studies on GPs’ referral decisions in general. These studies show that referrals often have a re-assuring purpose for both the patient and the GP, and not a purely medical purpose<sup>146-151</sup>. However, the GPs’ stories revealed that they perceive COPD patients - as opposed to other, younger and ‘healthier’ patients - as particularly vulnerable. It seems that this was a special risk attribution that lowered the threshold for ‘action’ considerably (GP study<sup>121</sup>). Certain symptoms, such as coloured sputum, may not have triggered antibiotic prescribing in a patient without underlying COPD. Indeed, an observational study on variations of GPs’ antibiotic prescribing for acute rhinopharyngitis suggests that it is mainly the patients’ characteristics - as opposed to a physicians’ practice style - that explains the choice of treatment. The authors found, for instance, that GPs were more likely to prescribe antibiotics ‘unnecessarily’ to patients with respiratory comorbidities<sup>152</sup>. This emphasizes, in my view, that, in addition to the perceived complexity of the illness and the ‘difficult’ COPD patient<sup>98</sup>, GPs perceive the management of COPD patients with worsening symptoms as particularly ‘serious’.

Further, the patients’ stories revealed that, from their perspective, decision-making about the use of antibiotics and oral corticosteroids is a ‘serious undertaking’ (Patient study<sup>113</sup>). Yet, COPD patients seem to have a different risk perception than GPs. Instead of being most worried about further deterioration of symptoms, patients’ concerns seemed to focus on the self-treatment medications’ side effects, particularly the effect on their general future health. Many had also a quite strong, yet somehow diffuse, awareness that one should not take antibiotics unnecessarily as they could lose their effect in the future (Patient study<sup>113</sup>). Importantly, particularly for patients who experience a rather diffuse development of symptoms, such concerns seemed to contribute to hesitation and insecurity, eventually rejection of starting self-treatment without a confirmation from a doctor (Patient study<sup>113</sup>).

Previous studies have comparable findings, e.g. that COPD patients can be worried about the medications' side effects<sup>79,88</sup>, and there is in fact a considerable body of literature on patients' medication related concerns in general<sup>153-157</sup>. As I see it, patients' treatment perceptions are not very present in the self-treatment debate. Davies et al., who as part of the overall PEXACO project explored clinicians' views on self-treatment, found that clinicians assumed patients to rather overuse self-treatment medications for, for instance, minor colds<sup>71</sup>. Seemingly, the assumption that patients tend to overuse medications is quite common, as is the attempt to 'conquer' this with information, patient education and appeals to patients to use medicine 'rational'. I would argue that the findings from the Patient study and the GP study indicate that some COPD patients deal more cautiously with antibiotics and oral corticosteroids than GPs. Certainly, it is not possible to say from our studies who makes the 'better' treatment decisions in terms of medical accuracy. What I regard as quite concerning, however, is that patients' concerns seemed sometimes quite exaggerated and could, in combination with uncertainty, result in hesitation to start treatment (Patient study<sup>113</sup>), a hesitation that may result in an unfavourable outcome. This suggests that patient education is still important, yet the focus of educational strategies should also be on treatment perceptions. Therefore, we suggested to include the Necessity-Concerns-Framework<sup>120</sup> as a potentially useful theoretical framework for the theoretical foundations of the self-treatment concept<sup>83</sup>. It is an extension of Leventhal's Common Sense Model of Illness Representations<sup>82</sup>, which is regularly brought up in the COPD self-management literature, and the extension highlights that patients' can experience a "necessity-concerns-dilemma" when weighing up the personal need for treatment and the concerns about potential negative consequences<sup>120</sup>.

Overall, as I interpret the findings from the GP study and the Patient study, both perceived the decision-making situation as somehow 'risky' or 'serious', yet the focus of GPs' and patients' concerns, and their risk rationality seemed to focus on quite different aspects of the overall phenomenon. Neither the GPs' nor the patients' risk perception and risk management approach may be regarded as rational or irrational, but reflect an individual negotiation of risk and uncertainty in a 'real world' context<sup>158</sup>. Importantly, risk management of individuals, which is informed by social relations, experience, emotions and intuition, may not match with policy intended, 'desirable' risk management that is often based on economic evaluations, standardisations and abstractions of risk<sup>158-160</sup>. When it comes to managing

COPD exacerbations, I see this mismatch reflected when looking at our findings in the light of the rationales that underlie the current ‘trends’/goals in care policies for COPD exacerbations (see *Literature review*). For instance, COPD patients’ medication related concerns and resulting hesitation seem contradictory to one of the major purposes of the self-treatment concept that aims for early/prompt treatment initiation. Therefore, we argued in the Patient study that caution is recommended when assuming that introducing self-treatment of COPD exacerbations would ‘automatically’ result in early treatment initiation. Concerning GPs’ approach to deal with uncertainty and risk, there seems to be a contradiction between the precautionary decision-making approach to treatment and hospitalizations, and the overall policy goal to reduce hospitalization rates and ‘unnecessary’ use of antibiotics (and oral corticosteroids). Indeed, a ‘wait and see’ approach to treatment, and taking responsibility for a ‘high risk’ COPD patient in primary care, may in many cases be out of a GPs’ ‘comfort zone’. However, the important question, then, would be how to overcome these controversies/tensions and work towards a common goal? It seems as if providing more information about how something *should* be done according to medical, economical or public health ‘rationality’ in guidelines, or self-treatment plans, is only helpful to a limited extent. For instance, when it comes to antibiotic prescribing in general, even though GPs’ may experience ‘prescribing against the evidence’ as uncomfortable, the rather abstract risk of bacterial resistance development seems less relevant to GPs’ decision-making<sup>161</sup> than more concrete risks, of which the consequences may not only affect patients but also the GPs themselves<sup>162</sup>. In terms of self-treatment, it does not seem that more efforts in educating patients about the medical nature of COPD exacerbations and the pharmacological effect of antibiotics and oral corticosteroids can turn patients into more ‘effective’ self-treaters<sup>85</sup>. Focusing on and addressing potential tensions between different perspectives on risk and necessity for treatment seems, in my view, most promising to overcome decision-making based on ‘misunderstandings’. As an example, I want to refer to Altiner et al.’s study that showed the effectiveness of an interventional strategy focusing on doctor–patient communication and patient empowerment to reduce antibiotic prescriptions in primary care<sup>163</sup>. Comparable approaches may be worth considering for future interventions on the management of COPD exacerbations.

### **5.1.3 The relational dimension of decision-making**

The findings of the Patient study and the GP study suggest that management decisions for COPD exacerbations involve different actors within and across care sectors, and that the nature of the relationship between actors can have a considerable influence on the management of COPD exacerbations. Care relations can refer to the patient-physician relationship but also to relations in broader context, such as interprofessional relations and relations between care sectors.

#### *The patient-physician relationship*

The patient-physician relationship can be described as “the medium in which data are gathered, diagnoses and plans are made, compliance is accomplished, and healing, patient activation, and support are provided.”<sup>164</sup>. One could also describe it as the medium in which decisions are made.

As described above, involving patients in the decision-making and considering their experiential knowledge emerged as a valuable resource for GPs (GP study<sup>121</sup>), particularly experience from patients with frequent COPD exacerbations and recurrent symptom patterns. This group of patients is, however, only a subgroup of patients, and not all patients may have similar experience (Patient study<sup>113</sup>). Moreover, we know from the literature on patient involvement/shared decision-making/patient empowerment that not all patients want to be involved in care decisions, and that involving patients successfully (e.g. in terms of patient satisfaction and health outcomes) in ‘real life’ care decisions depends on many interrelated factors<sup>165-168</sup>. As the participating GPs emphasized, involving patients into the decision-making always encompasses balancing the patients’ knowledge with preferences that, even though important to consider, may not always serve medically appropriate management (GP study<sup>121</sup>). We know from the GP study that this balancing can be particularly difficult when GPs feel uncertain themselves. In terms of antibiotic prescribing, other studies have shown that GPs can feel pressured to prescribe, and for instance in order to preserve the relationship to patients, may give in to patients’ demands<sup>43,46,48</sup>. Also the clinicians’ perception of the patients’ expectations has been shown to strongly predict prescribing<sup>47</sup>. Importantly, as discussed above, COPD patients may not necessarily want prescriptions in the first place (Patient study<sup>113</sup>). Moreover, some of the patients’ narratives reminded us that the patient-

physician relationship is first and foremost a care relationship, and that providing reassurance and comfort may be primary to a physician's supportiveness (Patient study<sup>113,161</sup>).

It was indeed the patients' stories on help seeking that revealed the importance of a 'good' patient-physician relationship to care, despite the fact that, or maybe because, these patients have got the opportunity for self-treatment. Even though our study suggests that the majority of patients liked the *idea* of self-treatment (Patient study<sup>113</sup>), i.e. providing a sense of security, Nici seemed right when emphasizing that "having action-plans is one thing, but putting them into practice is another story"<sup>61</sup>. Except the subgroup of patients that did not seem to experience difficulties with self-treatment, our findings showed clearly that medical uncertainty can be as present in the patients' homes as in the GPs' office (Patient study<sup>113</sup>). One could ask how patients can be able to differentiate between comorbidities and pure COPD exacerbations when such diagnostics are already challenging for GPs (GP study<sup>121</sup>). Indeed, it seemed as if in situations of uncertainty, including cases of treatment failure, even the most confident 'self-treaters' would have appreciated professional assistance (Patient study<sup>113</sup>). From a medical perspective and reasons of patient safety, it seems implicit that patients should contact their doctor when self-treatment is not working. Even though many self-treatment interventions provide patients with the opportunity to contact a case manager if needed<sup>68,169</sup>, it has been speculated that case managers can delay assessment by a healthcare professional<sup>61</sup>. Our findings can neither confirm nor reject this, but they indicate that the 'help seeking part' of self-treatment, particularly issues of trust and responsibility in the patient-physician relationship, should be closer investigated. Indeed, our results showed that distrust in the doctor's ability to help may make patients use the self-treatment opportunity to bypass unwanted encounters with doctors. Another help seeking pattern emerging from the patients' stories was that patients may reject self-treatment except for emergency situations as they consider the expertise and responsibility for such 'serious' decisions should be in the hands of professionals. Or, insecurity regarding responsibility and feelings of obligation to succeed with self-treatment may result in hesitation to seek help when feeling uncertain (Patient study<sup>113</sup>). Comparable findings, i.e. that introducing self-management as care form can 'disturb' the existing patient-physician relationship concerning views on what oneself or the other part is responsible for, have been made in a qualitative study on asthma self-management<sup>170</sup>. Also Blakeman has raised concerns that introducing new means of healthcare might threaten patients' established relation to healthcare professionals and become a barrier

to the implementation of these new care forms<sup>171</sup>. For COPD, ‘responsibility’ has often been linked to stigma and COPD being a self-inflicted disease, which has been found related to patients’ self-management behaviour<sup>172-175</sup>. Therefore, it might be particularly important in terms of COPD self-treatment to be aware that insensitive communication when giving self-treatment instructions can lead to misinterpretations, e.g. increasing feelings of self-blame and rejection<sup>176</sup>. Perhaps, adapting the educational part in self-treatment interventions according to these relational/interpersonal aspects may be one key to more successful self-treatment interventions.

### *Interprofessional relations and relations between care sectors*

According to the findings of the GP study, not only GPs and patients but also patients’ family members, other healthcare professionals and organizational/infrastructural factors are involved in shaping decisions (GP study<sup>121</sup>). The most important function of these other actors seemed to be the reduction of medical uncertainty and related concerns through sharing expertise and responsibility.

For instance, GPs emphasized the advantage of collaborating with hospital-based physicians/hospitals with access to more advanced diagnostic technologies. Comparably, Risør et al.’s study on both GPs’ and pulmonologists’ views suggests that collaboration can help reduce uncertainty around comorbidities<sup>98</sup>. The primary reason for referring a patient, however, may not be diagnostics but the GPs’ - perhaps the patients’ - evaluation that the illness is too severe to justify treatment at home. As seen in the GP study, whether or not a patient finally is admitted depends not only on the GPs’/ patients’ evaluation, but also on the admitting physicians’ agreement that hospital treatment is necessary (GP study<sup>121</sup>). It seemed as if the GPs have had experienced difficulties with justifying referrals that were not based on objective clinical criteria but a more holistic evaluation based on tacit/situational/contextual knowledge grounded in the patient-physician relationship (GP study<sup>121</sup>). Hence, there was not only ambiguity about what counted as legitimate reason for hospitalization, but also regarding boundaries of responsibility. The challenges experienced by GPs seem to be grounded in cultural differences of the professions that may be based on “educational experiences and the socialization process that occur during training of each health professional”<sup>177</sup>. In the GP study, we argued that due to not speaking “the same language”<sup>72</sup>, referral decisions based on a

holistic evaluation might not match with more biomedical oriented treatment criteria applied in specialist care. In this regard, the imbalance of expertise in COPD guideline development committees, i.e. underrepresentation of primary care expertise (Guideline study<sup>112</sup>), may contribute to reinforce tensions in inter-professional relations. It may indeed be the cultural habits, assumptions and experiences that fill the existing gap of scientific/biomedical knowledge during the development of recommendations<sup>178,179</sup>. More clinical evidence would probably help to close the gaps regarding medical scientific knowledge, but may only help to a certain extent to close the ‘cultural’ gaps between professions and care sectors. Therefore, involving the expertise of all stakeholders in developing care standards should also include awareness of different professional cultures to improve implementation of care standards<sup>180</sup> and interprofessional collaboration<sup>177</sup>.

Cultural barriers are only one of several structural and professional barriers to interprofessional collaboration<sup>181-183</sup>, and are not limited to cooperation between GPs and hospital-based physicians/pulmonologists. Discrepancies regarding the perspective on a condition’s severity, necessity for treatment and areas of responsibility can, for instance, also challenge collaboration between patients, informal caregivers and healthcare professionals<sup>184,185</sup>. This is, in my view, very relevant considering the findings from the GP study that emphasize the important role of informal caregivers and primary care services as ‘security network’ for GPs to managing ‘high’ risk COPD patients (GP study<sup>121</sup>). We argued in the GP study that more important than the type of service or the ‘title’ of actors, such as ‘nurse’ or ‘pulmonologist’, seems their function as ‘insurance’. Having this ‘insurance’ could attenuate consequences of wrong decisions through facilitating follow-up of patients in their homes and timely access to more advanced care if necessary (GP study<sup>121</sup>). Currently, intermediate care models, such as Hospital at Home, which provides “active treatment by healthcare professionals in the patient’s home for a condition that otherwise would require hospital care”<sup>186</sup>, seem to be a type of service that holds the ‘security network’/‘insurance’ function in today’s organization of COPD care. I would argue that the supportive and collaborative nature of a ‘security network’, i.e. to share expertise and responsibility among carers, could be a key component of such models. Also in terms of self-treatment, our findings have shown the importance of providing assistance and support, which is why I consider calls for a collaborative understanding of the self-treatment idea as reasonable<sup>187,188</sup>.



Considering that healthcare professionals can have concerns regarding patient safety when it comes to self-treatment<sup>71</sup>, understanding self-treatment as collaborative treatment may also have a positive effect on physicians' will to implement self-treatment.

## **5.2 Discussion of methods**

This part of the discussion can be regarded as an extension of the methods section that primarily addressed the 'procedural' aspect of the methods and how we used them. Here, I will discuss how the choice of methods and the way I applied them in the three studies have an impact on my results, and describe my strategies to ensure the credibility of my research. Moreover, I will address ethical considerations regarding the interview studies.

### **5.2.1 The Guideline study: A systematic review of COPD guidelines**

The purpose of the Guideline study was to get an overview over the recommendations for treating COPD patients with exacerbations with antibiotics and oral corticosteroids.

Moreover, by assessing aspects of guideline development, such as composition of guideline development committees, rigour of literature review and characteristics of the evidence underlying the recommendations, our aim was to evaluate the relevance of treatment criteria to a primary care setting. We conducted a rigorous and systematic search to get hold of COPD guidelines, but we might have missed guidelines published in other languages other than the ones included, and local guidelines used in different hospitals that may not be accessible through databases. If we, optimally, had included all existing COPD guidelines, we might have found slightly more diversity in treatment criteria, yet this we would have not altered the overall results. Assessing the quality of guideline development including the evidence underlying the recommendations was complicated by the different guidelines' compositions and ways to present the development process, recommendations and links to evidence.

Therefore, we might have got an impression of guideline development that is not similar to the probably very complex 'real' process of guideline development. That we did not use the AGREE II tool<sup>111</sup> to its full extent is, in our view, reasonable as our main interest was in the relevance of treatment criteria to a primary care setting, and not in the overall guideline quality. The assessment of the evidence may be biased in terms of selection, as we, due to the different ways of presenting recommendations and evidence in the guidelines, only included

trials that were directly linked to a recommendation. However, according to the AGREE II tool, an explicit link between recommendations and evidence is an important quality criterion<sup>111</sup>. In order to strengthen our findings concerning applicability of existing evidence to a primary care setting, we added trials included in the latest Cochrane reviews about treating COPD exacerbations with systemic corticosteroids<sup>23</sup> and antibiotics<sup>22</sup> into our assessment. Overall, we argue, that our review enabled us to get an overview over the criteria on which the assessment and treatment of COPD exacerbations should be based on in primary care from an 'EBM perspective', and was useful to highlight challenges that reside within an evidence-based approach to managing COPD exacerbations. It is, however, important to note that our review only gives an 'instant picture' of guidelines and recommendations. Therefore, the validity and relevance of our findings may decrease as the understanding of COPD exacerbations and development of diagnostic means progresses, and new guidelines/recommendations are being released.

### **5.2.2 Methodological rigour in qualitative research**

In quantitative research, credibility of results is often evaluated by a set of criteria, e.g. validity and reliability, that refer to whether a method can measure what is intended to be measured (validity), and whether the method can reproduce the results (reliability), respectively<sup>189</sup>. In the qualitative research tradition, which is typically grounded on different ontological and epistemological assumptions than quantitative research (see *Methodological considerations*), it may be problematic to apply exactly the same quality criteria. Consequently, different sets of evaluation criteria have been proposed for qualitative research. Lincoln and Guba, for instance, suggested credibility, transferability, dependability and confirmability<sup>190</sup>, and Malterud relevance, validity, transferability and reflexivity<sup>1,191</sup>. According to Malterud, relevance refers to the usefulness of scientific knowledge in terms of its originality, and can apply to research questions, results, or to terms, concepts and methods<sup>1</sup>. Validity and transferability refer to whether the methods used investigate what one wants to investigate and to the degree to which the produced knowledge applies to another context than the actual study setting, respectively<sup>1,108</sup>. Overall, however, I understand that the underlying concern regarding the quality of qualitative interview studies lies in the researcher's ability to make good choices and to conduct the research in a systematic way, based on reflection on the relation between him- or herself, reality, the methods and the

results. Reflexivity is also central to Stige et al.'s suggestion of an agenda to evaluate qualitative research<sup>116</sup>. They note that “the diversity of traditions that characterize research suggests that general checklists or shared criteria for evaluation are problematic”<sup>116</sup>, as “the practice of rule-based evaluation is only defensible when the study to be evaluated is based on a corresponding epistemological foundation”<sup>116</sup>. Reflexivity requires the researcher to critically question whether the steps undertaken are reasonable, defensible and supportive of what the researcher concludes<sup>108</sup>. Drawing on Stige et al.'s suggestion, I regard this discussion of methods as a “reflexive dialogue”<sup>116</sup> that addresses the “challenges of producing rich and substantive accounts” and the “challenge of dealing with preconditions and consequences of research”<sup>116</sup>.

### **5.2.3 The Patient study and the GP study: Interview studies**

In the method section, I have presented the interview forms (semi-structured in-depths interviews and FGDs) and analytic method (thematic analysis) that were used in the Patient study and the GP study, respectively, and described briefly how I designed the studies, gathered the data and conducted the analysis (see *Methods*). Here, I want to discuss my choices regarding the methods used and explain how I tried to ensure trustworthiness of my results.

The aim for this investigation (the qualitative part) was to explore the decision-making concerning management of COPD exacerbations from the perspective of those who make these decisions as part of their everyday life, in ‘real world’. Interviews are a good way to get insight into how people experience their “lifeworld”<sup>105</sup>, and as Kvale and Brinkmann describe it, “provide us with valid knowledge about our conversational reality”<sup>108</sup>. From this understanding, interview knowledge is produced rather than collected, and what we can learn from interview knowledge depends therefore on, among other things, the type of interview, the relation between the interviewer and interviewee, and the context in which the interview is conducted and analysed<sup>108</sup>. For the Patient study, the main interest was to explore COPD patients’ experiences and reasoning regarding a certain phenomenon, i.e. self-treatment. In order to get an ‘in-depths’ understanding of their reasoning, we chose individual semi-structured interviews. FGDs, which were used for the GP study, are more dynamic in nature, and are more adequate to use when the study aim is to get a rather broad understanding of a

phenomenon<sup>192</sup>. While individual interviews are a dialogue between the researcher and the participant that allows, among other things, inviting the participant to elaborate his personal stories more in detail, FGDs involve several individuals who engage in the discussion. FGDs are typically more steered by the participants themselves. The group interaction characteristic of this interview form can stimulate and unravel opinions, which are less accessible in individual interviews, and gives the participants the opportunity to define themselves what is relevant or important within the topic of interest<sup>192</sup>. Overall, it is important to remember that the knowledge produced in the Patient study and in the GP study, is based on the participants' narrations that reflect memories of past events. Therefore, the participants' stories did not reproduce events as such, but provided a perspective of how the participants explain these events within their "social and political worlds"<sup>193</sup>.

### **5.2.3.1 Patient study**

Before data collection, the researcher has to decide on which participants to include in the study. For the Patient study, we wanted to include patients from the 'real world', as my literature studies had uncovered that there is little knowledge about how self-treatment of COPD exacerbations is actually practiced by COPD patients that are not part of self-management programs (see *Literature review* and *Gaps of knowledge*). Moreover, we wanted to include patients with mostly mild to moderate COPD, as it is probably these patients who are taken care of in primary care. Initially, we included patients with and without self-treatment medications, which was due to an originally broader aim of the Patient study, i.e. focus on self-management of exacerbations in general and not only on self-treatment with antibiotics and/or oral corticosteroids. As described in the 'Method section', we decided to narrow down the aim of the study and only focus on COPD patients' experiences with self-treatment. Subsequently, we recruited four more COPD patients who had self-treatment medications on stand-by. Overall, our sample varied in terms of gender, age, working status, civil status, residence and severity of COPD (see Table 1). The heterogeneous sample and an inductive analytic strategy enabled us to get insight into a different self-treatment strategies and explanatory frameworks<sup>193</sup>. In terms of sampling, 'saturation' is another central feature regarding the credibility of qualitative research<sup>194</sup>. In the Patient study, this was an issue from the data collection phase to publishing, mostly due to the changes in the study aim and inclusion criteria. The reviewers, for instance, had problems to accept that 12 participants

were sufficient to obtain saturation. Morse notes that, in order to reach saturation, all aspects of the phenomenon must be explored both in broadness and depths, and that the data from different participants share essential characteristics<sup>194</sup>. Especially since I had interviewed 19 COPD patients in total, of which seven broadened my understanding of the phenomenon rather than simply replicating or adding up on the number of stories, I felt that my understanding of the phenomenon was comprehensive, and that the categories I developed were consistent. Even though I agree that it is debatable whether I should have included the seven interviews with COPD patients without self-treatment medications in the whole analytic process, I would argue that my dataset was both “adequate” (large enough for replication to occur and be noted) and “appropriate” (those interviewed were experts in the phenomenon of interest)<sup>194</sup>. Saturation, however, is not only depending on the number of interviews, or participants. Rather, the researcher needs to be skilled and prepared, for instance through theoretical awareness and knowledge about relevant literature, to ask the ‘right’ questions to the participants during the interview and to the data during the analytic process<sup>194</sup>.

In terms of interviewing, i.e. data collection, I interviewed most of the participants in their homes. This added a certain contextual understanding about how the participants lived. The two participants I interviewed at UiT The Arctic University of Norway felt indeed more ‘unknown’, or ‘anonymous’ to me. However, for qualitative interview studies, it is not only the physical context of the interview situation that influences knowledge production, but also the relational context, i.e. what is “happening between the researcher and the participant”<sup>108</sup>. The latter relates for instance to the questions the researcher asks, and how he or she asks them. According to Malterud, if we want to gain knowledge about something we did not know before, it is important to be not too steering in the interview situation, but let the participants’ version of the phenomenon of interest unfold on the participants’ premises<sup>1</sup>. I opened the interviews, after an introduction of myself, the study and the nature of a research interview, with an open question about what comes in the participant’s mind when thinking of the term ‘COPD exacerbation’, and what they associate with it. The purpose of this was to find a common ground with the participants in terms of what composes a ‘COPD exacerbation’, or using Malterud’s words, “to shift focus from the *voice of medicine* to the *voice of the lifeworld*”<sup>1,105</sup>. However, when reading the results, it should be kept in mind that the participants may in some cases not have talked about exacerbations in a medical sense, but

about illness episodes resulting in actions such as self-treatment or help seeking. Moreover, physicians might, for instance, be used to ‘clinical interviewing’, which differs from a research interview in terms of what type of knowledge the interviewer wants to obtain and for which purpose<sup>1</sup>. It was in some cases challenging to balance letting the participants tell their story and keeping track of my own agenda. Especially the participants who had not received self-treatment medications seemed often more concerned with other aspects of living with COPD than with how to deal with exacerbations. Yet, it was important to have an open mind to the participants’ own agenda<sup>1</sup>. For instance, in retrospect, I believe that the many stories that addressed health contacts and relationships to healthcare professionals (not only in terms of treatment of exacerbations) helped me to understand self-treatment as a relational, collaborative activity.

Writing down some reflective thoughts directly after the interviews and discussing ‘how it went’ with my supervisor helped me to establish a “metaposition”<sup>1</sup>, which I hope also improved my interview skills gradually during the data collection process. Moreover, during the data collection phase, I became already aware of certain topics that seemed overall relevant, and could start to develop a theoretical understanding about these topics through literature studies. The transcription of qualitative research interviews can also be regarded as part of the analytic process, as it serves the researcher to get an overview over the whole dataset and develop first thoughts about important topics. Due to time restrictions, I only transcribed one patient interview myself and hired an external person for the job. I obtained oral consent from my participants for that someone else could hear their stories (though anonymised), instructed him carefully, and had regular meetings with him to resolve any ambiguity regarding the meaning of phrases. Overall, I think that outsourcing the transcription did neither bring considerable disadvantages regarding the results of the study, nor any important ethical dilemmas.

We chose an inductive and semantic approach to analysis for both the Patient study and the GP study. A deductive and latent approach might have shed light on other aspects and challenges than those my ‘version’ highlights. Other researchers with other backgrounds but similar analytic strategy may also have chosen to highlight other aspects. The researcher’s background and theoretical stance influences which questions that researcher asks to the data, and what the researcher sees in the data. As the anthropologists Andersen and Risør stated,

interviewing people to find out what they do and why requires “reflexivity on social context, the nature of verbal statements and the situatedness of the interview encounter.”<sup>193</sup>. By trying to ask questions to the data that address preconditions for and consequences of the participants’ actions instead of only looking at the actions themselves, and by looking for actions/explanations that were unexpected, surprising or seemed contradictory, I tried to avoid simple, naïve explanations of causal relations. Another strategy to improve the analysis of qualitative data and validity of analytic constructs is to triangulate the analysis, e.g. to involve several researchers or peers in the interpretation of data<sup>195</sup>. I applied this strategy through discussion of my codes and ideas for themes with others, for instance my supervisors or peers. As also described in the Methods section, I tried to enhance my understanding of the data through regarding my thoughts in the light of existing theoretical concepts in a kind of ‘explorative manner’, i.e. trying to apply different concepts (such as Attachment Theory<sup>119</sup> and the Necessity-Concerns-Framework<sup>120</sup>) on my analytic categories to find controversies and inconsistencies in my constructs. Overall, through reflection, discussion and reading I developed an understanding that self-treatment of COPD patients is as much a question of the patient-physician relationship, trust and responsibility as it is of clinical signs, clear symptoms and medical knowledge. It might be particularly difficult for healthcare researchers from a medical tradition to not relating medical scientific knowledge to rational behaviour, and other types of knowledge to irrational and erroneous beliefs and behaviours. It was therefore, I would say, particularly helpful to work closely together with a medical anthropologist (Mette Bech Risør) who challenged my own interpretations through discussions and suggestions of relevant theoretical concepts.

### **5.2.3.2 GP study**

For the GP study, the interviews were already conducted when I engaged in the research project. As for the Patient study, it is important to note that through interviewing people about what they did in the past, and why, we can only know something about what people think they do, and not what they are actually doing. In order to gain knowledge about what GPs ‘really’ do in clinical problem-solving situations, and to get insight into the cognitive processes during the decision-making, other data collection methods, such as the Think aloud Method that produces data on what comes to the participants’ mind during a problem solving task<sup>196</sup>, may have been more appropriate. Sampling was done purposefully in all participating

countries, yet through different ‘logistics’ in the sampling/recruitment (see Table 3). The GPs in our sample had different backgrounds in terms of clinical experience, gender and workplace, healthcare system, local organization of healthcare system and sociocultural background. The heterogeneity in the sample enabled us to identify essential features, common themes and concerns across the individual cases<sup>103</sup>. Yet, we acknowledged that this focus on common views produced in a focus group setting limits the direct applicability of our findings to a specific setting.

In terms of the sampling strategy through personal contacts and networks, many participants of one group knew each other. This might have created a safe setting for the discussion, but could also have been a barrier to critical and open-minded comments. Regarding the moderation, one should remember that even though the moderators in the respective countries were trained beforehand in the FGD method, most were novices of the method and their individual moderation style has probably influenced the interview course.

For the GP study, as I did neither conduct nor transcribe the FGDs, these early analytic phases were not, or less, relevant as in the Patient study. Therefore, my analysis started with thorough repeated reading of the transcripts and eventually writing memos about initial thoughts. During the first coding, I tried to code, among other things, clinical signs and examinations that the GPs use for hospitalization and treatment with antibiotics and oral corticosteroids, but realized soon that this was not ‘working’. In retrospect, I would say, this was because I tried to code the data with a medical/clinical view. It took many discussions, memo writing, re-thinking many of my initial codes and engaging with more sociologically grounded concepts on medical practice (such as Donald Schön’s “The Reflective Practitioner”<sup>197</sup>), to change my ‘analytic view’. My analysis of the data challenged also another pre-assumption I obviously had, i.e. that GPs always act as ‘perfect agent’ for the patient. Leaving this view behind opened up for further development of the analytic categories that encompassed not to solve the problem (decision-making), but also to define the problem, the “problem-setting”<sup>197</sup>.

As Andersen and Risør emphasized, social responses, as for instance a management decision of a GP, may often be implicit, taken for granted, and may therefore be difficult for people to verbalize<sup>193</sup>. Beckstead et al. reported that physician have rather modest insight into their decision-making, i.e. that their tacit policies (what they do) differ from their stated



policies (what they think they do)<sup>198</sup>. For the participants in the GP study, I could sometimes ‘sense’ this difficulty for the GPs to express the logic behind their actions - their professional routine - in the data. Moreover, I experienced the interpretation of the GPs accounts within their sociocultural background challenging, as my contextual understanding was, at least for most of the countries, limited to the organization of healthcare systems and did not encompass cultural variations regarding, for instance, patient-involvement, and relationships to political institutions (even though these variations were apparent in the data). There could have been ‘hidden’ meanings in the GPs’ accounts that were not made explicit during the discussion as all the participants including moderator were from the same sociocultural context and may have understood them without further explanation. Also, working with translated transcripts carried the risk that phrases/ideas did not reflect their actual meaning. We tried to resolve these issues by keeping up communication between the researchers in the participating countries.

Being critical to how to express, and conceptualize the participants’ accounts is also important when it comes to reporting findings. In this regard, I want to comment on terms that I used to describe the ‘easiness’ of a treatment decision in both the Patient study and the GP study. Patients and GPs could perceive decisions as straightforward or as difficult, but one should be cautious to assume that easy decisions are appropriate decisions. For instance, it might be easy to always prescribe/take oral corticosteroids when experiencing worsening dyspnoea, yet as we have argued previously, relying on such general criteria may lead to overtreatment (Guideline study<sup>112</sup>)/uncritical use of the medications (GP study<sup>121</sup>/Patient study<sup>113</sup>). Moreover, from decision-making theory, we know that decisions which are perceived more difficult are eventually more deliberated and thought through<sup>76</sup>. Decisions may be perceived as ‘easy’ if made via mental short cuts, e.g. heuristics or pattern-recognition<sup>199,200</sup>, and these rather subconscious decision-making processes are related to a number of biases and may result in irrational decisions<sup>201</sup>.

Finally, some reflections about transferability or to which degree my findings are generalizable to other contexts than the actual study setting. Generalizability of qualitative research may be more controversial than in a quantitative research tradition. On the one hand, one could say that qualitative research aims to add an understanding of human experience through studying particular cases. Such cases are always contextually embedded and may therefore be difficult to generalize. On the other hand, qualitative research that

succeeds with revealing an understanding of a phenomenon on a higher abstraction level, or a more theoretical understanding of a phenomenon, may indeed be suitable for extrapolation<sup>202</sup>. Overall, the aim of research, regardless of methodology, must be to produce knowledge that is useful beyond the study setting, yet without claiming universal generalizability<sup>191</sup>. Sampling, sampling strategies and the participant characteristics are considerably influencing what the researcher can conclude with, and to which settings the findings are relevant<sup>191</sup>. We applied similar sampling strategies in the Patient study and the GP study in terms of aiming for varied samples regarding participant demographics (see Tables 1 and 3) within a group of persons that can be regarded as experts in the phenomenon of interest. Our samples in both interview studies included social actors from ‘real world’ clinical practice as opposed to actors that belonged to an ‘artificial’ reconstruction of the ‘real world’ as found in scientific experiments or randomized trials. For both the Patient study and the GP study, I would argue, our findings therefore add a new and valid dimension to the phenomenon of self-treatment of COPD exacerbations, and management of COPD exacerbations, respectively, grounded on ‘real world’ experiences. The aim of both studies was to describe and conceptualize a phenomenon using an inductive and semantic approach to data analysis (see *Methods*). Through abstraction and conceptualization of the data, which included to describe and enrich analytic themes with existing theoretical terms and within existing theoretical concepts, I believe that we were able to broaden the relevance and transferability of our findings to overall phenomena/concepts. For the Patient study, these concepts related mainly to patients’ health and illness behaviour and help seeking behaviour, and for the GP study to concepts such as medical uncertainty, medical decision-making and care concepts (GP study<sup>121</sup>). Moreover, I would argue that our findings are relevant to different settings. They can inform both clinical practice in routine care (for both patients and healthcare professionals) and future research (research concepts, research problems and study designs). I consider our findings also relevant to health policies/political decision-makers in a reciprocal way, as they provide empirical knowledge from - and about - those social actors that healthcare policies aim to influence, and about how these social actors may actually be influenced by healthcare policies.

### **5.3 The ethics of interview studies**

Consequences and potential harm for the participants, including voluntary participation, always have to be considered in scientific inquiry. In interview studies, such harms may occur

during the very interview situation, particularly when topics are highly sensitive<sup>108</sup>. The topics for the Patient study might not appear highly sensitive from an objective point of view, yet could be for the participants. I experienced once that a participant did not want to talk about a certain topic, which I of course respected. I have great respect for their openness and will to share intimate details of their lives and appreciated their engagement during the interviews. All but two participants invited me to their homes. I did not feel that their motivation to participate derived from the gift coupon they received as compensations to their time and effort. Rather, it seemed as if they were motivated by being helpful and by contributing with their knowledge, and most of them seemed to enjoy that someone was interested in hearing their story.

The interviewer, who is the “main instrument to obtain knowledge”<sup>108</sup>, has a crucial role in a qualitative inquiry, both to ensure quality of the scientific knowledge and in terms of showing morally responsible research behaviour<sup>108</sup>. Much of the researcher’s interviewing skills have to be acquired through experience<sup>108</sup>. Even though I had read about and theoretically thought-out interviewing, I surely lacked experience as a novice researcher. For instance, I experienced it sometimes difficult to balance stopping a participant when drifting too far off the interview’s topic without a feeling of insulting him or her. Moreover, even though my professional background as medical doctor and general practitioner trainee was helpful in the sense that I knew the diseases, treatments and pathways through the healthcare systems many participants were talking about, it could be difficult to not let my relation to the participant become a “pseudo-therapeutic”<sup>108</sup> doctor-patient relationship. For instance, it was challenging to know how far I should go in terms of answering the participants’ questions about their health problems or explaining medical issues they had obviously misunderstood (for instance regarding usefulness of antibiotics or side effects of oral corticosteroids). Moreover, I had to remind myself several times to keep neutrality when participants talked about negative experiences with the healthcare system and particular doctors I was in two occasions able to recognize just from the participants’ stories. I tried to resolve these challenges through openness and explanation about the nature of a research interview, and hope that I could keep the balance between professional distance and personal closeness/friendship<sup>108</sup>.

For the GP study, the fact that some participants knew each other might have created a safe setting for in-depth discussions. However, to reflect on one's own decision-making, or to disclose insecurity regarding own practice may have caused discomfort. Hopefully, the moderators were able to dissolve such potential discomfort and provided the opportunity for de-briefing subsequent to the discussions.

Research should be relevant to science and society, which I think the study aims fulfil given the great burden of COPD and knowledge gaps regarding management of the illness in primary care. Through publishing my findings in open access journals, presentation at a congress and an article a medical 'newspaper'<sup>203</sup>, I was able to give something back to the scientific and medical community. COPD patients and GPs might benefit indirectly through improvements in patient care, or through more awareness and improvement of their working conditions, respectively.

The participants of both studies received a small remuneration, which should show our thankfulness for them giving us their time and contribution to our research. This may have contributed to a certain 'willingness' to take part in the study. However, we did not consider such a small amount to have contributed to a selection bias, or an ethical issue, e.g. that those who were in need of money were particularly eager to participate, or did only participate because of the remuneration.

## **6 Conclusion and future perspectives**

### **Conclusion**

This thesis aimed to explore decision-making concerning COPD exacerbations in primary care, focusing on treatment with antibiotics and/or oral corticosteroids, help seeking and hospitalization. The investigation started with a systematic review of current COPD guidelines and underlying evidence to assess how COPD exacerbations should be treated in primary care according to the best available evidence. Furthermore, we explored decision-making of patients and GPs, focusing on self-treatment with antibiotics and/or oral corticosteroids and on GPs' decisions on treatment and hospitalization.

The findings of the three papers lead to the conclusion that it is difficult to make treatment decisions based on a purely medical interpretation of symptoms, signs and diagnostic tests. Medical uncertainty plays a major role in the management of COPD exacerbations, and worries about the consequences of ‘wrong’ decisions emerged as a strong driver of decision-making. Patients’ and GPs’ perceptions of ‘risk’ may affect treatment and hospitalization in ways that are conflicting with overall care goals, e.g. low hospitalization rates, rational use of antibiotics/oral corticosteroids and early self-treatment of exacerbations. Clinical and personal knowledge about patients, and patients’ own experiential knowledge from having lived with COPD and from previous exacerbations can be a valuable resource for interpreting the clinical picture. Experiential knowledge seems also important for patients to feel confident in self-treatment, which is why patients with recurrent exacerbations and clear symptom patterns seem most suitable for this care form. Self-treatment can play an important role for some patients. Yet it should be regarded as supplement to regular care to ensure timely help by a GP or other healthcare professional when needed. Instructing patients in self-treatment should encompass potential medication-related concerns, and making a self-treatment plan should include a ‘plan’ for help seeking. A well-functioning primary care infrastructure seems important, as it could provide assistance for patients in their homes and provide a sense of security among GPs, eventually reducing precautionary decisions while ensuring patient safety. Access to more advanced diagnostic technology and to specialist expertise seems also important to reduce GPs’ uncertainty related worries. However, different rationalities on risk and on what counts as ‘appropriate’ decision, as well as unclear areas of responsibility, can be barriers to successful collaboration between different healthcare professionals, as well as between healthcare professionals and patients.

Overall, the findings of this thesis support an integrative and collaborative approach to management of COPD exacerbations. The heterogeneous, versatile and often individualized nature of COPD exacerbations requires a flexible framework to decision-making that integrates both medical knowledge and other types of knowledge that are grounded in human experience and relationships. Such an integrative understanding of knowledge may guide future clinical research and guideline development in considering primary care evidence and expertise from primary care stakeholders and patients to a larger extent. It may also facilitate

collaborative management of COPD exacerbations that allows for sharing expertise and responsibility between patients and the involved carers.

### **Future perspectives**

The findings of the Guideline study uncovers a need for more research in the primary care setting that includes patients with milder illness and comorbidities. In the future, when the biomedical understanding of COPD and its exacerbations will improve, it might be possible to identify reliable biomarkers or other clinical indicators to better target treatment with antibiotics and oral corticosteroids. It would be interesting to gain a better understanding of how patients' symptom experience is related to pathophysiological processes, to results of clinical examination, point of care testing, as well as to the effect of antibiotics and oral corticosteroids. Such knowledge could strengthen primary care of COPD patients with exacerbations, and could also inform future COPD guidelines, including recommendations for choosing patients for self-treatment. Overall, it should be remembered that COPD exacerbations can indeed be severe, and that relocating care responsibility towards primary care, and also towards the patients themselves, may entail a larger number of patients with more severe illness in primary care. This might require an adaption of organization and competence in primary care that can ensure monitoring of patients in their homes, and, for self-treatment, to provide enough resources to develop and implement patient education. It will be important to clarify the role of different types of healthcare facilities/professionals, such as primary care teams, and of informal carers, in self-treatment, help seeking and treatment support in homes, both in an overall context but also in local healthcare contexts. In the future, telehealth solutions will certainly play a more important role for both self-treatment and regular care, particularly for patients who find it difficult to reach the GPs' office due to living in rural areas or because of physical disabilities.

However, such innovative care strategies should not replace but rather supplement regular care, which, after all, rests on the relationship between the involved persons. In this regard, it seems useful to organize primary healthcare in a way that enables the development of long-term relationships between patients and healthcare professionals. Moreover, interprofessionalism and communication skills will be similarly important as biomedical understanding of illness in the education of future healthcare professionals.

## ***Closing remark***

*This investigation is set in a part of the world where COPD patients have usually access to advanced medical technology and medicines. In other parts of the world, the developing world for instance, COPD may be equally prevalent, yet the preconditions to providing care may be less favourable. Moreover, in this part of the world, there may exist a considerable gap of knowledge about how to best possibly prevent and treat COPD. We are talking about the global burden of COPD, but our efforts to improve care for these patients seem to me often rather local than global. Some years ago, for instance, I was attending a conference on respiratory diseases, and it was striking to see the different premises on how COPD care is based in a global context. That is, while researchers in one parallel session were concerned with improving health outcomes with new medicines, those in another parallel session discussed how to provide electricity to people in Sub-Saharan Africa in order to prevent respiratory illness from biomass fuelling. I am not saying that one discussion was better or more important than the other was, and both are probably relevant in their respective contexts. However, in my mind, these two parallel sessions reflected a health inequity that is still reality and probably tragic for many COPD patients and other people. Inequities in health are, however, not only a concern in the developing world; they might only be more severe and therefore more 'visible' than health inequities in the Western societies. With this closing remark, I want to remind the research community of its power and, in my mind, obligation, to shed light on and work towards an eradication of health inequity in both a global and local context.*

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# Appendix



## Intervjuguide pasientstudie

- Kan du fortelle **om deg selv**, hva du fyller dagene dine med og hvordan du bor, hva du jobber med?.
- Når ble **KOLSen** oppdaget? Hvilken behandling for du? Har du noen **andre sykdommer** du må ta medisiner for?

### Pasientens forståelse av, reaksjoner (emosjonelt, kognitiv) på og atferd ved en forverring?

- Hva **betyr «KOLS forverring»** for deg? Hvordan **kaller** du det?
- **Hvordan vet du** at det er KOLSen og ikke noe annet?
- Hva får det deg til å **tenke/føle??**
- Hva får de **tankene/følelser deg** til å **gjøre?**
- Hva synes du er **det verste** med en forverring?
- Hvordan går det med **jobb/sosialt liv/samliv/humør** når du har en forverring?
- Hva gjør du for å **takle du** utfordringene?
- **Hva eller hvem hjelper deg** mest når du har en forverring?
- Hvem **søker du råd** hos?
- Hva tror du kunne **hjelpe deg enda mer?**

### Pasientens holdninger til og erfaringer med egenbehandling og beredskapsmedisiner?

- **Hvem ga** deg medisinerne?
- **Hvorfor** har du fått medisinerne?

- Kan du **fortelle om veiledning** du har fått i hvordan du skal tolke symptomer og bruke medisiner?
- Var det **noe spesielt du tenkte**?
- Hvordan **føltes** det å få medisinene?
- Hva **sa legen skal du gjøre** når du får en forverring?
- **Når** skal du bruke antibiotika/prednisolon?
- Har du fått noe **skriftlig** også? Kan jeg få **se** det?
- Synes du det **er lett å forstå**?
- Kan du fortelle om **en situasjon** hvor du har brukt antibiotika/steroider?
- Var det **vanskelig å vite** om du skulle ta medisinene?
- Hvis aldri brukt: har du noen gang **vurdert å bruke** de?
- Hva **gjorde at du bestemte deg** for å bruke de/ikke bruke ? Hva gjorde **du i stedet**?
- Ville du **anbefale til en venn** eller mann/kone å ha beredskapsmedisiner?
- **Hjalp** medisinene deg?
- Hva ville du **gjøre hvis du ikke blir bedre** av å ta medisinene?

#### Howdan påvirkes **opplevelse av behandling i helsevesenet**?

- Kan du fortelle om en **situasjon hvor du kontaktet legen** da KOLSen ble verre?
- Hva spesielt gjorde at du **tok kontakt**?
- Hva **gjør legen** når du kommer pga KOLS?
- Synes du han/hun gjør en **god jobb**?
- **Stoler** du på legen din?
- Hva er **annerledes på sykehuset**?

- Hvem **liker du best å kontakte** når du trenger hjelp med KOLS?
- Hva kan fastlege/lege på sykehuset **hjelpe deg med**?
- Har du **mindre behov** for å ta kontakt med lege nå?
- Synes du det er **vanskeligere å kontakte** legen nå?
- Hvor **viktig er legen** for deg når det gjelder behandlingen KOLS (forverring)?
- Har behandlingen du får **forandret seg** etter at du fikk medisinene?
- Hvis du kunne **ønske deg noe fastlegen gjør annerledes**, hva ville det være?

Hvordan påvirkes opplevelse av **mestring, ansvar, autonomi, trygghet**?

- Hva er **fordeler og ulemper** med å behandle seg selv?
- Blir det **lettere for deg å leve** med KOLS?
- Har du mer **kontroll** på KOLS nå?
- Føler du at du har **mer ansvar** for din helse?
- Var det noen gang **ubehagelig eller utrygg** å måtte bestemme selv?
- Er det noen personer eller et eller annet som **støtter** deg?

Er det **noe annet** du har lyst å fortelle og som vi ikke har snakket om enda?