Improving pharmaceutical care for patients with Chronic Obstructive Pulmonary Disease

A survey on patient experiences and preferences concerning disease management interventions

Master thesis in Pharmacy

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Preface

This Master`s thesis was executed at the Centre for Pharmacy, Department of Clinical Science from august 2021 to November 2022, in collaboration with Respiratory ward 1 (*Lungeavdelinga post 1*) and Respiratory ward 3 (*Lungeavdelinga post 3*) at Haukeland University Hospital, Bergen. The work has been challenging and instructive, and eye-opening in terms of the patient group and their struggles. Conversations with the patients, impressions from the Pulmonary department and the knowledge acquired through the work with this project will surely be of further use when working as a pharmacist.

I would like to thank my supervisors, Svein Haavik and David Wright, for constructive, motivating, and inspirational feedback throughout the work, and facilitation of the project when challenges were met along the way.

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Bergen, November 20, 2022.   *Helen Eldholm*

Abstract

Purpose: This study aimed to investigate COPD service elements received by patients at discharge or post-discharge, and to investigate patient interest in future services, based on interventions that has been reported to indicate positive outcomes on readmission rates. Frequent readmission rates and the resulting economic burden for our health care system are important problems for both patients and the society.

Method: A literature review was undertaken to inform questionnaire content. Nine main topics was extracted from interventions provided and reports of clinical outcomes on admission rates. Services with the potential to benefit the patients were identified and evaluative questions concerning previous experiences and preferences were formulated targeting the objectives. The questionnaire was presented to voluntary participants at the Pulmonary department in Haukeland University Hospital, in collaboration with Respiratory ward 1 (*Lungeavdelinga post 1*) and Respiratory ward 3 (*Lungeavdelinga post 3*).

Results: 20 informants matching the inclusion criteria was requited over a 3-month period. Results showed that many of the intervention services, identified in literature to reduce readmission rates for COPD patients, were not previously experienced by informants in the study group. Discussions about medicines, what to do if symptoms exacerbate or support on smoking cessation were frequently not provided. The survey indicated a high level of interest in receiving the services investigated, especially medication optimization, check-up on COPD status post-discharge and medication use, and discussions on how to recognize symptoms of exacerbations and on how medicines contribute to symptom relief.

Conclusion: Patient experiences may indicate that service provision for COPD patients could be improved and potentially realize significant patient benefit. As demonstrated by the National Health Service (NHS) in England, enhanced service provision may be offered through collaboration between community pharmacists, municipal pharmacists, and general practitioners. Further research to confirm validity of the findings, identification of functional service elements and location for new services is needed.

Keywords: Community pharmacy, community pharmacist, COPD, COPD-management, post-discharge services, primary care

Contents

1 Introduction

In 2022, chronic obstructive pulmonary disease (COPD) is the third-leading cause of death worldwide and represent an important public health challenge (1, p. 1, 2). The burden of COPD to the patients and our health care systems is substantial, as many COPD patients suffers from frequent exacerbations that often result in hospital admissions or emergency department visits.

The Norwegian Directorate of Health is currently working on improvement of the strategy for prevention, diagnosis, treatment, and rehabilitation of chronic diseases where the overall goal is a reduction of 25% in premature deaths caused by chronic diseases from year 2010 to 2025. In 2012, a guideline for diagnosis and follow-up of procedures for patients with COPD were outlined as part of this strategy. The new 2022 update is a revised edition of the 2012 guideline and includes considerable professional changes concerning diagnosis and pharmacological treatment of COPD, as effects on reduction in the proportion of premature deaths caused by chronic respiratory diseases has not been acceptable. The update highlights that pulmonary rehabilitation is considered the most important service for disease management, but that rehabilitation service provision varies considerably in different primary care settings. The guideline specifically addresses recommendations to medical practitioners in primary care (i.e., practitioners offering municipal health care services) and other health care professionals offering rehabilitation services and is part of the work dedicated to reducing premature deaths caused by respiratory diseases, such as COPD (3).

The GOLD initiative (Global initiative for chronic obstructive lung disease) is an international panel of medical COPD experts working together to raise awareness of and improve prevention and treatment of COPD. The annual GOLD reports are evidence-based and provides international strategies for prevention, diagnosis, and management of COPD, and are used to drive national agendas on COPD management (1). The national guideline provided from the Norwegian Directorate of Health are partly based on recommendations from the GOLD initiative (3).

1.1 Chronic Obstructive Pulmonary Disease (COPD)

Chronic obstructive pulmonary disease (COPD) is a chronic disease of the lower respiratory tract. It is associated with airflow limitation and destruction of the lung tissue, usually as a result of long-term exposure to tobacco smoke or other harmful particles or gases (4, p. 1079). A core feature is that symptoms change due to exacerbations and progression of the disease. Exacerbations (i.e., episodes with increased respiratory inflammation) can be triggered by respiratory infections, airborne pollutants or, in many cases, factors that are unknown for the patient and therefore difficult to circumvent (1, p. 4). Self-management of the disease is important as patients experience substantial worsening in their physical health, but deterioration caused by COPD progression can be delayed by quality self-management interventions (2).

1.1.1 Pathophysiology

COPD is often used as a collective term for chronic obstructive bronchitis and emphysema (i.e., infection in the bronchi and damage of the tiny air sacks in the lungs, respectively). The two conditions often occur simultaneously when cigarette smoking is the cause of the disease (5, 6). In the 2022 GOLD report it is emphasized that emphysema describes only one of several structural abnormalities present in the lungs of patients with COPD (1, p. 4).

The chronic airflow limitation seen for COPD patients is usually progressive and appears to be associated with a modified inflammatory response to chronic irritants in the lungs (1, p. 13). Increased number of mucus-secreting goblet cells in the bronchial mucosa is seen in the microscope (4, p. 1079). The characteristic chronic productive cough experienced by many patients is related to the increased number of these goblet cells and mucus hypersecretion (1, p. 15). In COPD, the walls of the bronchi and bronchioles are infiltrated with specific inflammatory cell types (1, p. 13). Inflammation makes the epithelial layer ulcerated, and over time columnar cells are replaced with squamous epithelium cells. Then follows scarring and thickening of the bronchial walls, as normal repair and defense mechanisms has been disrupted by the chronic inflammatory response. Thickening of the bronchial walls narrows the small airways (4, p. 1079). Further development of COPD leads to progressive squamous cell metaplasia (i.e., the replacing of the specialized columnar cells in the lung with squamous epithelium) and fibrosis of the bronchial walls, which changes the nature of the lung tissue. In chronic inflammations, fibrosis is the replacement of damaged tissue with connective tissue.

Fibrosis in the lung results in reduced elasticity and loss of function in the affected areas (7). The physiological consequence is development of airflow limitation (4, p. 1080).

Emphysema is an abnormal, permanent enlargement of the terminal air sacs (*alveoli*), accompanied by destruction of their cell walls. The alveoli at the end of the bronchioles are where gas exchange takes place and oxygen diffuses from the lungs and enters the bloodstream. Enlargement of the alveoli is thought to be a secondary result of small airway inflammation and destruction, causing loss of elastic properties and collapse of the small airways during expiration. Hence, if airway narrowing is combined with emphysema, the resulting airflow limitation is even more severe (4, p. 1080).

The small airways are particularly affected in the early stages of COPD. The initial inflammation is reversible and improvement in airway function can be achieved if smoking cessation (or removal of other triggering factors) takes place at the early stages. In the later stages of COPD, the inflammation continues, even if smoking cessation is achieved (4, p. 1080).

1.1.2 Etiology

Smoking of tobacco products accounts for most cases of COPD in developed countries. However, less than 50% of heavy smokers develop COPD during their life (1, p. 8). Hereditary factors (e.g., genetic variations or abnormalities) and abnormal lung development are risk factors that make some individuals predisposed to development of COPD. This might explain why both active and passive exposure should be considered significant risk factors, and why the risk factors are many and diverse. Indoor pollution other than tobacco smoke (e.g., from burning of biomass fuels), outdoor air pollution, childhood respiratory infections, low socioeconomic status, occupational conditions (e.g., exposure to dusts, chemical agents or fumes), increasing age and female gender are all conditions that may have etiological significance for developing COPD (1, p. 13, 5). Nevertheless, development of COPD is proportional to the number of cigarettes smoked per day, and smoking cessation is considered one of the most important interventions for the patients (4, p. 1079).

1.2 GOLD classification system and progression of COPD

The diagnosis of COPD is based on the presence of clinical symptoms (e.g., dyspnea, chronic cough or sputum production) and airflow limitation measured by spirometry (1, p. 22). The GOLD classification system is used for assessing the severity of COPD. It divides patients into one of four GOLD stages based on the level of airflow limitation (1, p. 29). It was assumed that most patients would experience a progression in the disease where the severity of COPD correlated with the degree of airflow limitation. Today the classification is an important part of COPD assessment, as much more is known about general characteristics of patients at the different GOLD stages. By evaluating airflow limitation together with its impact on health status and risk of exacerbations by using standardized questionnaires (e.g., COPD Assessment TEST), the results are combined and exploited in the attempt to offer the patient optimized and personalized therapy (1, p. 32).

Airflow limitation is measured by spirometry after administration of a short-acting bronchodilator by inhalation. The criterion for airflow limitation is a fixed ratio of FEV_1/FVC < 0.70. In this ratio, FVC (*forced vital capacity*) is the volume of air forcibly exhaled from the point of maximal inspiration. FEV_1 (*forced expiratory volume in one second*) refers to the volume of air exhaled during the first second of the same exhalation (1, p. 26).

The extent of inflammation, fibrosis and fluids leaking from the blood vessels due to the inflammation correlates with the reduction in FEV_1 and FEV_1/FVC ratio (1, p. 14).

The GOLD classification categorizes COPD as either mild, moderate, severe, or very severe. Progression of COPD is measured as the annual reduction in FEV_1 and varies considerably from patient to patient. FEV_1 can also be used to monitor response to therapy and to predict mortality (8, p. 476). Table 1.1 presents the different GOLD stages and cut points used to classify airflow limitation in the diagnosis of COPD.

Table 1.1 *Classification of airflow limitation severity in COPD based on post-bronchodilator FEV_1 after spirometry. Additional symptomatic assessment is required to determine health status impairment* (1, p. 29).

In patients with FEV_1/FVC < 0.70:		
GOLD 1	Mild	$FEV_1 \geq 80\%$ predicted
GOLD 2	Moderate	$50\% \leq FEV_1 < 80\%$ predicted
GOLD 3	Severe	$30\% \leq FEV_1 < 50\%$ predicted
GOLD 4	Very severe	$FEV_1 < 30\%$ predicted

Abbreviations: *FEV_1: forced expiratory volume in one second; FVC: forced vital capacity*

1.3 COPD exacerbation and health care resource utilization

Exacerbations of COPD are one of the most frequent reasons for hospital admissions. Such adverse events represents a significant economic burden concerning our health care resources (1, p. 7). The 2022 GOLD report states that in the EU, the total cost of respiratory disease is estimated to be about 6% of the total annual healthcare budget, COPD accounting for 56% (or 38.6 billion Euros) of this cost (1, p. 7). There are studies indicating that hospital admissions and related readmissions may be prevented by implementing relatively simple interventions. For example, structured education programs enhancing self-management of the disease has been indicated as highly cost-effective in comparison with usual care (9-11). For patients who suffer from frequent hospital admissions and readmissions, these interventions also have the potential to improve the perceived health-related quality of life (1, p. 43).

1.4 Norwegian national guidelines for treatment of COPD

The overall goals of COPD treatment are relief of symptoms and prevention of exacerbations or other complications, as the disease is uncurable when first manifested in the lungs (8, p. 477). The professional guideline for treatment of COPD is a norming product published by the Norwegian Directorate of Health to promote quality and equality of opportunity in health care practices. The guideline presents recommendations concerning medical assessments and interventions for patients at different stages of the disease (3). The guideline are based on recommendations from the Global Initiative (GOLD, 2021), the National Institute for Health and Care Excellence (NICE, 2018) and the Swedish guidelines for treatment of COPD (Socialstyrelsen, 2020) (3). Concerning pharmacological treatment, medicines prescribed to patients with COPD should aim to reduce the symptoms, increase functional level, and reduce frequency of exacerbations for the individual patients. The overall goal is to increase the experienced quality of life for the patient when the COPD is in a stable phase (3).

1.4.1 Stable COPD

In the Norwegian guideline, COPD is categorized as stable if a patient with chronic symptoms of the disease have not experienced any sign of exacerbation over the last four weeks (3). Medicines should be prescribed as a supplement to other non-pharmacological interventions, i.e., smoking cessation, physical exercise, prophylactic prevention of respiratory infections, and vaccination against influenza virus and pneumococcus bacteria.

Patients without daily symptoms of COPD should be prescribed a short-acting beta-2-agonist (SABA) or a short-acting muscarinic antagonist (SAMA) to use as needed within the recommended daily dose-range for bronchodilation (3).

Patients that experience daily symptoms and/or exacerbations defined as two or more moderate exacerbations, or one or more hospital admissions per year can be prescribed a long-acting muscarinic antagonist (LAMA) or a long-acting beta-2-agonist (LABA). If the effect is still insufficient, combination treatment with LAMA/LABA can be prescribed. Steroids for inhalation can be added to the medication regime if the patient still experience severe airway obstruction or moderate exacerbations (with or without hospital admissions). Prophylactic treatment with antibiotics or xanthines (theophylline) is not recommended for patients with COPD in the Norwegian guideline. If the patient is also diagnosed with asthma, inhalation steroids should be prescribed to treat the related symptoms (3).

1.4.2 COPD exacerbations

Rapid initiation of treatment is important to prevent that COPD exacerbations develop into more severe conditions for the patient. The treatment can be carried out by the patient if adequate coaching for specific situations and a written action plan has been provided by trained health care professionals. Exacerbations are also treated at medical practices, at the emergency ward or in hospital, depending on the onset and severity of the exacerbation (3). If the exacerbation is mild (but beyond the usual daily symptoms), increased use of bronchodilators (preferably aerosols combined with an inhalation chamber), or treatment with peroral corticosteroids or peroral antibiotics may be sufficient actions. In these cases, a self-treatment plan should be available, and the patient should also have received adequate training by health care professionals regarding how to use the plan (3). In particular, the patient must learn how to recognize any alarm symptoms and when to contact other health care services and understand when and how to use the prescribed medicines. The plan should also include specific techniques for breathing, relaxation, and rest. In the case of self-treatment at home, medicines need to be prescribed in advance and be available for the patient (3). If the patient is experiencing a more significant increase in symptoms of COPD, treatment with corticosteroids or antibiotics can be initiated after medical consultation at the GP or emergency room (ER). SABA (or SAMA) may be given from an inhalation chamber every five minutes until the symptoms ease. GP or staff at the ER will also consider severity of the exacerbation and evaluate need for hospital admission (3).

1.5   Pharmacological treatment of COPD

For short-term management of exacerbations as well as long-term relief of symptoms, three main groups of medicines are used in the pharmacological treatment of COPD. These are the beta-2-agonists, the anticholinergics, and the steroids. Local treatment by inhalation therapy is the preferred route of administration (3).

1.5.1   Beta-2-agonists

Beta-2-agonists are medicines that binds to and stimulates beta-2-adrenoceptors. The bronchial smooth muscle is relaxed by activation of these receptors. They are called bronchodilators because the symptomatic effect is dilatation, or widening, of the airways. Milder symptoms is treated with short-acting beta agonists (SABA), while moderate and severe COPD are treated with long-acting beta-2-agonists (LABA) (4, p. 1082).

1.5.2   Anticholinergics

Bronchodilation can also be achieved with anticholinergic agents. Muscarinic antagonists bind to muscarinic receptors (a type of cholinergic receptors) and inhibits bronchoconstriction induced by the nervous system. Like the beta-2-agonists, the agents are categorized as short-acting muscarinic antagonists (SAMA) and long-acting muscarinic antagonists (LAMA). They give prolonged and greater bronchodilatation compared to the beta-2-agonists (4, p. 1083).

1.5.3   Steroid treatment

Inhaled corticosteroids (ICS) are listed as the fourth step of pharmacological treatment in the Norwegian guideline (3). Initiation of ICS treatment should be considered if symptom relief achieved by combination therapy with LAMA/LABA is inadequate. Medical prescription should be evaluated individually relative to measured FEV_1, the rate of annual moderate exacerbations or hospital admissions, and presence of eosinophilia, i.e., for patients with moderate to severe symptoms. For COPD, ICS is not used in monotherapy but prescribed in combination with LABA or LAMA/LABA, as corticosteroids and beta-2-agonists show synergistic effects by activation of the beta-2-receptor gene and increase of anti-inflammatory effects, respectively. The guideline notes that overuse of inhaled ICS is common, and that increased risk of pneumonia has been demonstrated for fluticasone and budesonide (3, 12).

Physicians are advised to consider possible harmful long-term effects before prescribing as there is no clear indication for ICS in treatment of COPD (3). Peroral corticosteroid tablets are prescribed for short-term treatment of moderate COPD exacerbations, usually as five-day courses of prednisolone (3, 8, p. 479).

1.5.4 Rescue treatment and oxygen therapy

In the context of COPD, rescue treatment or rescue packs refers to short courses of steroids and/or antibiotics that has been prescribed and issued in advance (9). The purpose is easy access to treatment that can be initiated at home if the patient received sufficient education concerning when to initiate and how to use the prescribed medicines. However, there is not much statistical evidence for the effectiveness of rescue packs on hospitalization rates. A before-and-after study in England described improvement in the utilization of rescue packs after COPD support services provided in community pharmacies with reference to the NHS agenda to involve community pharmacists in treatment of chronic diseases. Significant improvements in utilization of rescue packs were reported and suggested to contribute to lowered COPD exacerbation rate and estimated cost-effectiveness of support services compared to use of NHS services in terms of emergency visits and hospital admissions (9). A multinational qualitative study on clinicians' views on self-treatment on COPD exacerbations found differences in attitudes among general practitioners and pulmonologists concerning utilization of rescue packs. The importance of patient education and continued communication was highlighted, and clinicians made reports on insufficient time and recourses available for careful considerations regarding patient selection and education to ensure safe implementation of the service (13). The Norwegian COPD guideline also make demands on personalized written self-treatment plans for the individual patients that qualifies for this type of self-management arrangements (3).

Domiciliary long-term oxygen therapy (LTOT) can be initiated by pulmonologists for patients with severe COPD, suffering from symptoms like exercise-induced hypoxia, acute dyspnea, resting hypoxemia or signs of cor pulmonale (3, 8, p. 480). Cor pulmonale is the resulting right-sided heart failure that occurs due to a primary lung disease and pulmonary hypertension, resulting in worsening of dyspnea, fatigue and chest pain (8, p. 476). Oxygen is administered continuously via nasal prongs to maintain oxygen saturation > 90% for more than fifteen hours per day (4, p. 1083). LTOT has demonstrated improved survival for some patients (e.g., patients with severe resting chronic hypoxemia), although more recent work has

not demonstrated improved long-term outcomes. Oxygen therapy can alleviate symptoms during activity and exercise, but also represents practical challenges for both patients and physicians (14).

1.6 Non-pharmacological treatment

It is strongly recommended that all COPD patients should be offered advice concerning smoking cessation, physical training, and recommended vaccinations. Exposure to harmful particles, gases or fumes should be limited, e.g., protective equipment should be available if exposure is a problem in the patients working environment (3).

Personalized training with physiotherapists or referral to lung rehabilitation can be important non-pharmacological interventions. Vaccine against influenza virus should be offered each year, and pneumococcal vaccine should be offered every ten years to reduce risk of complications in cases of infection (3).

1.7 Disease state management

The 2022 GOLD report includes a conceptual definition of COPD self-management:

"*A COPD self-management intervention is structured but personalized and often multi-component, with goals of motivating, engaging and supporting the patients to positively adapt their health behavior(s) and develop skills to better manage their disease*" (1, p. 64).

Cravo et al states that despite of guidelines and decades of evidence on benefits, self-management is still under-utilized in critical care for COPD compared to other chronic diseases, and that what is considered self-management range from information leaflets to multiple component interdisciplinary interventions (2). Health coaching is important to improve patient capability in self-management. Self-management interventions have been demonstrated to improve outcomes for patients with COPD, and health coaching empowers patients with the skills necessary to implement successful interventions. Negotiated, written action plans for symptoms of exacerbations seem to be of special importance concerning reduction in probability of respiratory-related hospital admissions. Also, positive effects on risk of readmission and ED visits have been reported for health coaching initiated at hospital discharge (1, p. 64, 15, 16). A recent 2022 systemic review of 27 randomized controlled trials (RCTs) and cluster-randomized trials (CRTs) also concluded that self-management interventions in COPD are associated with lowered probability of respiratory-related hospital

admissions. Self-management interventions were also found unlikely to cause harm or increase mortality risks for COPD patients (17).

1.7.1 COPD education and smoking cessation

Physicians and other health care professionals should encourage and motivate active smokers to smoking cessation, as it is a crucial part of a patient's self-management of the disease. Continued smoking is associated with increased progression of COPD and a higher risk of exacerbations (3). Trained health care professionals can guide and educate patients with basic information to build knowledge and skills that enables them to become active partners in their healthcare. Patient education alone does not automatically change behaviors or motivate patients, but play important parts in the individual patients ability to cope with COPD and improve health status (1, p. 97-98). Apart from smoking cessation and basic information, other topics that can be included in an education program may be general approach to therapy, aspects of the medical treatment (e.g., inhalation devices and/or inhalation technique), advice about when to seek help and decision-making during exacerbations. Ideally, frequency of education modules and relevant content should be considered for each patient individually and in light of the patient`s needs, preferences and personal goals (1, p. 98-99).

1.7.2 Medicine adherence and medication review

As comorbidity is often associated with COPD, these patients often have higher levels of polypharmacy, higher mortality, and increased risk of hospitalization. Negotiating and sharing of a self-management plan have been shown as critical to improve the patient's responsibility concerning medication adherence (2). Medication non-adherence is one of the explanations to why many COPD patients have suboptimal disease control (18).

Medication reviews can be defined as systematic assessments of a patient`s medication management. It is a procedure used to examine and optimize the use of medicines (prescribed or bought over the counter), and minimize medication-related problems and prevent patient injury caused by use of medicines (19, 20). Collaboration with the patient is essential to inform clinical decision making and optimize adherence. Medication reviews will often result in elucidation of medication-related problems (actual or potential), and initiate a medication optimization process (20).

In Norway, medication reviews (*Legemiddelgjennomgang*) are the responsibility of medical practitioners by law (19). For patients using four or more different medicines, general

practitioners (*fastlegen*) should perform a medication review when considered necessary (or at least once a year) based on a medical assessment (21). Medication reviews can be executed by the general practitioner alone, and/or in collaboration with relevant health care professionals, e.g., a pharmacist or a nurse. According to the law, i.e., *Regulations on GP arrangements in the municipalities*, medication reviews can be executed without involvement of the patient, even though many problems will only be identified through clinical consultations and confidential discussions. Interventions to address non-adherence or medicine-related problems usually require illumination and understanding of the patient's own perspective (21).

1.7.3   Inhalation technique

Many of the medicines used for COPD are administered by inhalation. Incorrect inhalation technique compromises delivery of the inhaled medicine in the lung and is an example of unintentional non-adherence causing inadequate disease control (1, p. 58, 18). Research has demonstrated competence in inhaler use amongst COPD patients as low as 31% (6). For adequate disease state management, inhalation technique should be refreshed by routine education and re-checking to achieve optimized clinical effects. Evidence suggest that patients forget proper instructions causing decline in inhalation technique over time (22). Changes in airway limitation as COPD progress can also impact the inhalation technique and require interventions to select the most appropriate drug formulation or inhaler device (e.g., aerosol sprays compared to a powder discus, or additional use of inhalation chambers).

Table 1.2 summarize the general principles for non-pharmacological and pharmacological treatment of COPD. As for other chronic diseases, pharmacological treatment should always supplement non-pharmacological interventions.

Table 1.2 *Simple presentation of the general recommendations for treatment of COPD. Both stable COPD and COPD exacerbations are treated according to the severity of the disease for the individual patient.*

	Stable COPD	**COPD exacerbation**
	Smoking cessation, exercise, vaccination, COPD education, IT assessment	
Step 1	SAMA or SABA	(Self-treatment plan) ↑ Bronchodilator
Step 2	LAMA or LABA	(Self-treatment plan) Peroral steroid Peroral antibiotic
Step 3	LAMA / LABA	GP or ED: SAMA or SABA Steroid Antibiotic
Step 4	ICS Medication review	Hospital admission
	Training with physiotherapist, pulmonary rehabilitation	

Abbreviations: *IT: Inhalation technique; SAMA: Short-acting muscarinic antagonist; SABA: Short-acting beta agonist; LAMA: Long-acting muscarinic antagonist; LABA: Long-acting beta agonist; ICS: Inhaled corticosteroid; GP: General practitioner; ED: Emergency department*

1.8   COPD and primary health care

New models of care that utilize a multidisciplinary approach are needed to meet the burden of COPD on the individual patient as well as on the health care system. Pharmacists are well positioned for the purpose of enhancing and supporting primary care for people with COPD (6). In a systemic review on promoting community pharmacy practice for COPD management from 2020, Hu et al concludes that despite suggestions on intervention service provision in community pharmacies in literature, systematic testing of the relationships between intervention services provided by community pharmacists and final outcomes for COPD patients (e.g., reduction in exacerbations or overall healthcare costs) are needed to evaluate effectiveness of these service, even though there are reports on improved health status after pharmacist interventions (23-25).

1.8.1 The role of community pharmacies

Identification of people with undiagnosed COPD has been proposed as a possible role for the community pharmacies (26). Risk assessment and early onset of interventions, or referral to non-pharmacological interventions (e.g., smoking cessation, COPD action plan) by pharmacists may all be important contributions from the community pharmacy setting (6). Another potential role is providing support to patients with established COPD (26). Significant health benefits for patients have been observed after assessment of inhaler technique and medication adherence, medication counselling and continuity of care by regular follow-ups provided by community pharmacists (6).

It has also been suggested that community pharmacists can involve in transition of care processes to reduce the frequency of readmissions or emergency department (ED) visits after discharge from hospital. A case study from 2017 describes how community pharmacists within 72 hours of discharge offered a comprehensive medication review that were included in the patient`s medical record. The pharmacists also provided one follow-up telephone call 7 days after the first encounter (for evaluation of drug-related problems and adherence), and one last telephone call 30 days after discharge (for assessment of hospital readmissions and ED visits). Services provided were documented using standardized forms and assessment tools. Even though the final study group consisted of only 9 patients, none of them were readmitted or visited an ED within 30 days of discharge (27).

1.8.2 Pharmacist-led interventions

Pharmacist-led interventions can have significant impacts on medication adherence and inhalation technique for COPD patients. More quantitative analysis concerning efficacy are needed, but improvements in outcome measures has been reported (18, 22). Even though evidence is not conclusive, educational interventions on inhalation technique and medication adherence may be cost-effective in terms of reduced hospitalization and exacerbation rates. Significant improvements in medication adherence after COPD management interventions from community pharmacists in England was demonstrated by Wright et al by offering COPD support in different community pharmacies. This study also reported mean cost-savings associated with the interventions due to reduction in hospital admissions. However, a high dropout rate from the initial intervention group (from 306 to 137 COPD patients) and a variable frequency for patient follow-up limits the value of the results (9).

Different study designs and inconsistent presentation of results make it difficult to compare the studies, e.g., when no statistical data are included, or if intervention elements are not

standardized: A pilot study from Canada investigated impact of community pharmacists in COPD management but reports no statistical outcomes (28). A study in Australia investigated the effect on educational interventions concerning inhalation technique using the pressurized Metered Dose Inhaler (pMDI) in a community pharmacy setting. The results on handing out written and giving verbal information, and especially, on providing additional physical demonstrations on inhalation technique were statistically significant, when concerning this type of inhaler device (29). A four-year study from Japan reported significant results on improved adherence to inhaled medicines after repeated inhalation technique instructions from community pharmacists, but again results were limited by small sample size, lack of control group and changes in the intervention group over time during the study (30). Hesso et at discuss in their systemic review that evidence concerning positive impact of community pharmacists on COPD management is growing, although most studies are limited by small study groups, short duration, variable study designs and non-standardized interventions (22).

A more recent systemic review from 2020 also concluded that pharmacist-led interventions were significant with respect to medication adherence and inhalation technique for COPD patients (18). Jia et al performed a systematic search for randomized control trials in several scientific databases, and 13 articles were included in the review. In contrast to Hesso et al, all publication dates were included. Also, they excluded studies where pharmacists were not the primary implementors of interventions. A quantitative meta-analysis of 12 articles was also included in the Jia et al review, where results suggested that pharmacist-provided interventions had significant improvements in medication adherence for the COPD patients. However, their final statement is also that more research is needed to establish evidence for the clinical effectiveness of the interventions (18).

Most studies report effects on patient adherence to medication use or technique, and not on clinically important outcomes that make a difference for the patients and the health care system (e.g., hospitalization, readmission, or mortality rates), which make it difficult to justify the added costs of implementing new services in the primary health care system.

Also, uniform models for intervention structures and measuring tools are needed to ensure that interventions are implemented as high-quality services. Jia et al states that interventions based on the IMB-model (Information-Motivation-Behavioral skills model) may be worthy of clinical validation based on their findings, but notes that their review is also limited by small number of studies, risk of bias, and that most studies included in the review used unreliable self-reporting on adherence as a measuring tool (18).

1.8.3 Health-related quality of life

Undoubtedly, COPD has a negative impact on the quality of life. The burden is difficult to grasp for those not affected by the disease. Pain, fatigue, dyspnea, chronic cough, reduced mobility, and sleep interruptions are some of the unpleasant features associated with COPD. Many comorbidities contributing further to reduced quality of life (e.g., cardiovascular disease, skeletal muscle dysfunction, diabetes, depression, anxiety, and lung cancer) are also commonly seen for COPD patients (1, p. 22, 6).

Early interventions can significantly reduce frequency of exacerbations, improve the perceived quality of life, and reduce costs for the patient as well as our health care system. Pharmacists are educated in clinical skills and represent great potential beyond the traditional dispensing of medicines in the pharmacies. They are already contributing to management of an increasing selection of chronic diseases by providing guidance on health promotion, medication management and improved patient self-care, and are thus contributors to improved health-related quality of life for the patients (6, 26). As experts in medicines and their use, community pharmacists can be utilized in assessment of medication adherence and inhalation technique, provision of smoking cessation services and customized health coaching for patients diagnosed with COPD in primary health care.

1.9 Summary

Frequent readmission rates for COPD patients and the resulting economic burden for our health care system are important problems for the patients as well as for the society. Non-pharmacological interventions are the fundament in management of COPD for all patients, and smoking cessation may be considered the most important intervention. Pharmacological interventions aim to maintain or increase the patients' functional level, which also is important in preventing exacerbations.

Adherence to prescribed medicines play important parts in symptom relief and adequate disease control, both in stable COPD and during the event of an exacerbation, e.g., when utilizing rescue packs with in-advance prescriptions of antibiotics and steroids.

As many medicines for COPD are administered by inhalation, inhalation technique assessment is important to maintain optimal inhaler use and medication delivery in the lungs. Improved self-management and decision-making skills will help the patient to cope with the disease in daily life, and education programs are suggested as cost-effective interventions with potential to reduce frequency of hospital admissions. Self-management is important in

implementation of early interventions or rapid initiation of treatment in the event of mild to moderate exacerbations. Adequate health coaching in combination with personalized written action plans may prevent or reduce the severity of an exacerbation.

To address these problems, the aim of this project was to investigate COPD service elements received by patients in the discharge or post-discharge setting. The project also attempts to investigate patient interest in possible future services, based on interventions that has been reported in literature to indicate positive outcomes on readmission rates for COPD patients. Preferred locations for follow-up health care services post-discharge are also investigated. Prevention of COPD exacerbations is crucial in detaining progression of the disease, as the general health status deteriorates each time the patient suffers from an exacerbation.

2 Method

A patient survey was designed with the aim to describe patient experiences with the current medicine related practices associated with discharge procedures, and to identify patient preferences for service provision from health care professionals.

A copy of the initial project description shared with the Pulmonary department prior to the survey can be found in appendix 1.

2.1 Project description

2.1.1 The Pulmonary department

The project was executed in collaboration with the Pulmonary department at Haukeland University Hospital in Bergen, Norway. Two bedspace subunits at the department, Respiratory ward 1 and Respiratory ward 3, were involved.

Respiratory ward 1 (*Lungeavdelinga post 1*) has sixteen bed spaces, where up to twelve spaces is intended for patients in need of respiratory monitoring and breathing aid. Ward 1 treats patients admitted with COPD, respiration failure and pneumonia. Respiratory ward 3 (*Lungeavdelinga post 3*) has twenty bed spaces, and treat patients admitted with lung cancer, lung infections, COPD, and cystic fibrosis. Respiratory ward 3 is also equipped to isolate patients admitted with tuberculosis. Currently, the two subunits also treat patients admitted due to Coronavirus disease. A brief presentation of the two respiratory wards and their intended functions are presented in table 2.1.

Table 2.1 *Intended functions for Respiratory ward 1 and Respiratory ward 3 at the Pulmonary department in Haukeland University Hospital.*

	The Pulmonary department	
	Respiratory ward 1	Respiratory ward 3
Bedspaces:	16	20
Diagnoses:	COPD	Lung cancer
	Respiration failure	Lung infections
	Pneumonia	COPD
		Cystic fibrosis
Special functions:	Respiratory monitoring	Isolate for tuberculosis
	Breathing aid	

2.1.2 Literature search

Two literature searches were executed in the PubMed database using the Advanced Search Builder. The first search investigated published information concerning COPD patients at discharge and pharmaceutical interventions. The second search investigated published data concerning COPD patients at discharge and connections to community pharmacies. The terms used in the first and second literature search are shown in table 2.2 and 2.3, respectively.

Table 2.2 *Terms used in the PubMed Advanced Search Builder - literature search 1*

		Add with OR				
Population	**Add with AND**	Discharge	Transfer	Leave	Release	
		Hospital	Clinic	Secondary care	Ward	Inpatient
		Chronic Obstructive Pulmonary Disease	Chronic bronchitis	COPD		
Intervention		Medicine*	Medication*	Pharmaceutical care		

Table 2.3 *Terms used in the PubMed Advanced Search Builder - literature search 2*

		Add with OR				
Population	**Add with AND**	Discharge	Transfer	Leave	Release	
		Hospital	Clinic	Secondary care	Ward	Inpatient
		Chronic Obstructive Pulmonary Disease	Chronic bronchitis	COPD		
Intervention		Community pharmacy	Community pharmacist			

Most of the selected articles concerned pharmacist involvement in COPD management. The COPD interventions used in the articles and statistical data on outcomes (if reported) were

extracted. Interventions that indicated positive outcomes for COPD patients reported as a reduction in frequency of hospital readmissions (or emergency department visits) were identified and used as a fundament in the development of the patient survey (see chapter 2.1.3). The identified interventions are reflected in the topics (see table 2.4) and choice of questions included in the survey.

2.1.3 Design of questionnaire

A selection of relevant scientific articles from the two literature searches was used as the basis for the design of a qualitative patient survey questionnaire. Intervention elements that could relate to pharmacists or pharmacy settings were identified and sorted to present main topics for the questionnaire. Based on nine topics (see table 2.4), evaluative questions were formulated in English, and further translated to Norwegian. Efforts were used to achieve a translation as close as possible to the English version, yet natural to the Norwegian language, and use of plain language without medical terminology were emphasized. The number of questions and length of the survey was considered, as longer questionnaires are associated with lower odds of response (31).

Table 2.4 *The main topics for interventions covered in the survey questionnaire as identified from relevant literature to indicate positive outcomes for COPD patients*

Intervention topics covered in questionnaire:
Medication reconciliation
Medication optimization
Disease state management
Post-discharge clinic
Knowledge and use of medicines assessment
Medication education
Discharge counseling
Smoking cessation
Follow-up phone call / consultation

The first part of the survey (question 1 to 14) was designed to investigate patient experiences concerning medicine-related interventions which may be included in admission or discharge procedures. The second part (question 15 to 30) were designed to map patient preferences concerning similar interventions, and preferred locations for the intervention services. The

participant responses were registered on a 5-point Likert-type scale, with an additional option not to rate the answer on the scale with "Unsure" (see table 2.5). Four questions were included at the end of the questionnaire to obtain feedback on the questionnaire itself to enable the researcher to pilot the tool. Age and gender were collected for patients who completed the survey.

Table 2.5 *The two 5-point Likert-type scales used in the questionnaire for part 1 and part 2, respectively. The questionnaire was presented to participants in Norwegian language.*

			Likert-type scales used in questionnaire			
English **Part 1**	Always	Often	Sometimes	Rarely	Never	Unsure
Part 2	Strongly agree	Quite agree	Neither agree nor disagree	Quite disagree	Completely disagree	Unsure
Norwegian **Part 1**	Alltid	Ofte	Noen ganger	Sjelden	Aldri	Vet ikke
Part 2	Sterkt enig	Ganske enig	Verken enig eller uenig	Ganske uenig	Helt uenig	Vet ikke

2.2   Data collection

Survey data were collected from August throughout October 2022 in the pulmonary department at Haukeland University Hospital. The questionnaire was initially designed as a self-completion survey. However, most of the patients who gave their consent to participate needed assistance to complete the survey, and method of administration and reason for assistance were recorded. If assistance were required, the questions and response scale were read aloud to the patient, and the researcher would register the patient's selected response on the paper version of the questionnaire.

2.2.1   Inclusion criteria for survey

Inclusion criteria for the survey were diagnosis of COPD and hospital admission due to exacerbation of COPD. Exclusion criteria were hospital admission due to causes other than COPD exacerbation.

2.2.2 Identification of candidates

Two meetings were arranged with the Pulmonary department prior to the survey. Practical implementation was discussed with the two section leaders at Respiratory ward 1 and Respiratory ward 3. The rest of the staff were then informed about the survey and it`s background. The two lung units identified potential candidates for inclusion in the survey during their daily internal meetings. Potential candidates were invited to participate in the survey by their assigned nurse. If a written consent to participate was obtained, the survey questionnaire was presented to each patient by the master's student and completed as described in chapter 2.2.

2.2.3 Collection of survey data

Survey data were collected on a paper version of the questionnaire created using the digital SurveyXact tool for questionnaire-based surveys (32). Participants were instructed to choose the statement on the response scale that best reflected how often the event or intervention presented in the question had taken place according to their own experiences and memory, or according to their agreement or disagreement with the evaluative questions.

2.2.4 Evaluation of pilot questionnaire

The questionnaire, survey process and responses to the pilot questions were reviewed to identify any need for changes or adjustments. Possible discrepancies between the questionnaires that were self-completed and the questionnaires that were researcher completed were investigated.

2.3 Data processing and analysis

Data analysis was largely descriptive using means, medians, and proportions to describe responses as appropriate. Data processing for statistical analysis was performed in IBM SPSS Statistics software, after raw data input in Microsoft Excel Spreadsheet Software.

2.3.1 Statistical analysis

Ordinal survey data concerning previous experiences, preferences and satisfaction with the survey were presented as medians and interquartile ranges. Responses where last point for each survey question was selected by respondents (i.e., "Unsure" responses) were excluded

from data analysis to present the median for the ranked responses. Blank responses were also excluded from the calculations.

2.3.1.1 Frequency analysis (descriptive statistics)

A frequency analysis was performed to summarize response frequencies and investigate the spread of data. A split data analysis was also executed to provide the median for each question together with 25th and 75th percentile scores for the grouping variables "Gender", "Age group" and "Assistance".

2.3.1.2 Mann-Whitney U test

Mann-Whitney U tests were performed to compare response differences between two different groups. The test aimed to investigate if the scaled responses for each question were significantly influenced by the participants gender, age group, or if they received assistance to complete the survey or not. Table 2.6 presents the variables and groups used in the test.

Table 2.6 *Statistical variables and groups used in the Mann-Whitney U test.*

Mann-Whitney U test	
Dependent variable	**Independent variable (with groups)**
Response on Likert scale in questionnaire	Gender (male, female)
	Age (age 50-69, age 70-89)
	Assistance (help, no help)

2.3.1.3 Cross-tabulation analysis (descriptive statistics)

Cross tables were paired with the related p-value from the Mann-Whitney U tests to investigate for significant differences in response distribution (p-value < 0.05).

2.3.1.4 Spearman´s rank correlation test

Spearman´s rank correlation was used to relate satisfaction to services received or services wanted. Question 12 were tested towards the other questions in questionnaire part 1 to investigate for positive or negative associations between patient satisfaction and the services previously received in the discharge setting. Table 2.7 presents the first part of the questionnaire concerning patient experiences.

Table 2.7 *List of questions used in the first part of the questionnaire. Associations between patient satisfaction (Q12) and services received were investigated using the Spearman´s rank correlation test in SPSS Statistics.*

Q	Questionnaire part 1 – Patient experiences
1	Before I was discharged, someone checked that the medicines I was given in hospital were exactly the same as those that I was taking before I came in
2	Someone asked about my medicines and whether I wanted to change anything when I was admitted
3	Someone checked how well my COPD was under control within a week of discharge
4	I received follow-up for COPD at a lung outpatient clinic within a week of discharge
5	I received follow-up for COPD in a community pharmacy within a week of discharge
6	Someone checked that I understand how my medications help to prevent COPD from getting worse
7	Someone checked that I use my medications for COPD in the right way
8	I have had the chance to discuss how the medicines I use for COPD can prevent my symptoms from getting worse
9	I discussed what I can do myself to prevent COPD-symptoms with a health care professional
10	I discussed what I should do if my COPD-symptoms get worse with a health care professional
11	I discussed how my medications work to prevent COPD-symptoms with a health care professional
12	**I am satisfied with the information about COPD I have received from health care professionals**
13	I have been offered help to quit smoking
14	I was offered a follow-up interview with a health care professional over the phone to check how I am getting on with my medicines

In the same manner, question 25 were tested towards the other questions in questionnaire part 2 to investigate for positive or negative associations between patient preferences and the services wanted. Table 2.8 presents the second part of the questionnaire using similar questions concerning patient preferences on COPD service provision.

Table 2.8 *List of questions used in the second part of the questionnaire. Associations between patient satisfaction (Q25) and services wanted were investigated using the Spearman´s rank correlation test in SPSS Statistics.*

Q	Questionnaire part 2 – Patient preferences
15	I would like someone to check that the medicines I am going to get in hospital are exactly the same as those that I was taking before I came in
16	I would like someone to check that my medicines are the best ones for me and that they work the way they are supposed to
17	I would like someone to check how well my COPD are under control within a week of discharge
18	I would like to be offered follow-up for COPD at a lung outpatient clinic within a week of discharge
19	I would like to be offered follow-up for COPD in a community pharmacy within a week of discharge
20	I would like someone to check that I use my medications for COPD in the right way
21	I would like to discuss what I can do myself to prevent COPD-symptoms
22	I would like to discuss how to recognize symptoms related to COPD getting worse
23	I would like to discuss what I should do if my COPD-symptoms get worse
24	I would like to discuss how my medications work to prevent COPD-symptoms
25	**I would like to receive more information about COPD from health care professionals**
26	I would like to be offered help to quit smoking
27	I would like to be offered a follow-up interview with a health care professional over the phone to check how I am getting on with my medicines
28	I would like to have a conversation about COPD in the hospital
29	I would like to have a conversation about COPD in a community pharmacy
30	I would like to have a conversation about COPD at home (over the telephone or in a digital meeting via Teams, Zoom or similar)

Significant correlations (p-value < 0.05) were presented as scatter plots of raw data in Excel Spreadsheet. "Unsure" and "blank" responses were excluded from the raw data, as in the SPSS analysis.

2.4   Ethical approval and privacy concerns

2.4.1   REK presentation assessment

A presentation assessment (*fremleggingsvurdering*) was executed by the regional committee for medical and healthcare research (*Regional komité for medisinsk og helsefaglig forskning, REK*) (33). No further submissions were required for approval of the project, as it were considered to concern quality assurance on health care services, rather than direct medical and healthcare research on the patients involved. A copy of the evaluation document from REK can be found in Appendix 2.

2.4.2   Registration in RETTE

The project was also registered in RETTE, the University in Bergen's own system for overview and control of the processing of personal data. RETTE is a risk and compliance assessment system (*System for **r**isiko og **ette**rlevelse*) intended for student and research projects to determine if further privacy impact assessments are required (34).

2.4.3   Anonymization of survey participants

Participants who completed the survey questionnaire was given a unique identifier number for anonymization. Personal data registered in this project were restricted to data on age and gender. The identity of participants is further protected by the duty of confidentiality for health care professionals in the Norwegian Health Personnel Act, §21 – 29 e, which is valid for health care students as well as professionals (35-37).

2.4.4   Consent to follow-up study

Some of the participants gave written consent to be approached in a PhD follow-up study. In these cases, the form for ethical consent was handed over to a PhD student within the research group for further scientific use. The form used to document ethical consent from informants can be found in appendix 3.

3   Results

3.1   Background information from literature search

Twenty-five articles were considered relevant and included as background information for development of the questionnaire. The papers were further investigated for interventions in COPD management and related outcomes on readmission rates for COPD patients. One paper included a cost-utility analysis of a pharmacy-led self-management program. One paper that investigated an educational program on inhaler technique (but without pharmacist involvement), and one paper on shared decision making and experiences of patients with chronic conditions were also included.

Table 3.1 and 3.2 presents the identified interventions used as background services for the design of the questionnaire, as extracted from literature search 1 and 2, respectively.

Table 3.1 Intervention service elements for COPD management as extracted from literature search 1.

Authors	Interventions in COPD management								
	Medication reconciliation	Medication optimization	Disease state management	Knowledge and use of medicines assessment	Post-discharge clinic	Medication education	Discharge counseling	Smoking cessation	Follow-up phone call / consultation
Evans D et al[38]	✓*	✓*		✓*		✓*	✓*	✓*	
Layman SN et al[39]		✓	✓	✓					
McFarland MS et al[40]		✓*	✓						
Vitacca M et al[41]				✓		✓			
Kim J et al[42]	✓*	✓*				✓*	✓*	✓	✓
O´Reilly EA et al[43]	✓* ✓		✓* ✓	✓* ✓		✓*	✓*		✓
Bloodwort LS et al[44]	✓*	✓		✓* ✓					✓
Patton AP et al[27]	✓	✓		✓	✓				✓
Wright EA et al[10]	✓			✓		✓*			✓
Farris KB et al[45]	✓*		✓*	✓*		✓*	✓*		✓
Fera T et al[46]	✓*			✓*		✓*			✓
Luder HR et al[47]	✓	✓	✓	✓		✓			✓
Freeman CR et al[48]	✓	✓		✓		✓			✓
Kayyali R et al[49]					✓*				
Hohner E et al[50]	✓*	✓*	✓*	✓*		✓*			✓

✓*: *inpatient setting or at discharge;* ✓: *post-discharge setting*

Table 3.2 *Intervention service elements for COPD management as extracted from literature search 2.*

Authors	**Interventions in COPD management**								
	Medication reconciliation	Medication optimization	Disease state management	Knowledge and use of medicines assessment	Patient interview / questionnaire	Medication education	Discharge counseling	Smoking cessation	Follow-up phone call / consultation
Jia X et al[18]			✓*	✓*	✓*	✓*		✓*	✓
Davis E et al[51]	✓	✓	✓	✓		✓		✓	
Hu Y et al[23]			✓	✓	✓	✓		✓	✓
Hesso I et al[22]			✓	✓	✓	✓		✓	✓
Twigg MJ et al[26]			✓	✓		✓		✓	
Khdour MR et al[52]		✓	✓	✓	✓	✓			✓
Alton S et al[25]	✓					✓			✓
Fathima M et al[6]		✓		✓		✓			✓
Eisenhower C[53]	✓*						✓*		
Khdour MR et al[11]			✓	✓		✓			✓

✓*: *inpatient setting or at discharge;* ✓: *outpatient or post-discharge setting*

Table 3.3 presents information on study design and clinical outcomes for the articles reviewed from literature search 1. Statistical outcomes on readmission rates were considered in the selection of intervention topics for the questionnaire.

Table 3.3 *Intervention outcomes as extracted from literature search 1. Clinical endpoints and statistical significance (if reported) were considered in the development of the questionnaire.*

Authors	Study design	Patients enrolled	Clinical endpoint (primary)	Outcome measures
Evans D et al[38]	Pilot study (2020)	In total: 50 With COPD: 18	30-day readmission rate (COPD exacerbation)	Intervention: 16 % Control: 20 %
Layman SN et al[39]	Retrospective review (+ follow-up PSM* observational analysis) (2020)	In total: 114 After PSM: 64	30-day readmission rate (COPD)	Intervention: 13 % (3.1 %) Control: 17 % (15.6 %) P = No report (0.196)
McFarland MS et al[40]	Multisite, single health care system, quasi-experimental, matched interrupted time series design (2020)	In total: 484 With COPD: 66	30-day / 90-day acute care utilization rate (ED visit or hospital readmission, all-cause)	Intervention = 26.9 % / 62.4 % Control = 28.9 % / 74.4 % P = 0.6852 / 0.0062
Kim J et al[42]	Retrospective study (2021)	In total: 65	180-day composite COPD-related hospitalizations and ED visits	Intervention = 35 instances Control = 79 instances P = 0.0364
O´Reilly EA et al[43]	Retrospective chart review (2020)	In total: 23 With COPD: 11	30-day hospital readmissions (for patients with COPD and/or HF)	Intervention = 0 % Control = 12.3 %
Bloodwort LS et al[44]	Prospective, randomized controlled trial (2019)	In total: 96 With COPD: 15	30-day (60-, 90- and 180-day) readmission rates (index diagnosis related) for AMI, COPD, chronic HF, pneumonia	Intervention = 5.8 % Control = 6.9 % P = 0.761
Wright EA et al[10]	Prospective experimental study with matched control (2019)	ITT group: 615 PP group: 187 With COPD: ITT group: 223 PP group: 80	30-day readmission rate (all-cause)	Intervention = 15% (ITT), 9 % (PP) Control = 15 % (both ITT and PP) P = 0.98 (ITT) / 0.02 (PP)

Authors	Study design	Patients enrolled	Clinical endpoint (primary)	Outcome measures
Farris KB et al[45]	Randomized controlled trial (2014)	In total: 945 With asthma or COPD: 255	30-day / 90-day readmission rate (all-cause; hypertension, hyperlipidemia, HF, coronary artery disease, MI, stroke, TIA, asthma, COPD, oral anticoagulation)	Intervention = 16.7 % / 17.4 % Control = 14.6 % / 16.0 % P = 0.29 / 0.77
Fera T et al[46]	Case study (2014)	In total: 175 With COPD: 145	30-day readmission or ED-visit rate (all-cause; COPD, HF, polypharmacy)	Intervention = 22 % Control = 42 % P = 0.01
Luder HR et al[47]	Prospective, quasi-experimental study (2015)	In total: 90 With COPD: 29	30-day readmission and ED visit rate (all-cause; COPD, CHF, pneumonia)	Intervention = 17 % Control = 30 % P = 0.074 For readmission only, after intervention by pharmacist: P = 0.017
Freeman CR et al[48]	Stepped wedge, cluster randomized trial (2021)	In total: 306 Interven. group: 177 Control group: 129	12 months hospital readmissions and 12 months non-admitted ED visits (patients with primary discharge diagnosis of CHF / COPD exacerbation / 5 or more long-term medicine prescriptions at discharge)	Intervention = 136 readmissions / 45 ED visits Control = 282 readmissions / 88 ED visits IRR = 0.79 / 0.46

Abbreviations: *PSM: Propensity score matching; IRR: Incidence rate ratio; HF: Heart failure; CHF: Congestive heart failure; ITT-group: Intention-to-treat group; PP-group: per-protocol group*

3.1.1 Questionnaire

A copy of the questionnaire presented at the respiratory wards can be found in appendix 4. Appendix 5 presents an English translation of the questionnaire.

3.2 Analysis of survey responses

3.2.1 Demographic information

In total 45 patients were invited to participate in the survey, and 20 participants completed the questionnaire. Relevant study group characteristics are presented in table 3.4.

Table 3.4 *Participant demographic information (n = 20).*

Variable	Response, n (%)	Age, ($\overline{y}$)
Gender:		
Male	12 (60)	73.5
Female	8 (40)	74.5
Total (n = 20)		73.9
Age group (y):		
50-59	1	
60-69	6	
70-79	8	
80-89	5	

In contrast to the initial self-completion survey plan, most of the questionnaires were researcher-completed as described in chapter 2.2. Various reasons for the altered approach included visual impairment and need for reading aid, practical considerations related to breathing support, or simply that they were not in their best condition but still wanted to make their contribution to the survey.

3.2.2 Main findings

3.2.2.1 Frequency distribution of survey responses by percentage

Patient experiences:

Figure 3.1 presents the main results in terms of response distribution for question 1 to 7 concerning patient experiences on discharge or post-discharge services. It can be seen that most patients never or rarely had been offered the services investigated. Medication reconciliation appears to be the service most frequently experienced.

Figure 3.1 *Response distribution by percentage for question 1 to 7 concerning patient experiences on COPD service provision.*

Figure 3.2 presents main results in terms of response distribution for question 8 to 14, also concerning patient experiences on discharge or post-discharge services. It can be seen that in the study group, around 50% or more never or rarely had been offered the investigated services. Follow-up telephone call from health care professionals seem to be the less frequent service offered. Almost 50% never or rarely had counseling on how to prevent symptoms, and more than 60% never had counseling on what to do if symptoms get worse. Despite the low scores concerning investigated services, the patients seem to be satisfied with information provided about COPD from health care professionals.
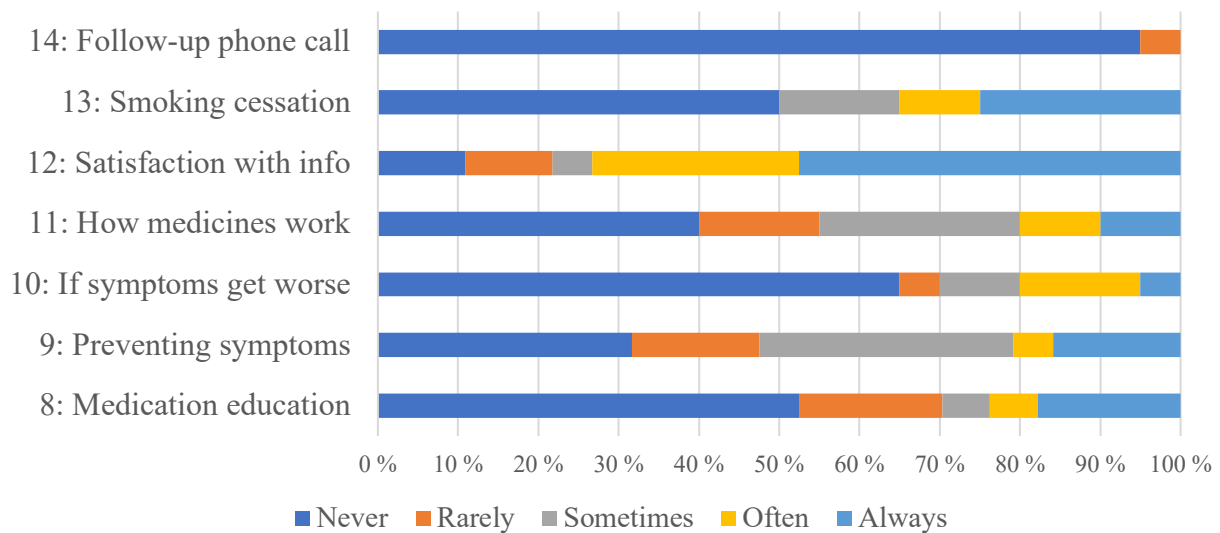
Figure 3.2 *Response distribution by percentage for question 8 to 14 concerning patient experiences on COPD service provision.*

Patient preferences:

Figure 3.3 presents the main results in terms of response distribution for question 15 to 22 concerning patient preferences on possible discharge or post-discharge services. It can be seen that for all questions 15 to 22, at least 50% of the respondents agreed that they would like the service, except for question 19, where patients were less positive regarding follow-up for COPD in a community pharmacy within the first week of discharge. However, more than 80% strongly or quite agreed that they would like a check-up on disease management within a week of discharge.
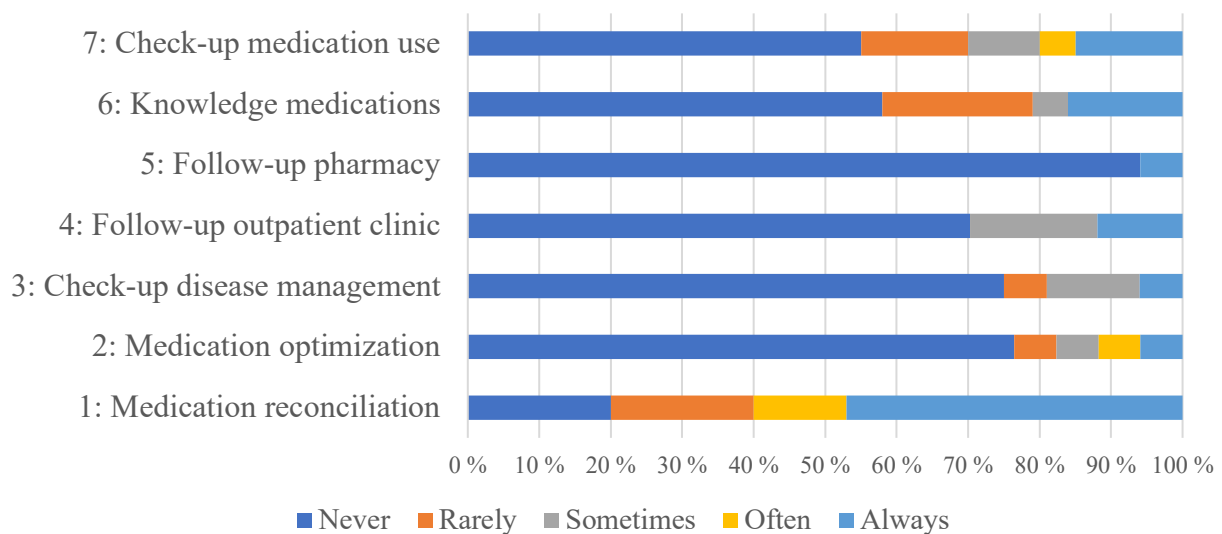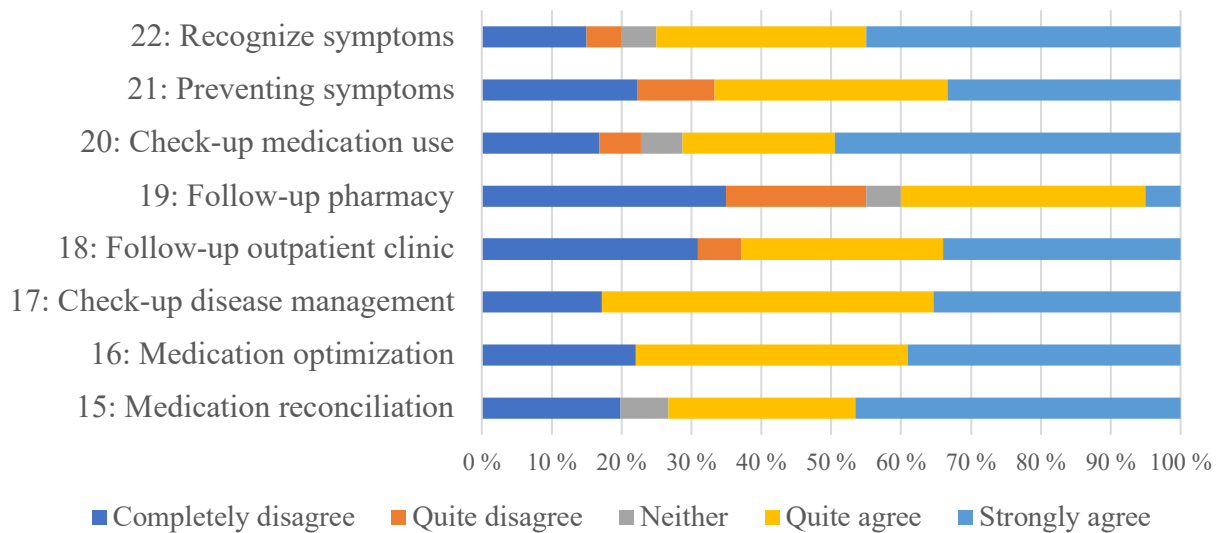
Figure 3.3 *Response distribution by percentage for question 15 to 22 concerning patient preferences on COPD service provision.*

Figure 3.4 presents main results in terms of response distribution for question 23 to 30, also concerning patient preferences on possible discharge or post-discharge services. It can be seen for question 23 and 24 that 80% or more quite or strongly agreed that they would like to be offered the counseling service. Most patients were not interested in receiving support on smoking cessation. Around 50% were interested in receiving a follow-up telephone call and approximately 60% of the patients were interested in receiving more information about COPD from health care professionals. It can also be seen that the hospital was the most preferred location for conversations about COPD.
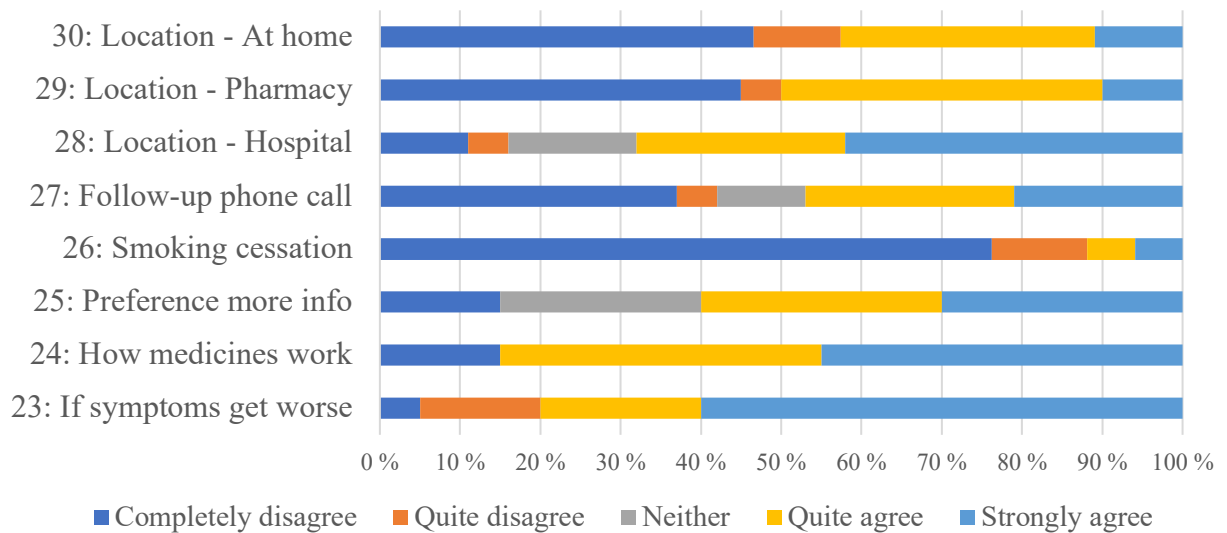
Figure 3.4 *Response distribution by percentage for question 23 to 30 concerning patient preferences on COPD service provision.*

3.2.2.2 Mann-Whitney U test and cross-tabulation analysis

Mann-Whitney U test – Gender:

Figure 3.5, 3.6 and 3.7 presents results from cross-tabulation analysis and associated p-values from the Mann-Whitney U test when comparing the male and female group.

Significant differences in ranked responses between males and females were found for question 3, 19 and 27, concerning check-up on disease management, post-discharge follow-up within the first week of discharge and provision of a follow-up phone call service, respectively.

3: "Someone checked how well my COPD was under control within a week of discharge."
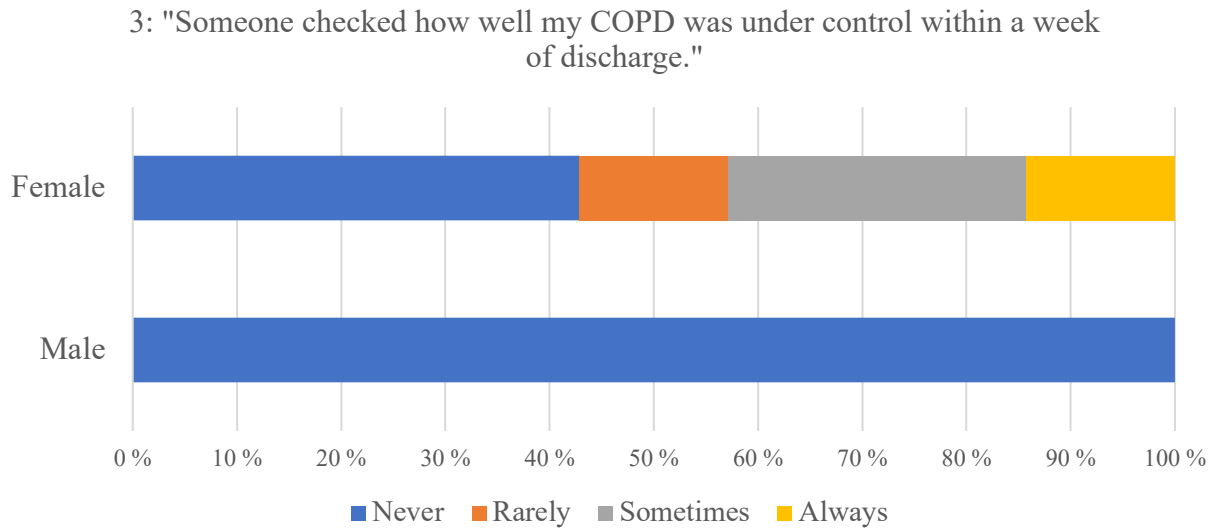
Figure 3.5 *Differences in male and female responses to question 3 concerning experiences on receiving check-up on disease management post-discharge.*

19: "I would like to be offered follow-up for COPD in a community pharmacy within a week of discharge."
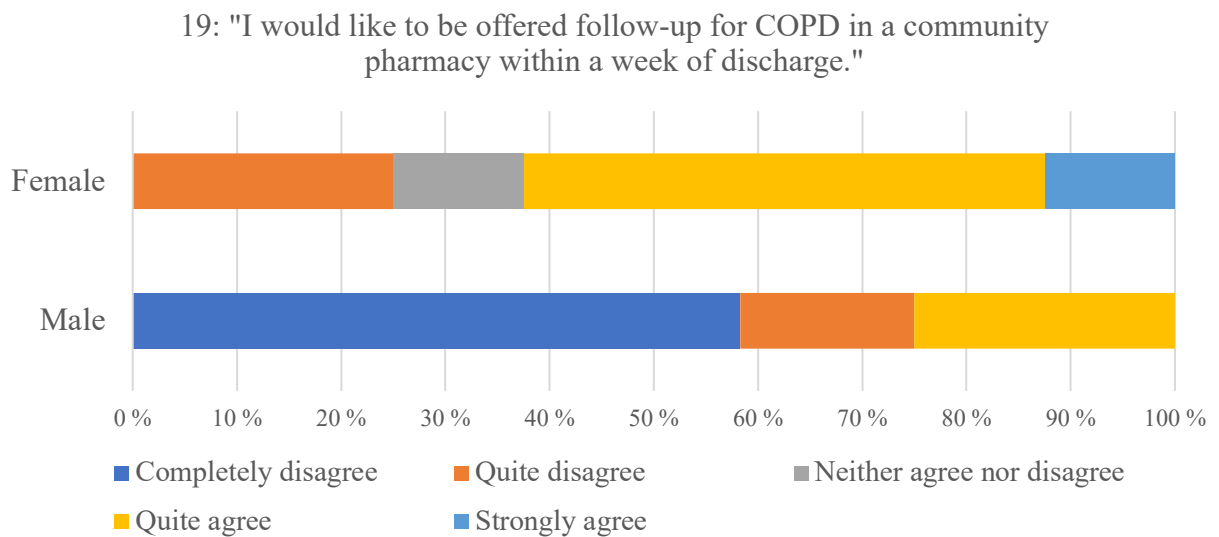
Figure 3.6 *Differences in male and female responses to question 19 concerning preferences in location for post-discharge follow-up services within the first week of discharge.*

27: "I would like to be offered a follow-up interview with a health care professional over the phone to check how I am getting on with my medicines."
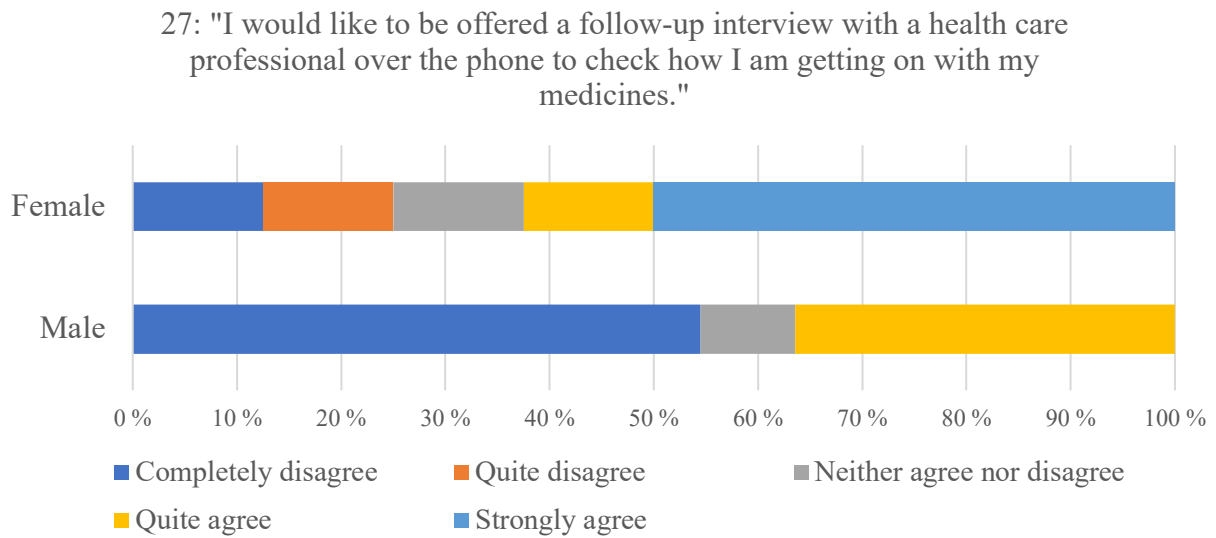
Figure 3.7 *Differences in male and female responses to question 27 concerning preferences on receiving a follow-up interview over the phone to assess for medication adherence and medicine related problems.*

Mann-Whitney U test – Age group:

Figure 3.8 presents the significant result from the Mann-Whitney U test when comparing the two age groups, 50-69 years, and 70-89 years. Significant differences in ranked responses between the two age groups were found for question 1, concerning medication reconciliation service provision.
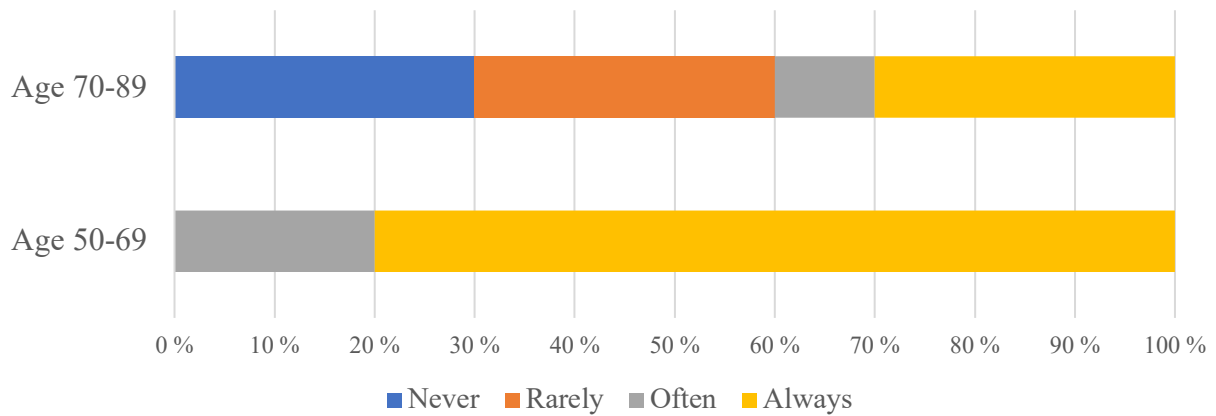
Figure 3.8 *Differences in age group responses to question 1 concerning experiences on receiving medication reconciliation services.*

Mann-Whitney U test – Assistance:

Figure 3.9 presents the significant result from Mann-Whitney U test and cross-tabulation analysis, when considering the assisted and non-assisted group. The group that self-completed the questionnaires were always offered smoking cessation support, while almost 60% of the patients with researcher-completed questionnaires seem to never have been offered support on smoking cessation.

13: "I have been offered help to quit smoking."
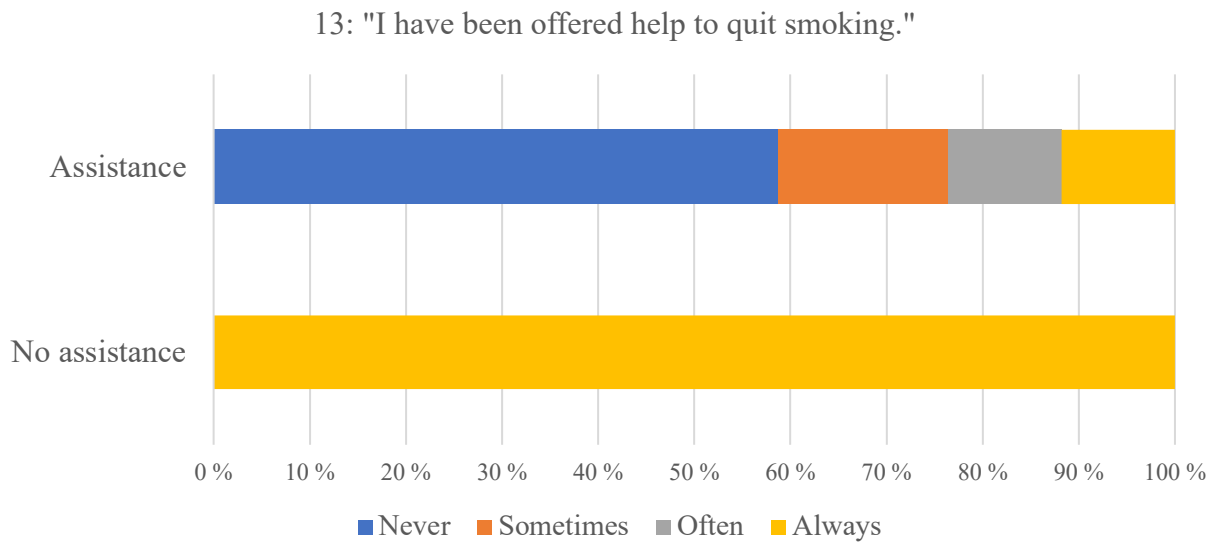
Figure 3.9 *Differences in responses between researcher-completed (assistance group) and self-completed questionnaires (no assistance group) to question 13 concerning experiences on receiving support for smoking cessation.*

Grouped frequency analysis:

Table 3.5, 3.6 and 3.7 presents median values and associated quartiles (Q1 and Q3) for responses from the male and female group, the two age groups and the researcher-completing and self-completing group, respectively. The coding used for questionnaire responses in SPSS are informed in appendix 6.

Table 3.5 *Comparison of median values and interquartile ranges of response scores for the male and the female group for question 1 to 34 in the questionnaire.*

Question	Male		Female	
	Median	**Q1, Q3**	**Median**	**Q1, Q3**
1	6	4,6	3	2, 6
2	2	2,3	2	2, 2
3	2	2,2	3	2, 4
4	2	2,2	3	2, 5.5
5	2	2,2	2	2, 2
6	2	2, 3	3	2, 6
7	2	2, 3	3.5	2, 5.5
8	2	2, 3.5	3	2, 6
9	3	2, 4	4	2.25, 5.5
10	2	2, 2.75	3	2, 4.75
11	2.5	2, 4	3.5	2.25, 4.75
12	5	5, 6	5.5	3.25, 6
13	2	2, 5.75	4	2, 5.75
14	2	2, 2	2	2, 2
15	5	2, 6	6	4.75, 6
16	5	2, 6	5	5, 6
17	5	2, 5.5	5.5	5, 6
18	3	2, 6	5	5, 6
19	2	2, 4.5	5	3.25, 5
20	6	4, 6	5	3, 6
21	5	2, 6	5	3, 6
22	5	2.25, 6	6	5, 6
23	6	3, 6	6	5, 6
24	5.5	2.75, 6	5	5, 6
25	5	2.5, 6	5	4, 5
26	2	2, 2	2	2, 3
27	2	2, 5	5.5	3.25, 6
28	5	4, 6	5	4, 6
29	2	2, 5	5	3.5, 5
30	2	2, 5	5	2.25, 5
31	5	4.25, 5	5	3.25, 5.75
32	4.5	4, 5	5	4.25, 5.75
33	5	5, 5	5	5, 5.75
34	4.5	3, 5	3	2, 6

Abbreviations: *Q1, lowest quartile (25th percentile); Q3, highest quartile (75th percentile)*

Table 3.6 *Age group comparison of median values and interquartile ranges of response scores for question 1 to 34 in the questionnaire.*

Question	Age group 50-69		Age group 70-89	
	Median	**Q1, Q3**	**Median**	**Q1, Q3**
1	6	5.5, 6	3	2, 6
2	2	2, 4	2	2, 2
3	2	2, 2	2	2, 3.75
4	2	2, 4	2	2, 4
5	2	2, 2	2	2, 2
6	2	2, 6	2	2, 3
7	3	2,5	2	2, 3.5
8	2.5	2, 3.75	2	2, 5
9	4	3.5, 4.5	3	2, 4.5
10	2	2, 5	2	2, 4
11	4	2, 4	3	2, 4.5
12	5.5	5, 6	5	3, 6
13	2	2, 6	4	2, 5.5
14	2	2, 2	2	2, 2
15	6	3.5, 6	5	3.5, 6
16	5	4.25, 6	5	2.75, 6
17	5	4.25, 5.25	5	5, 6
18	3	2, 6	5	2, 6
19	3	2, 5	4	2, 5
20	6	3.5, 6	5	3.5, 6
21	4	2, 6	5	3.5, 6
22	5	4, 6	5	3.5, 6
23	6	3, 6	6	5, 6
24	5	5, 6	5	5, 6
25	4	4, 5	5	4, 6
26	2	2, 3	2	2, 3
27	4.5	2, 5.25	4	2, 5.5
28	5	4, 6	5	3.5, 6
29	2	2, 5	5	2, 5
30	3	2, 5	2.5	2, 5
31	5	4, 5	5	3.5, 5.5
32	4	4, 5	5	4, 5.5
33	5	5, 6	5	5, 5
34	5	2, 5	3.5	3, 5.75

Abbreviations: *Q1, lowest quartile (25th percentile); Q3, highest quartile (75th percentile)*

Table 3.7 *Comparison of median values and interquartile ranges of response scores in researcher-completed (assistance) and self-completed (no assistance) questionnaires.*

Question	No assistance		Assistance	
	Median	**Q1, Q3**	**Median**	**Q1, Q3**
1	3	3, 3	5.5	2.75, 6
2	3	2, -	2	2, 2
3	2.5	2, -	2	2, 2.5
4	2	2, 2	2	2, 4
5	2	2, 2	2	2, 2
6	3	2, -	2	2, 3
7	3	2, -	2	2, 4
8	4	3, -	2	2, 3.5
9	4	2, -	3.5	2, 4
10	2	2, -	2	2, 4.5
11	4	2, -	3	2, 4
12	6	6, 6	5	3.5, 6
13	6	6, 6	2	2, 4.5
14	2	2, 2	2	2, 2
15	5.5	5, -	5	3, 6
16	6	6, 6	5	2.75, 6
17	6	6, 6	5	5, 6
18	4	2, -	5	2, 6
19	2	2, -	4	2, 5
20	4.5	3, -	5.5	4.25, 6
21	6	6, 6	5	2.25, 5.75
22	6	4, -	5	4, 6
23	6	5, -	6	4, 6
24	6	5, -	5	5, 6
25	5	4, -	5	4, 6
26	2	2, 2	2	2, 2.75
27	4	2, -	4	2, 5
28	4	2, -	5	4, 6
29	2	2, 2	5	2, 5
30	2	2, -	3	2, 5
31	3	2, -	5	4.5, 5.5
32	3	2, -	5	4, 5
33	5	2, -	5	5, 5.5
34	3	2, -	4.5	3, 5

Abbreviations: *Q1, lowest quartile (25th percentile); Q3, highest quartile (75th percentile)*

3.2.3 Spearman´s rank correlation test

Patient experiences:

Table 3.8 presents the questions that demonstrated positive correlation with patient satisfaction on information received from health care professionals in Spearman's rank correlation test.

Table 3.8 *Results from Spearman´s rank correlation test showing positive correlation between patient satisfaction (question 12) and knowledge assessment (question 7), medication education (question 8), discharge counseling (question 9, 10, 11) and smoking cessation (question 13).*

Q	Questionnaire – Patient experiences
7	Someone checked that I use my medications for COPD in the right way
8	I have had the chance to discuss how the medicines I use for COPD can prevent my symptoms from getting worse
9	I discussed what I can do myself to prevent COPD-symptoms with a health care professional
10	I discussed what I should do if my COPD-symptoms get worse with a health care professional
11	I discussed how my medications work to prevent COPD-symptoms with a health care professional
12	**I am satisfied with the information about COPD I have received from health care professionals**
13	I have been offered help to quit smoking

Figure 3.10 show positive correlation between question 12 (y-axis) and question 7 (x-axis), indicating that the most satisfied patients were offered services where their medication use were checked up on.

7: "Someone checked that I use my medications for COPD in the right way."

P = 0.003

Figure 3.10 *Scatter plot showing positive correlation between patient experience and knowledge assessment (question 7) from the Spearman´s rank correlation test.*

Figure 3.11 show positive correlation between question 12 (y-axis) and question 8 (x-axis), indicating that the most satisfied patients had been offered services where the patients had the chance to discuss how their medicines prevents symptoms of COPD.

8: "I have had the chance to discuss how the medicines I use for COPD can prevent my symptoms from getting worse."

P = 0.005

Figure 3.11 *Scatter plot showing positive correlation between patient experience and medication education (question 8) from the Spearman´s rank correlation test.*

Figure 3.12 demonstrates the positive correlation between question 12 (y-axis) and question 9 (x-axis), indicating that the most satisfied patients had discussed what they could do themselves to prevent exacerbation of COPD-symptoms with a health care professional.

9: "I discussed what I can do myself to prevent COPD-symptoms with a doctor, a nurse or a pharmacist."
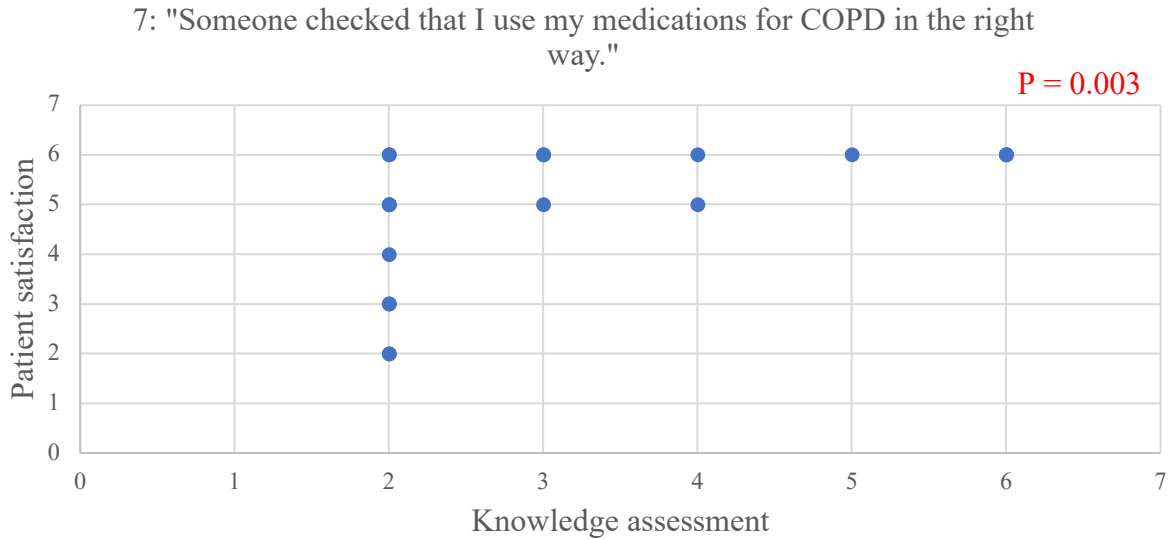
P = 0.015

Figure 3.12 *Scatter plot showing positive correlation between patient experience and discharge counseling (question 9) from the Spearman´s rank correlation test.*

Figure 3.13 demonstrates the positive correlation between question 12 (y-axis) and question 10 (x-axis), indicating that the most satisfied patients had been offered advice on self-management or decision-making in the event of an exacerbation from a health care professional.

10: "I discussed what I should do if my COPD-symptoms get worse with a doctor, a nurse or a pharmacist."
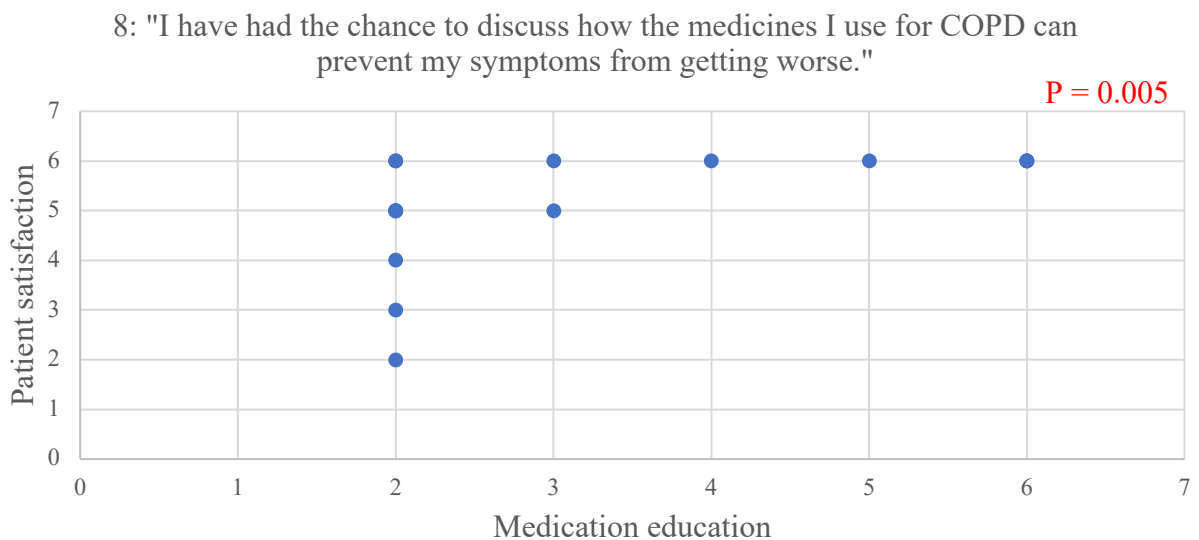
P = 0.004

Figure 3.13 *Scatter plot showing positive correlation between patient experience and discharge counseling (question 10) from the Spearman´s rank correlation test.*

Figure 3.14 demonstrates the positive correlation between question 12 (y-axis) and question 11 (x-axis), indicating that the most satisfied patients had discussed their medicines and how they work with a health care professional.

11: "I discussed how my medications work to prevent COPD-symptoms with a doctor, a nurse or a pharmacist."
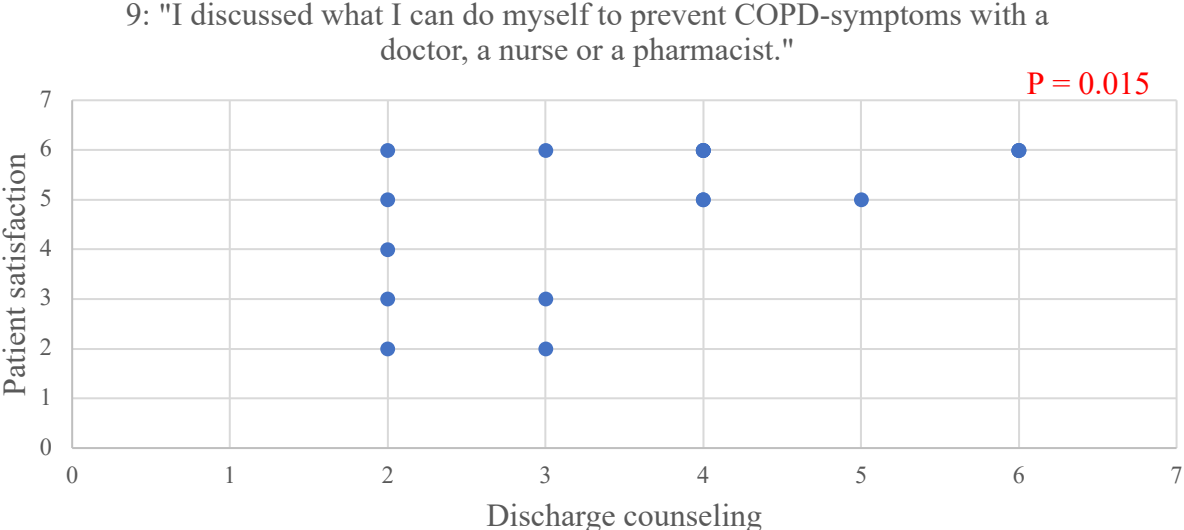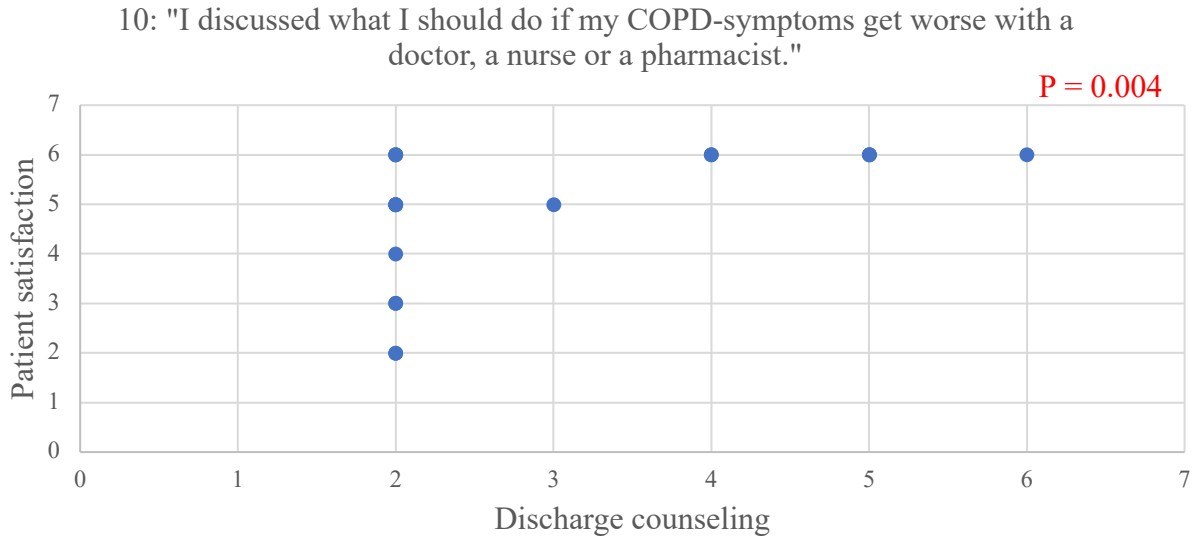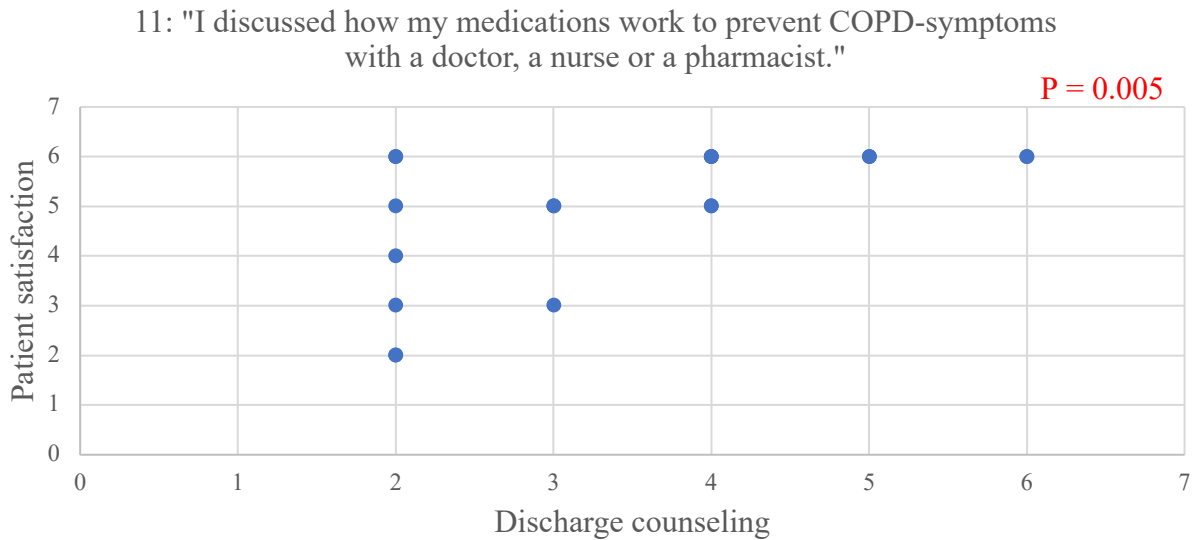
P = 0.005

Figure 3.14 *Scatter plot showing positive correlation between patient experience and discharge counseling (question 11) from the Spearman´s rank correlation test.*

Figure 3.15 demonstrates the positive correlation between question 12 (y-axis) and question 13 (x-axis), indicating that the most satisfied patients were offered support on smoking cessation.

Figure 3.15 *Scatter plot showing positive correlation between patient experience and smoking cessation (question 13) from the Spearman´s rank correlation test.*

Patient preferences:

Table 3.9 presents the questions that demonstrated positive correlation with patient preferences on receiving more information from health care professionals in Spearman's rank correlation test.

Table 3.9 *Results from Spearman´s rank correlation test showing positive correlation between patient preferences (question 25) and discharge counseling (question 21, 22 and 24).*

Q	Questionnaire – Patient preferences
21	I would like to discuss what I can do myself to prevent COPD-symptoms
22	I would like to discuss how to recognize symptoms related to COPD getting worse
24	I would like to discuss how my medications work to prevent COPD-symptoms
25	**I would like to receive more information about COPD from health care professionals**

Figure 3.16 demonstrates the positive correlation between question 12 (y-axis) and question 21 (x-axis), indicating that the patients were interested in discussions on self-management in prevention of symptoms.

21: "I would like to discuss what I can do myself to prevent COPD-symptoms."

P = 0.002

Figure 3.16 *Scatter plot showing positive correlation between patient preference and discharge counseling (question 21) from the Spearman´s rank correlation test.*

Figure 3.17 demonstrates the positive correlation between question 12 (y-axis) and question 22 (x-axis), indicating that the patients were interested in discussions on how to recognize symptoms of an exacerbation.

22: "I would like to discuss how to recognize symptoms related to COPD getting worse."
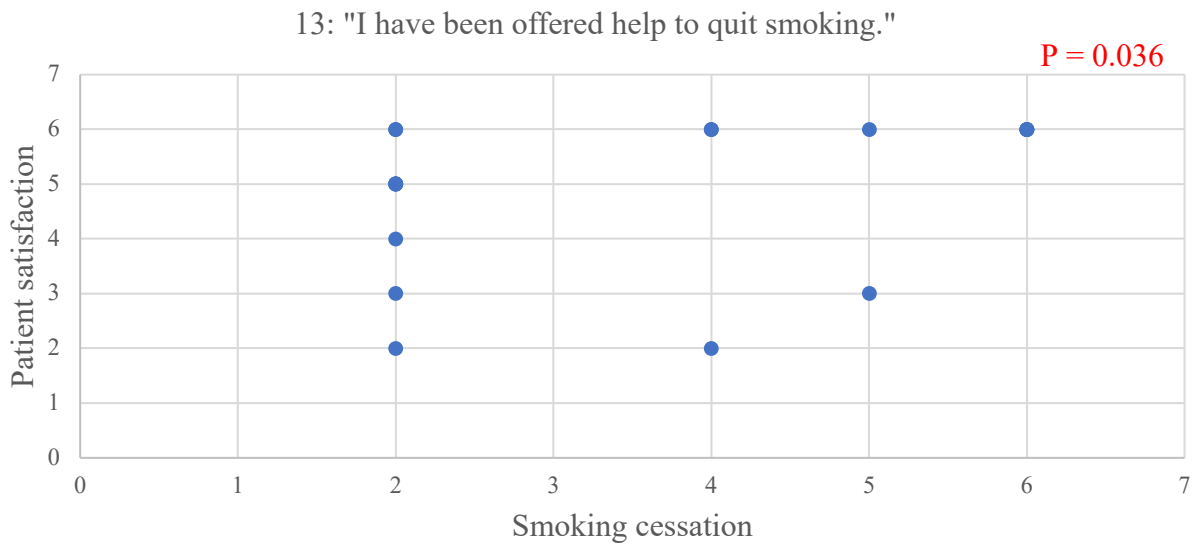
P = 0.034

Figure 3.17 *Scatter plot showing positive correlation between patient preference and discharge counseling (question 22) from the Spearman's rank correlation test.*

Figure 3.18 demonstrates the positive correlation between question 12 (y-axis) and question 24 (x-axis), indicating that the patients were interested in discussions on how their medicines work to prevent symptoms of COPD.

24: "I would like to discuss how my medications work to prevent COPD symptoms."
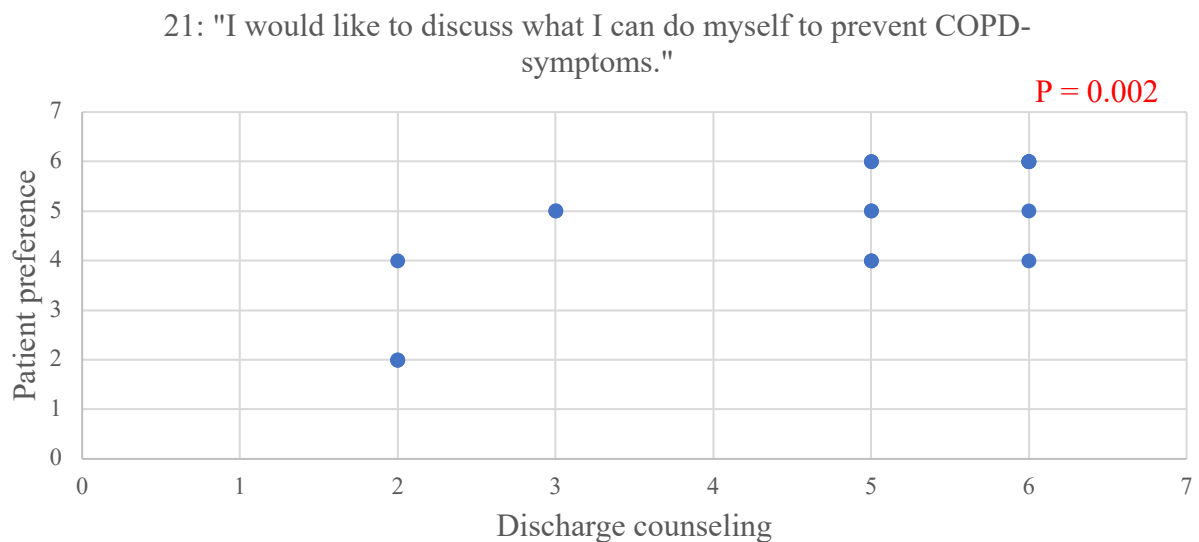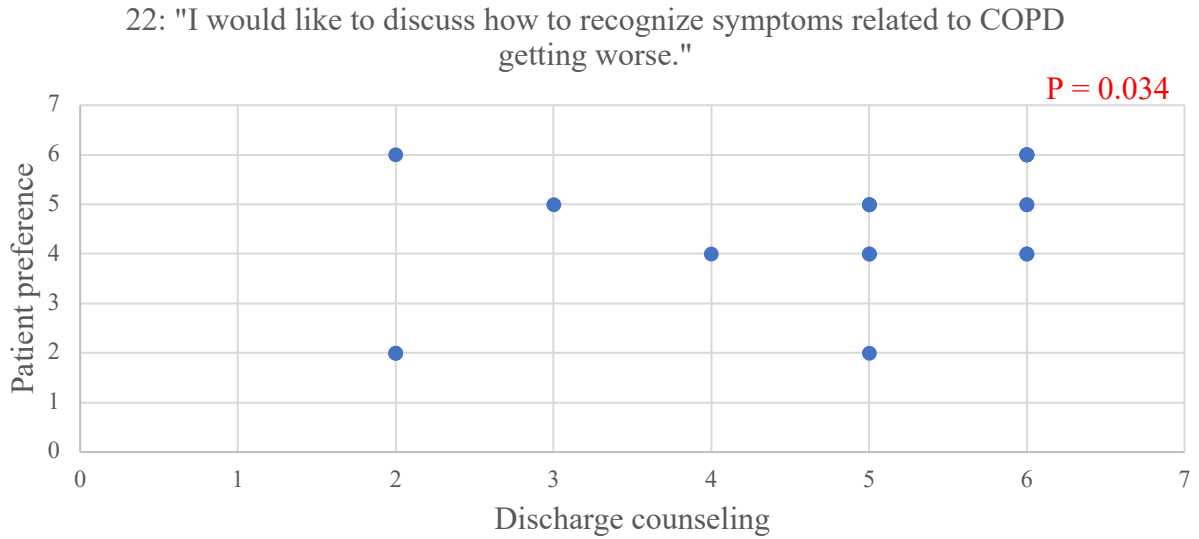
P < 0.001
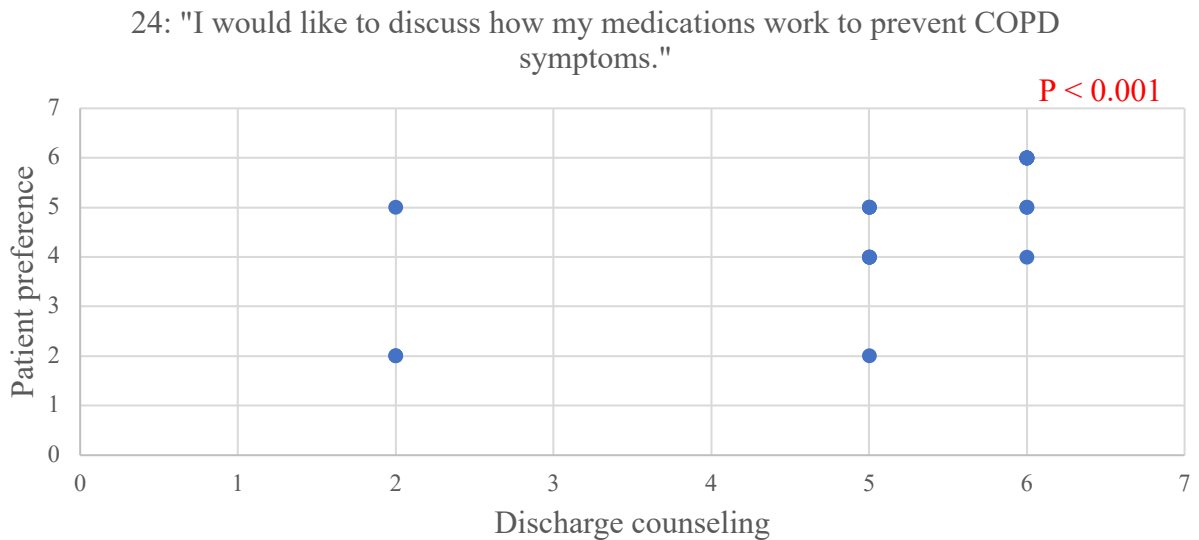
Figure 3.18 *Scatter plot showing positive correlation between patient preference and discharge counseling (question 24) from the Spearman's rank correlation test.*

3.2.4   Participant feedback on questionnaire

Figure 3.19 presents the results in terms of response distribution for question 30 to 34 concerning patient feedback on the questionnaire, included for evaluation purposes.
It can be seen from question 31 and 32 that most of the patients agreed that the questions were easy to understand and to answer. Most patients quite agreed that the number of questions was appropriate (question 33), however, approximately half strongly or quite agreed that there were too many questions in the questionnaire.
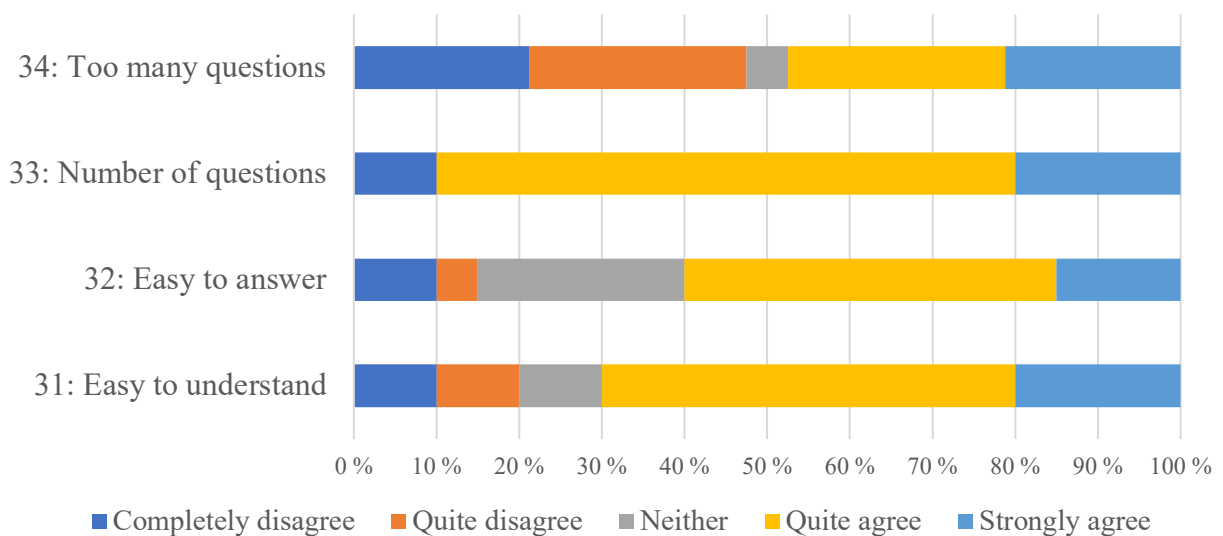
Figure 3.19 *Patient feedback on the questionnaire. The participants impression of the questions and the length of the questionnaire were evaluated.*

Mann-Whitney U tests comparing the group with researcher-completed questions (assistance group) and the group with self-completed questions (no assistance group) did not give significant results in frequency distribution of ranked responses between the two groups (i.e., $P > 0.05$ when comparing the differences between the responses).

Appendix 7 informs all p-values from the Mann-Whitney U tests and includes results from cross table analysis of grouping variable gender ($P > 0.05$).

4 Discussion

4.1 Main findings

The results show that many of the intervention services, identified in literature to prevent readmission rates for people with COPD, are not experienced by patients from this hospital. Discussions about medicines, what to do if symptoms exacerbate or support on smoking cessation are frequently not provided.

The results show variations in whether the patients discussed what they can do themselves to prevent symptoms of COPD or not.
Interestingly, however, over half of patients were satisfied with the information they were given.

The survey indicates a high level of interest in receiving the services investigated. Medication optimization, check-up on COPD status within a week of discharge, check of medication use, and discussions on how to recognize symptoms of exacerbations and how medicines contribute to symptom relief seems to be the most preferred COPD management interventions.

The hospital was the most preferred location for receiving intervention services, but approximately half of the participants seemed to be open to receive intervention services in community pharmacies. Communication with health care professionals at home via telephone or digital meetings seems to be of lower preference.

Grouped analysis did not reveal considerable differences between gender or age groups, apart from indications that males may have lower preferences for being approached by health care professionals compared to the female group.

The most satisfied patients had received services where someone checked that they were using the medicines in the right way, and interventions where medicines, what to do to prevent symptoms, and what to do when symptoms exacerbate were discussed. Being offered support on smoking cessation also seems to be related to patient satisfaction.

Interest in more information about COPD correlated with information on what the patients can do themselves to prevent symptoms, how to recognize symptoms of exacerbations and how medicines work to relief symptoms.

4.2   Strengths and limitations

This survey is limited by a small study group and a short period available for data collection. Data on patient experiences may be biased by unknown information on admission rates for each participant.

Even though data collected by self-reporting may be considered unreliable, the direct patient involvement strengthens the reliability of the results, i.e., that the patient will rank the question in the same way if asked to repeat the survey. The small study group limits the validity of the results, i.e., how well the results represent the true situation for all COPD patients.

Another limitation of this study is related the organization of admissions at the hospital. Apparently, bed spaces and health care personnel were handed over from the Respiratory ward to the short-term wards UMO1 and UMO2 (*Utgreiingsmottak*) when these units were established in 2016. These units are part of the admission clinic (*Mottaksklinikken*) and accepts patients with unclear or complex conditions from all specialist areas at the hospital. The highly probable circumstance that COPD patients fulfilling the inclusion criteria for the survey never entered the Pulmonary department must be recognized.

4.3   Main findings related to possible future services for patients with COPD

Whilst many patients report receiving some interventions known to reduce hospitalization, many don't. With satisfaction related to service delivery, approaches to address these differences are required.

An article based on discussions in a virtual meeting between experts in COPD from Norway, Sweden and Denmark were published in 2021, addressing the gap between guidelines and clinical practice for management and treatment of COPD. The results from this study align with the results from this discussion, which concludes that there is need for improvement

concerning early detection of the disease, treatment strategies and disease monitoring. The call for primary care practitioners to become more aware of the immense impact of COPD on patients and to consider COPD as a chronic condition in the same way as other chronic diseases such as e.g., diabetes or heart disease are particularly highlighted (54).

Interpretation of the findings in this survey may imply a possibility that COPD patients experience a low level of support concerning disease self-management, and consequently suffer from insufficient disease control and cases of exacerbations that could have been avoided. This culminates in an unnecessary increase in workload for the staff in hospitals and acute health care, and a considerable contribution to cost overruns in health care budgets.

If this scenario corresponds to the current situation, clinical consequences for the patients may be lowered health status and increase in progression of the disease. This in turn is associated with more frequent and severe exacerbations, before reaching advanced progression states where palliative care is the remaining health care options. As health status decline, acute exacerbations that require hospitalization are also contributors to fatality rates as they are severe conditions with poor prognosis and increased risk of respiratory failure and death (1, p. 31).

The fact that the goals established by the Norwegian Directorate of Health concerning reduction in admission rates and mortality caused by chronic respiratory diseases have not been achieved may be partly explained by these results, as many of the services we know can impact these outcomes are not being routinely delivered.

With reference to Schrijver et al and the 2022 systematic review, turning to implementation of self-management interventions may also seem like a reasonable approach from a local perspective, considering the results and low scores regarding experiences on COPD service provision from this survey (17).

Whilst smoking is the main cause of COPD, many patients report not being offered smoking cessation support. This is a relatively simple intervention which can be delivered by any member of the ward team, or outside of the hospital e.g., at the general practitioner or even in community pharmacies.

Applicable for every relevant intervention, agreeing who is going to offer the service will ensure that every patient is offered it, and a record of their response to the initial offer could be included in their medical journal.

However, considering smoking cessation it should be noted that some patients in this study informed that they never had been smoking or already had quit smoking (some before being diagnosed with COPD), hence there were no need to be offered support.

When considering the main findings in this survey on patient preferences, checking the patient's medication use and routines, discussions on how to recognize symptoms of exacerbations and provision of customized pharmacodynamic information could be achieved using personalized action plans. These topics are all related to the potential of action plans in enhancing self-management and preventing hospital admissions.
Implementation of action plans in primary care would be possible if recourses in terms of trained health care professionals (preferably in interdisciplinary teams) and financial arrangements are granted.

There are ongoing discussions concerning the need for reorganization of health care services to meet the challenges associated with a wave of elderly patients and the shift towards patient centered health services.
Norwegians are also currently affected by what is referred to as "The general practitioner crisis" (*Fastlegekrisen*), as scarcity of general practitioners hits out on the health care services available for hundreds of thousands of citizens finding themselves without an assigned general practitioner (*fastlege*). This has greatest impact on the chronically ill patients with need for regular follow-ups, as they are forced to use emergency rooms or private clinics for usual healthcare.
On the other hand, all patients or their caregivers will visit their pharmacy post-discharge, and this provides an opportunity to deliver a number of service elements related to personalized action plans.

In Norway, the regional health trusts (*Regionale helseforetak, HF*) and public hospitals are owned by the government, but the primary and outpatient health services are the responsibility of the municipalities. Most Norwegian pharmacies today are owned by private business corporations abroad. This challenges the cooperation and flow of information between secondary care, primary care, and retail pharmacies, but collaboration between community pharmacies and other health care institutions is not unsurmountable.

In 2020, Oslo Economics executed a survey concerning collaboration between the medical service in the municipalities and pharmacists on behalf of the Norwegian Directorate of Health. The work of the National Health Service (NHS) in England concerning increased use of pharmacists in interdisciplinary teams were described, and the need for physical meeting points, and both digital and financial solutions supporting collaboration were highlighted. In the UK, financial arrangements have made employment of pharmacists in medical practices possible, where pharmacists relieve the workload of the general practitioners offering medicine related services. The driving force for these arrangements were a shortage in general practitioners, not unlike the current situation in Norwegian primary care (55, 56).

Employment of pharmacists in medical practices could enable check-up on COPD status within a week of discharge using e.g., standardized forms developed in collaboration with the general practitioners.

Comprehensive medication review and medication optimization services could also be implemented in a primary medical practice setting, where these pharmacist-led interventions could be offered more regularly as medical records are easily accessible. Hence pharmacists and general practitioners with licensed right of prescription can collaborate to optimize primary healthcare e.g., during transfer from secondary care.

Offering education elements and development of customized action plans would also be possible through such a collaboration, where the general practitioner would possess the overall responsibility for the services and opportunity to document interventions directly into health records.

A municipal or medical practice-based pharmacist could also serve as the conduit for communication between the general practitioner and the patient's preferred pharmacy. Medical practitioners have expressed a more positive attitude towards collaboration with municipal pharmacists (*kommunefarmasøyter*) due to concerns regarding the commercial role of the community pharmacists (*apotekfarmasøyter*) (56).

Many patients collect their regular medicines at local pharmacies, where it would be possible to file a copy of the patient's action plan, together with e.g., collecting habits from in-advance prescriptions to keep track of potential overuse of antibiotics and steroids, or misunderstandings on decision-making and implementation of the plan. Hence, the

community pharmacies could serve as an arena where COPD patients could turn to for information and support considering action plans and related medicines.

To deliver quality health care services in community pharmacies beyond dispensing of medicines, staffing in the pharmacies must be considered, as the current trend appear to be many but smaller pharmacies with fewer pharmacists available for extended service provision.

For improved integration of community pharmacies and pharmacists in primary health care, more research on relation between clinical outcomes and pharmacist-led interventions are needed to achieve a better understanding about how to utilize pharmacists in primary care with the patients' best interests in mind.

Statistical analysis – Gender:
Grouped statistical analysis demonstrated significant differences in answers between males and females in one question concerning previous experiences and two questions concerning intervention preferences. Even though not significant with respect to p-values, the figures from cross table analysis in appendix 7 show a tendency for the male group to give the questions lower and more negative scores (e.g., never, or completely disagree) compared to the female group.

Statistics Norway, the national statistical institute and main producer of official statistics, have previously reported differences in health and health care utilization between males and females, where e.g., females was reported to attend more medical consultations per year compared to males (57).
The lower preference to health-care utilization has been proposed to arise as a result of masculinity beliefs which stops them from seeking out to preventive health care (58).

With respect to intervention services, a consequence of behavioral differences as such may be that men are more likely to be under-diagnosed with COPD and hence not in position to benefit from early intervention services, which is unfortunate with respect to disease progression.

Statistical analysis – Age group:

One significant difference between the age groups was found in this survey related to experiences concerning medication reconciliation during hospital admissions, as this seems to have happened more frequent for the youngest participant group.

There is a possibility that this is related to the number of previous admissions and higher admission rates to the emergency ward for the younger patients, before being transferred to the Pulmonary department.

In contrast to the Pulmonary department in Haukeland University Hospital, the Admission clinic (*Mottaksklinikken*) has clinical pharmacists among its employees, ready to provide admitted patients with medical reconciliation services (59, 60).

Patients with known diagnosis of COPD and a history of respiratory-related admissions may be more likely to be transferred directly to the Pulmonary department, where no pharmacists are found among the permanent staff and other routines are implemented.

Differences in health-related quality of life (HRQL) across age-groups have been suggested to arise from a higher impact of dyspnea among younger patients. A cross-sectional study using similar age groups proposed explanations for less impact of dyspnea in older patients to be a result of tolerance and adaption to the disease with aging and change in expectations, giving a more optimistic view on living life with a diagnosis of COPD (61).

From these findings, one might expect the younger age group with a higher perceived impact of dyspnea to possess a more positive attitude towards being approached for intervention services compared to the older group, but trends as such were not observed in the results of this survey.

Statistical analysis – Assistance:

Assistance or no assistance was assessed merely for evaluation purposes.

The significant result on whether the patients had been offered help to quit smoking or not between the group that were assisted and the group that were not assisted may be biased by the small number of participants that self-completed the questionnaire.

However, a higher rate of "unsure" responses was observed for the self-completed questionnaires compared to the questionnaires that were researcher completed, indicating that the researcher's presence affected the understanding of the questions and eased the task of ranking the questions.

5 Conclusion

Interpretation of the results concerning patient experiences may indicate that service provision for COPD patients post-discharge could be improved and potentially realize significant patient benefit in line with the Norwegian government agenda.

Enhanced service provision may be offered through extended interdisciplinary collaboration between community pharmacists, municipal pharmacists, and general practitioners, as demonstrated by the National Health Service (NHS) in England.

Customized action plans have the potential to include preferred services and reduce exacerbation- and hospital admission rates but requires structured and well-organized implementation procedures.

Further research to confirm validity of the findings, identification of functional service elements and location for new services is needed.

6 Further research

To assure that health service providers meet the needs of the patients, patient involvement is necessary in development of new services, or in reorganization of existing services with the aim of improvement for the intended users. All services should be standardized and validated before implementation to ensure high quality and reproducibility, at local as well as national levels.

To address the limitations of this survey, it would be of interest to execute a similar survey of longer duration and possibility of recruitment of a higher number of participants. Executing the survey in more than one health trust or on a national level would enable comparison of service provision in terms of patient experience and preference in different municipalities. Before implementation of the survey, the questionnaire and procedure should be standardized and validated to assure a uniform method for data collection.

Extended privacy considerations and access to medical records would give possibility to compare patient preferences with GOLD progression level, or number of years since being

diagnosed with COPD, as one might expect preferences to vary as patients adapts to living with the disease.

Registration of number of readmissions for patients who attended the survey e.g., over a period of 12 months would enable us to investigate if patient preferences vary with number of hospital admissions per year.

Research on specific intervention elements using e.g., feasibility studies in development of intervention and research methodology, and possible locations for the new services is in the next stages of pronounced importance considering successful service provision.

Cost-utility analysis would put the anticipated effects from service provision in relation to numerical values and be highly useful for politicians and policymakers in charge of financial priorities in the health care system.

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Appendices

Appendix 1: Initial project description

Appendix 2: REK evaluation document (Norwegian)

Appendix 3: Form for ethical consent (Norwegian)

Appendix 4: Questionnaire (Norwegian)

Appendix 5: Questionnaire (English)

Appendix 6: Coding SPSS

Appendix 7: Mann-Whitney U p-values and cross-tables

Introduction for study:

Improving pharmaceutical care for COPD patients at discharge

Team: Svein Haavik, David J. Wright, Torbjørn Nygård, Helen Eldholm

Problems: Frequent readmission, economic burden

Interventions: Wide range of different elements, small scale studies, randomized controlled trials with few demonstrating significant differences (see table 1, articles by Wright and Fera; medicines reconciliation, knowledge/use of medicines assessment, counselling, follow-up call). Few, if any designed with patient input.
International guidance on developing complex interventions of this nature recommend a thorough review of the literature, and patient involvement within the design.

Knowledge gap: What does existing service consist of? What would the patients like to receive?

Research questions: What kind of services would COPD patients like to receive / do they currently receive, which would improve quality of care and experience? What can we learn from patient experiences of being readmitted soon after discharge to design future service?

Objectives:
- To describe current medicine related practices related to discharge practices
- To identify patient preferences for service provision with respect to content and location
- Innovative ideas for enhancing service delivery for COPD patients
- Identify any differences in patient preferences (right service for the right patient)

Method:

REK – Presentation assessment (framleggingsvurdering)

Phase 1: Patient survey

Design questionnaire to meet the above objectives
Content will include:
- Experience of COPD service elements within Bergen as identified in the literature (see table 1)
- Patient stated preference for each element
- Patient characteristics
  - CAT-score or GOLD level?
  - Types of medications prescribed
  - Smoking status?
  - Hospitals in which they have been admitted / number of times for admission
- Patient ideas for service enhancement
- Capture of significant events which may have contributed to previous readmissions
- Willingness to be approached by a researcher for consent to further qualitative interview

Inclusion criteria:

Diagnosis of COPD.

Provides verbal consent to complete survey (confirmation of consent in survey?).

Exclusion of patients without capacity?

Patients will be asked to respond to each question with respect to experience and preference using Likert scale.

Method of data collection will be either face-to-face, electronic, or postal (?).

The Cochrane review on how to optimize response rates to surveys will be used to inform survey design and implementation.

The number of surveys we intend to distribute:
Will depend on the number of new patients admitted to the ward each week over 3 months period.

Sample size of 50 will provide 95% confidence intervals with a width of between 16-28%
Sample size of 100 will provide 95% confidence intervals with a width of between 10-20%
Sample size of 200 will provide 95% confidence intervals with a width of between 8-14%

Data analysis will be largely descriptive.

Comparison between different characteristics and responses to Likert scales will be undertaken using Chi-Squared or Mann-Whitney U analysis.

Data governance

Survey will be anonymous, but each patient will be given a unique identifier.

Separate to this on a hospital computer a document will keep a list of unique identifiers and patient identifiers. This will allow second researcher to be able to identify those patients who consent to be approached to be identified (?).

Data will be destroyed 12 months post-completion of the study.

Dissemination

The results will be published in a research paper and a Masters Dissertation.

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK vest	Fredrik Kolstad Rongved	55589715	25.05.2022	374436

Svein Haavik

Fremleggingsvurdering: Oppfølging av KOLS-pasienter ved overføring mellom omsorgsnivåer i helsesystemet
Søknadsnummer: 374436
Forskningsansvarlig institusjon: Universitetet i Bergen

Prosjektet vurderes som ikke fremleggingspliktig

Søkers beskrivelse

Formålet for prosjektet er å undersøke hva slags tilbud som eksisterer for oppfølging av pasienter med KOLS, og hvordan farmasøyter i apotek kan bidra til å øke kvaliteten på helsetjenester som tilbys KOLS-pasienter etter utskrivning fra sykehus. I studien blir pasienter med diagnosen KOLS spurt om å besvare et spørreskjema i forbindelse med utskrivning fra Haukeland Universitetssykehus. Prosjektdeltagere blir identifisert av samarbeidende personale ved sykehuset.

Vi viser til fremleggingsvurdering mottatt den 12.05.2022. Henvendelsen er behandlet i samråd med komiteleder Nina Langeland.

REKs vurdering
Om søknadsplikten:
Bare medisinsk og helsefaglig forskning på mennesker, humant biologisk materiale, eller helseopplysninger må søke REK om forhåndsgodkjenning, jf. helseforskningsloven § 2. "Medisinsk og helsefaglig forskning" er definert i loven som "en virksomhet som utføres med vitenskapelig metodikk for å skaffe til veie ny kunnskap om helse og sykdom", jf. § 4 bokstav a.

Om prosjektet:
Formålet for prosjektet er å undersøke hva slags tilbud som eksisterer for oppfølging av pasienter med KOLS, og hvordan farmasøyter i apotek kan bidra til å øke kvaliteten på helsetjenester som tilbys KOLS-pasienter etter utskrivning fra sykehus. I studien blir pasienter med diagnosen KOLS spurt om å besvare et spørreskjema i forbindelse med utskrivning fra Haukeland Universitetssykehus.

Vurdering:
Denne forskningen handler om helsetjenesten og hvilket tilbud som KOLS-pasienter får.

REK vest
Besøksadresse: Armauer Hansens Hus, nordre fløy, 2. etasje,
Haukelandsveien 28, Bergen

| **E-post**: rek-vest@uib.no
Web: https://rekportalen.no

Det er ikke noen utfallsmål på helsen til deltakerne. Vi vurderer at dette prosjektet faller utenfor REKs virkeområde fordi prosjektet ikke søker å skaffe til veie ny kunnskap om helse og sykdom.

Konklusjon
Konklusjonen er at du ikke trenger å søke REK om forhåndsgodkjenning.

Vi gjør oppmerksom på at konklusjonen er å anse som veiledning, jf. forvaltningsloven § 11. Komiteen er ikke bundet av de råd som er gitt i dette brev. Du har fortsatt anledning til å søke REK og da vil du få et vedtak i saken.

Med vennlig hilsen
Fredrik Rongved
rådgiver

Kopi til:
Universitetet i Bergen
Helen Eldholm

VIL DU DELTA I FORSKNINGSPROSJEKTET OPPFØLGING AV KOLS-PASIENTER VED OVERFØRING MELLOM OMSORGSNIVÅER I HELSESYSTEMET?

FORMÅLET MED PROSJEKTET OG HVORFOR DU BLIR SPURT

Dette er et spørsmål til deg om å delta i et forskningsprosjekt for å undersøke hvordan man kan forbedre farmasøytisk omsorg for pasienter med diagnosen KOLS etter utskrivelse fra et sykehusopphold.

Du blir spurt om å delta fordi du har diagnosen KOLS og er innlagt på lungeavdelingen ved Haukeland Universitetssykehus i forbindelse med denne diagnosen. Aktuelle kandidater for forskningsprosjektet blir identifisert av leger og/eller sykepleiere ved lungeavdelingen.

Formålet for prosjektet er å undersøke hva slags tilbud som eksisterer for oppfølging av pasienter med KOLS, og hvordan farmasøyter i apotek kan bidra til å øke kvaliteten på helsetjenester som tilbys KOLS-pasienter etter utskrivelse fra sykehus.

HVA INNEBÆRER PROSJEKTET FOR DEG?

Ved oppstart av dette prosjektet ønsker vi å bruke et spørreskjema for å samle informasjon.

Vi vil stille spørsmål om hva slags type oppfølging du som KOLS-pasient tidligere har fått tilbud om, og om det er noen tjenester for KOLS-pasienter du kunne tenke deg å bli tilbudt. Spørsmålene besvares ved å krysse av for «Alltid / Ofte / Noen ganger / Sjelden / Aldri / Vet ikke», eller tilsvarende.

I prosjektet vil vi innhente og registrere opplysninger om deg fra spørreskjemaet. Opplysningene vil bli anonymisert.

MULIGE FORDELER OG ULEMPER

Vi ønsker å kartlegge KOLS-pasienters egne erfaringer med helsefaglig oppfølging.

Mulige fordeler ved prosjektet vil være å avdekke tiltak som kan forbedre kvaliteten på farmasøytiske helsetjenester som tilbys pasienter med KOLS.

Mulige ulemper ved deltagelse i prosjektet kan være tidsbruk knyttet til besvaring av spørsmål i spørreskjemaet som sendes ut.

Det forventes ingen helsemessig risiko forbundet med deltagelse i prosjektet.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE DITT SAMTYKKE

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Det vil ikke ha noen negative konsekvenser for deg eller din behandling hvis du ikke vil delta eller senere velger å trekke deg. Dersom du trekker tilbake samtykket, vil det ikke forskes videre på dine opplysninger.

Du kan kreve innsyn i opplysningene som er lagret om deg, og disse vil da utleveres innen 30 dager. Du kan også kreve at dine opplysninger i prosjektet slettes.
Adgangen til å kreve sletting eller utlevering gjelder ikke dersom opplysningene er anonymisert eller publisert. Denne adgangen kan også begrenses dersom opplysningene er inngått i utførte analyser.

Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte prosjektleder (se kontaktinformasjon på siste side).

HVA SKJER MED OPPLYSNINGENE OM DEG?

Opplysningene som registreres om deg skal kun brukes slik som beskrevet under formålet med prosjektet, og planlegges brukt frem til år 2026. Eventuelle utvidelser i bruk og oppbevaringstid kan kun skje etter godkjenning fra REK og andre relevante myndigheter. Du har rett til innsyn i hvilke opplysninger som er registrert om deg og rett til å få korrigert eventuelle feil i de opplysningene som er registrert. Du har også rett til å få innsyn i sikkerhetstiltakene ved behandling av opplysningene. Du kan klage på behandlingen av dine opplysninger til Datatilsynet og institusjonen sitt personvernombud.

Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger (=kodede opplysninger). En kode knytter deg til dine opplysninger gjennom en navneliste. Det er kun Svein Haavik (prosjektleder) og Helen Eldholm (farmasistudent) som har tilgang til denne listen.

Publisering av resultater er en nødvendig del av forskningsprosessen. All publisering skal gjøres slik at enkeltdeltakere ikke skal kunne gjenkjennes, men vi plikter å informere deg om at vi ikke kan utelukke at det kan skje.

Etter at forskningsprosjektet er ferdig, vil opplysningene om deg bli oppbevart i 12 måneder av kontrollhensyn.

OPPFØLGINGSPROSJEKT

Deltagere kan basert på svarene i spørreskjemaet bli utvalgt til å delta i et oppfølgingsprosjekt.

Aktuelle kandidater vil kontaktes for et tilbud om å delta i et intervju med en prosjektdeltager / farmasøyt.

Dersom du kunne tenke deg å delta i et oppfølgingsprosjekt for pasienter med KOLS kan du hake av for å bekrefte dette (se siste side).

GODKJENNINGER

Regional komité for medisinsk og helsefaglig forskningsetikk har gjort en forskningsetisk vurdering og godkjent prosjektet (prosjektets søknads-id: 374436).

Universitetet i Bergen og prosjektleder Svein Haavik er ansvarlig for personvernet i prosjektet.

KONTAKTOPPLYSNINGER

Dersom du har spørsmål til prosjektet eller ønsker å trekke deg fra deltakelse, kan du kontakte Svein Haavik per telefon 55974615 eller e-post: Svein.Haavik@uib.no, eller Helen Eldholm per e-post:
Helen.Eldholm@student.uib.no

Dersom du har spørsmål om personvernet i prosjektet, kan du kontakte personvernombudet ved institusjonen: Janecke.Veim@uib.no.

☐ Jeg kan kontaktes for deltagelse i et oppfølgingsprosjekt

Kontaktinformasjon: _____

Sted og dato   Deltakers signatur

                                                Deltakers navn med trykte bokstaver

Stedfortredende samtykke

Som nærmeste pårørende til _ (Fullt navn) samtykker jeg til at hun/han kan delta i prosjektet.

Sted og dato   Pårørendes signatur

                                                Pårørendes navn med trykte bokstaver

Appendix 4: Questionnaire (Norwegian)

Kjære deltager,

Takk for at du ønsker å være en del av prosjektet " Oppfølging av KOLS-pasienter ved overføring mellom omsorgsnivåer i helsesystemet".

Før jeg ble skrevet ut, hadde noen kontrollert at medisinene jeg fikk på sykehuset var nøyaktig de samme som jeg brukte før innleggelsen

Alltid Ofte Noen ganger Sjelden Aldri Vet ikke

❏ ❏ ❏ ❏ ❏ ❏

Dersom ja, omtrent hvor mange ganger i løpet av de to siste årene sjekket noen medisinene som beskrevet over?

_____

Noen spurte meg om medisinene mine og om jeg ønsket å endre noe da jeg ble innlagt

Alltid Ofte Noen ganger Sjelden Aldri Vet ikke

❏ ❏ ❏ ❏ ❏ ❏

Dersom noe ble endret med medisinene, hva slags endringer ble gjort?

_____

Noen sjekket hvor godt min KOLS var under kontroll innen en uke etter utskrivning

Alltid Ofte Noen ganger Sjelden Aldri Vet ikke

❏ ❏ ❏ ❏ ❏ ❏

Jeg fikk oppfølging for KOLS på en lungepoliklinikk innen en uke etter utskrivning

Alltid Ofte Noen ganger Sjelden Aldri Vet ikke

❏ ❏ ❏ ❏ ❏ ❏

Jeg fikk oppfølging for KOLS i et apotek innen en uke etter utskrivning

Alltid Ofte Noen ganger Sjelden Aldri Vet ikke

❏ ❏ ❏ ❏ ❏ ❏

Noen har spurt meg om jeg forstår hvordan medisinene mine bidrar til å forhindre at KOLS blir verre

Alltid Ofte Noen ganger Sjelden Aldri Vet ikke

❏ ❏ ❏ ❏ ❏ ❏

Noen har kontrollert at jeg bruker medisinene mine mot KOLS på riktig måte

Alltid Ofte Noen ganger Sjelden Aldri Vet ikke

❏ ❏ ❏ ❏ ❏ ❏

Jeg har fått gjennomgått hvordan medisinene jeg bruker mot KOLS kan forhindre at symptomene mine blir verre

Alltid Ofte Noen ganger Sjelden Aldri Vet ikke

❏ ❏ ❏ ❏ ❏ ❏

Jeg har fått gjennomgått hva jeg selv kan gjøre for å forebygge KOLS-symptomer med en lege, en sykepleier eller en farmasøyt

Alltid Ofte Noen ganger Sjelden Aldri Vet ikke

❏ ❏ ❏ ❏ ❏ ❏

Jeg har fått gjennomgått hva jeg burde gjøre hvis KOLS-symptomene mine blir verre med en lege, en sykepleier eller en farmasøyt

Alltid Ofte Noen ganger Sjelden Aldri Vet ikke

❏ ❏ ❏ ❏ ❏ ❏

Jeg har fått gjennomgått hvordan medisinene mine virker for å forebygge KOLS-symptomer med en lege, en sykepleier eller en farmasøyt

Alltid Ofte Noen ganger Sjelden Aldri Vet ikke

❏ ❏ ❏ ❏ ❏ ❏

Jeg er fornøyd med informasjonen om KOLS jeg har fått fra helsepersonell

Alltid Ofte Noen ganger Sjelden Aldri Vet ikke

❏ ❏ ❏ ❏ ❏ ❏

Jeg har fått tilbud om hjelp til å slutte å røyke

Alltid Ofte Noen ganger Sjelden Aldri Vet ikke

❏ ❏ ❏ ❏ ❏ ❏

Hvis du har fått tilbud om hjelp til å slutte å røyke, hvor fikk du tilbudet?
_____

Jeg har fått tilbud om oppfølgingssamtale med helsepersonell over telefon for å sjekke hvordan det går med medisinbruken min

Alltid Ofte Noen ganger Sjelden Aldri Vet ikke
❏ ❏ ❏ ❏ ❏ ❏

Jeg vil at noen skal kontrollere at medisinene jeg kommer til å få på sykehuset er nøyaktig de samme som jeg brukte før innleggelsen

Sterkt enig Ganske enig Verken enig eller uenig Ganske uenig Helt uenig Vet ikke
❏ ❏ ❏ ❏ ❏ ❏

Jeg vil at noen skal gå igjennom medisinene jeg bruker for å sjekke at disse er de beste for meg og at de virker slik det er meningen at de skal

Sterkt enig Ganske enig Verken enig eller uenig Ganske uenig Helt uenig Vet ikke
❏ ❏ ❏ ❏ ❏ ❏

Jeg vil at noen skal sjekke hvor godt min KOLS er under kontroll innen en uke etter utskrivning

Sterkt enig Ganske enig Verken enig eller uenig Ganske uenig Helt uenig Vet ikke
❏ ❏ ❏ ❏ ❏ ❏

Jeg ønsker å få tilbud om oppfølging av KOLS ved en lungepoliklinikk innen en uke etter utskrivning

Sterkt enig Ganske enig Verken enig eller uenig Ganske uenig Helt uenig Vet ikke
❏ ❏ ❏ ❏ ❏ ❏

Jeg ønsker å få tilbud om oppfølging av KOLS på et apotek innen en uke etter utskrivning

Sterkt enig Ganske enig Verken enig eller uenig Ganske uenig Helt uenig Vet ikke
❏ ❏ ❏ ❏ ❏ ❏

Jeg vil at noen skal kontrollere at jeg bruker medisinene mine mot KOLS på riktig måte

Sterkt enig Ganske enig Verken enig eller uenig Ganske uenig Helt uenig Vet ikke
❏ ❏ ❏ ❏ ❏ ❏

Jeg vil diskutere hva jeg selv kan gjøre for å forebygge KOLS-symptomer

Sterkt enig Ganske enig Verken enig eller uenig Ganske uenig Helt uenig Vet ikke
❏ ❏ ❏ ❏ ❏ ❏

Jeg vil diskutere hvordan man kan gjenkjenne symptomer knyttet til forverring av KOLS

Sterkt enig Ganske enig Verken enig eller uenig Ganske uenig Helt uenig Vet ikke
❏ ❏ ❏ ❏ ❏ ❏

Jeg vil diskutere hva jeg bør gjøre hvis KOLS-symptomene mine blir verre

Sterkt enig Ganske enig Verken enig eller uenig Ganske uenig Helt uenig Vet ikke
❏ ❏ ❏ ❏ ❏ ❏

Jeg vil diskutere hvordan medisinene mine virker for å forebygge KOLS-symptomer

Sterkt enig Ganske enig Verken enig eller uenig Ganske uenig Helt uenig Vet ikke
❏ ❏ ❏ ❏ ❏ ❏

Jeg vil motta mer informasjon om KOLS fra helsepersonell

Sterkt enig Ganske enig Verken enig eller uenig Ganske uenig Helt uenig Vet ikke
❏ ❏ ❏ ❏ ❏ ❏

Jeg ønsker tilbud om hjelp til å slutte å røyke

Sterkt enig Ganske enig Verken enig eller uenig Ganske uenig Helt uenig Vet ikke
❏ ❏ ❏ ❏ ❏ ❏

Hvis du ønsker tilbud om hjelp til å slutte å røyke, hvor foretrekker du å få tilbudet?

På sykehuset Etter utskrivning I et apotek Ikke aktuelt
❏ ❏ ❏ ❏

Jeg kunne tenke meg å få tilbud om oppfølgingssamtale med helsepersonell over telefon for å sjekke hvordan det går med medisinbruken min

Sterkt enig Ganske enig Verken enig eller uenig Ganske uenig Helt uenig Vet ikke
❏ ❏ ❏ ❏ ❏ ❏

Jeg vil ha samtaler om KOLS på sykehuset

Sterkt enig Ganske enig Verken enig eller uenig Ganske uenig Helt uenig Vet ikke
❏ ❏ ❏ ❏ ❏ ❏

Jeg vil ha samtaler om KOLS i et apotek

Sterkt enig Ganske enig Verken enig eller uenig Ganske uenig Helt uenig Vet ikke

❏   ❏   ❏   ❏   ❏   ❏

Jeg vil ha samtaler om KOLS hjemme (over telefon eller i et digitalt møte via Teams, Zoom eller lignende)

Sterkt enig Ganske enig Verken enig eller uenig Ganske uenig Helt uenig Vet ikke

❏   ❏   ❏   ❏   ❏   ❏

Jeg synes spørsmålene i spørreskjemaet var enkle å forstå

Sterkt enig Ganske enig Verken enig eller uenig Ganske uenig Helt uenig Vet ikke

❏   ❏   ❏   ❏   ❏   ❏

Jeg synes spørsmålene i spørreskjemaet var enkle å svare på

Sterkt enig Ganske enig Verken enig eller uenig Ganske uenig Helt uenig Vet ikke

❏   ❏   ❏   ❏   ❏   ❏

Jeg synes antall spørsmål i spørreskjemaet var passende

Sterkt enig Ganske enig Verken enig eller uenig Ganske uenig Helt uenig Vet ikke

❏   ❏   ❏   ❏   ❏   ❏

Jeg synes det er for mange spørsmål i dette spørreskjemaet

Sterkt enig Ganske enig Verken enig eller uenig Ganske uenig Helt uenig Vet ikke

❏   ❏   ❏   ❏   ❏   ❏

Survey questionnaire

English version

Before I was discharged, someone checked that the medicines I was given in hospital were exactly the same as those that I was taking before I came in

Always Often Sometimes Rarely Never Unsure

❏ ❏ ❏ ❏ ❏ ❏

If yes, approximately how many times within the last two years did someone check the medicines as described above?

_____

Someone asked about my medicines and whether I wanted to change anything when I was admitted

Always Often Sometimes Rarely Never Unsure

❏ ❏ ❏ ❏ ❏ ❏

If something was changed with the medication, what kind of changes were made?

_____

Someone checked how well my COPD was under control within a week of discharge

Always Often Sometimes Rarely Never Unsure

❏ ❏ ❏ ❏ ❏ ❏

I received follow-up for COPD at a lung outpatient clinic within a week of discharge

Always Often Sometimes Rarely Never Unsure

❏ ❏ ❏ ❏ ❏ ❏

I received follow-up for COPD in a community pharmacy within a week of discharge

Always Often Sometimes Rarely Never Unsure

❏ ❏ ❏ ❏ ❏ ❏

Someone checked that I understand how my medications help to prevent COPD from getting worse

Always Often Sometimes Rarely Never Unsure

❏ ❏ ❏ ❏ ❏ ❏

Someone checked that I use my medications for COPD in the right way
Always Often Sometimes Rarely Never Unsure
❏ ❏ ❏ ❏ ❏ ❏

I have had the chance to discuss how the medicines I use for COPD can prevent my symptoms from getting worse
Always Often Sometimes Rarely Never Unsure
❏ ❏ ❏ ❏ ❏ ❏

I discussed what I can do myself to prevent COPD-symptoms with a doctor, a nurse or a pharmacist
Always Often Sometimes Rarely Never Unsure
❏ ❏ ❏ ❏ ❏ ❏

I discussed what I should do if my COPD-symptoms get worse with a doctor, a nurse or a pharmacist
Always Often Sometimes Rarely Never Unsure
❏ ❏ ❏ ❏ ❏ ❏

I discussed how my medications work to prevent COPD-symptoms with a doctor, a nurse or a pharmacist
Always Often Sometimes Rarely Never Unsure
❏ ❏ ❏ ❏ ❏ ❏

I am satisfied with the information about COPD I have received from health care professionals
Always Often Sometimes Rarely Never Unsure
❏ ❏ ❏ ❏ ❏ ❏

I have been offered help to quit smoking
Always Often Sometimes Rarely Never Unsure
❏ ❏ ❏ ❏ ❏ ❏

If you have been offered help to quit smoking, where did you get the offer?
_____

I was offered a follow-up interview with a health care professional over the phone to check how I am getting on with my medicines
Always Often Sometimes Rarely Never Unsure
❏ ❏ ❏ ❏ ❏ ❏

I would like someone to check that the medicines I am going to get in the hospital are exactly the same as those that I was taking before I came in
Strongly agree Quite agree Neither agree nor disagree Quite disagree Strongly disagree Unsure
❏ ❏ ❏ ❏ ❏ ❏

I would like someone to check that my medicines are the best ones for me and that they work the way they are supposed to

Strongly agree   Quite agree   Neither agree nor disagree   Quite disagree   Strongly disagree   Unsure
❏ ❏ ❏ ❏ ❏ ❏

I would like someone to check how well my COPD are under control within a week of discharge

Strongly agree   Quite agree   Neither agree nor disagree   Quite disagree   Strongly disagree   Unsure
❏ ❏ ❏ ❏ ❏ ❏

I would like to be offered follow-up for COPD at a lung outpatient clinic within a week of discharge

Strongly agree   Quite agree   Neither agree nor disagree   Quite disagree   Strongly disagree   Unsure
❏ ❏ ❏ ❏ ❏ ❏

I would like to be offered follow-up for COPD in a community pharmacy within a week of discharge

Strongly agree   Quite agree   Neither agree nor disagree   Quite disagree   Strongly disagree   Unsure
❏ ❏ ❏ ❏ ❏ ❏

I would like someone to check that I use my medications for COPD in the right way

Strongly agree   Quite agree   Neither agree nor disagree   Quite disagree   Strongly disagree   Unsure
❏ ❏ ❏ ❏ ❏ ❏

I would like to discuss what I can do myself to prevent COPD-symptoms

Strongly agree   Quite agree   Neither agree nor disagree   Quite disagree   Strongly disagree   Unsure
❏ ❏ ❏ ❏ ❏ ❏

I would like to discuss how to recognize symptoms related to COPD getting worse

Strongly agree   Quite agree   Neither agree nor disagree   Quite disagree   Strongly disagree   Unsure
❏ ❏ ❏ ❏ ❏ ❏

I would like to discuss what I should do if my COPD-symptoms get worse

Strongly agree   Quite agree   Neither agree nor disagree   Quite disagree   Strongly disagree   Unsure
❏ ❏ ❏ ❏ ❏ ❏

I would like to discuss how my medications work to prevent COPD-symptoms

Strongly agree   Quite agree   Neither agree nor disagree   Quite disagree   Strongly disagree   Unsure
❏ ❏ ❏ ❏ ❏ ❏

I would like to receive more information about COPD from health care professionals

Strongly agree   Quite agree   Neither agree nor disagree   Quite disagree   Strongly disagree   Unsure
❏ ❏ ❏ ❏ ❏ ❏

I would like to be offered help to quit smoking

Strongly agree Quite agree Neither agree nor disagree Quite disagree Strongly disagree Unsure

❏　　❏　　❏　　❏　　❏　　❏

If yes, where would you prefer to receive the offer?

In the hospital Post-discharge In a pharmacy Not applicable

❏　　❏　　❏　　❏

I would like to be offered a follow-up interview with a health care professional over the phone to check how I am getting on with my medicines

Strongly agree Quite agree Neither agree nor disagree Quite disagree Strongly disagree Unsure

❏　　❏　　❏　　❏　　❏　　❏

I would like to have a conversation about COPD in the hospital

Strongly agree Quite agree Neither agree nor disagree Quite disagree Strongly disagree Unsure

❏　　❏　　❏　　❏　　❏　　❏

I would like to have a conversation about COPD in a community pharmacy

Strongly agree Quite agree Neither agree nor disagree Quite disagree Strongly disagree Unsure

❏　　❏　　❏　　❏　　❏　　❏

I would like to have a conversation about COPD at home (over the telephone or in a digital meeting via Teams, Zoom or similar)

Strongly agree Quite agree Neither agree nor disagree Quite disagree Strongly disagree Unsure

❏　　❏　　❏　　❏　　❏　　❏

I found the questions in the questionnaire easy to understand

Strongly agree Quite agree Neither agree nor disagree Quite disagree Strongly disagree Unsure

❏　　❏　　❏　　❏　　❏　　❏

I found the questions in the questionnaire easy to answer

Strongly agree Quite agree Neither agree nor disagree Quite disagree Strongly disagree Unsure

❏　　❏　　❏　　❏　　❏　　❏

I think the number of questions in the questionnaire were appropriate

Strongly agree Quite agree Neither agree nor disagree Quite disagree Strongly disagree Unsure

❏　　❏　　❏　　❏　　❏　　❏

I think there are too many questions in this questionnaire

Strongly agree Quite agree Neither agree nor disagree Quite disagree Strongly disagree Unsure

❏　　❏　　❏　　❏　　❏　　❏

Appendix 6: Coding SPSS

Coding of questionnaire responses in SPSS:

Likert-scale responses		SPSS code
Unsure	Unsure	1
Never	Completely disagree	2
Rarely	Quite disagree	3
Sometimes	Neither agree nor disagree	4
Often	Quite agree	5
Always	Strongly agree	6
Blank	Blank	9

Appendix 7: Mann-Whitney U p-values and cross tables

Question	Gender	Age	Assistance
Q1	0.210	0.043	0.460
Q2	0.663	0.619	0.385
Q3	0.012	0.202	0.602
Q4	0.072	0.743	0.525
Q5	0.264	0.480	0.724
Q6	0.142	0.740	0.490
Q7	0.175	0.433	0.450
Q8	0.137	0.913	0.074
Q9	0.467	0.296	0.643
Q10	0.238	0.545	0.803
Q11	0.421	0.562	0.473
Q12	0.860	0.399	0.156
Q13	0.560	0.932	0.010
Q14	0.414	0.173	0.674
Q15	0.186	0.556	0.650
Q16	0.309	0.960	0.098
Q17	0.095	0.413	0.223
Q18	0.199	0.447	1.000
Q19	0.012	0.934	0.120
Q20	0.329	0.545	0.880
Q21	0.508	0.557	0.078
Q22	0.077	0.966	0.535
Q23	0.483	0.787	0.630
Q24	0.900	0.931	0.357
Q25	0.841	0.285	0.701
Q26	0.300	0.787	0.583
Q27	0.035	0.927	0.836
Q28	0.828	0.927	0.675
Q29	0.054	0.667	0.058
Q30	0.131	0.927	0.508
Q31	1.000	0.865	0.088
Q32	0.220	0.208	0.116
Q33	0.338	0.768	0.149
Q34	0.794	0.896	0.730

Question 18 P = 0.199

Question 20 P = 0.329

Question 21 P = 0.508

Question 22 P = 0.077

Question 23 P = 0.483

Question 24 P = 0.900

Question 25 P = 0.841

Question 26 P = 0.300

Question 28   P = 0.828

Question 29   P = 0.054

Question 30   P = 0.131

Question 31   P = 1.000

Question 32   P = 0.220

Question 33   P = 0.338

Question 34   P = 0.794

91