Patient perspectives on the causes and prevention of rehospitalisation for exacerbations of chronic obstructive pulmonary disease: A qualitative study

Anna Hobman

A thesis submitted for the degree of
Masters in Health Science endorsed in Rehabilitation
at the University of Otago
New Zealand

Date: 30/06/2020

Abstract

Background: Chronic obstructive pulmonary disease (COPD) is the umbrella term for a group of lung diseases which are degenerative and marked by progressively worsening symptoms including: breathlessness; fatigue; acute exacerbation; multiple comorbidities; and eventually death.
Acute exacerbations of COPD (AECOPD) resulting in hospitalisation may be responsible for up to 25 percent of reductions in lung function. In New Zealand an estimated 23% of those discharged from hospital after an initial episode of AECOPD are readmitted within 30 days, a situation which is both costly and disadvantageous to the patient.

Objective: The aim of this study was to understand patients' perspectives on the causes and prevention of re-hospitalisation for AECOPD.

Method: Data for this study was collected from a subgroup of participants who had been recruited as part of a feasibility study using randomised controlled trial methods to explore the effectiveness of a novel self-management intervention, called "Taking Charge of COPD". All participants were initially recruited in hospital after an episode of severe AECOPD. The subgroup of participants in this qualitative study were interviewed 12 months later and ask about their views and experiences regarding what had helped or hindered them to stay well and out of hospital. Grounded theory was used to analyse results and construct concept. Data were also collected on disease specific health status (using the Chronic COPD Questionnaire), depression and anxiety (using the Hospital Depression and Anxiety Scale), and number of moderate episodes (requiring antibiotics or steroids) or severe episodes of AECOPD (requiring hospitalisation) during the prior 12 months.

Results: Twelve participants were interviewed (mean age 69.3 years (SD 13.6); range 29 – 84; 6 female, 2 Māori, 2 Pacific, 7 New Zealand European). These participants had experienced between 0 and 7 episodes of moderate AECOPD (average 1.8) and 0 to 3 episodes of severe AECOPD (average 0.7) in the 12 months since their original hospitalisation. Three main concepts were identified to describe the participants' views on what helped or hinder them to stay well and out of hospital: 1) *Being Proactive* – which encompasses practical steps participants took to reduce AECOPD; 2) *Being Positive* – which describes the importance of a positive mindset; and *3) Taking Charge* – the concept of believing in oneself. Impacting on each of these was the influence of significant others, particularly family and friends.

Conclusion: This research expands our understanding of how patients manage COPD and adds a patient’s perspective to the current knowledge on how to prevent AECOPD. Programmes which promote self-efficacy and positive mental health would be beneficial additions to AECOPD prevention, as could the inclusion of family or significant others in health planning/treatment plans.

Acknowledgements

The amazing individuals who gave me their time and shared their stories.

Professor William Levack PhD, MHealSc (Rehabilitation) BPhty, Dean of the University of Otago Wellington, who inspired me to start a Master's and to finish it. Thank you for your patience, your inspiration, your fun, and your down-to-earthness despite being so damn intelligent!

Bernadette Jones DPH RN – RGON Research Fellow, Otago University – Thank you for your making sure I put in that extra 10 percent when I had run out of energy.

Ingrid Hindmarsh – who gave me the tools to stay sane, and constantly reminded me that what I'm doing matters.

Moon – who kept me going with my "100 reasons why you're my favourite person" jar.

Sophia Hobman – who was there for every tear and every celebration.

Re-Connect/Stroke Special OP's – who were excited and waited patiently while I finished.

David McCrone – My editor, who kept me on my toes! You are wonderful.

I hope this study makes a difference. I know it will to the people I work with.

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AECOPD – Acute Exacerbation of Chronic Obstructive Pulmonary Disease

CI – Confidence Interval

COPD – Chronic Obstructive Pulmonary Disease

FEV$_1$ – Forced Expiratory Volume in One Second

MD – Mean Difference

The TCOPD study – Taking charge of COPD study

OR – Odds Ratio

RR – Relative Risk

SD – Standard Deviation

Chapter 1: Introduction

Chronic obstructive pulmonary disease (COPD) is the umbrella term for a group of degenerative lung diseases characterised by inflammation, airflow obstruction and lung hyperinflation. COPD is the fourth leading cause of death globally and affects 15% of New Zealand adults (Broad & Jackson, 2003). Approximately 35,300 New Zealanders live with severe COPD requiring hospitalisation (Telfar & Zhang, 2016). COPD cannot be cured, and exacerbations of the condition come and go throughout a person's life with the disease. Acute exacerbations of COPD (AECOPD) are significant points in the disease progression and mark a decline in lung function and quality of life. This is markedly worse when exacerbation leads to hospitalisation. There is considerable interest in developing strategies to reduce hospitalisation rates for AECOPD because of the high public cost and health burden associated with these events. Most of the research on preventing hospitalisation for AECOPD has focused on quantitative data identified as important by researchers and clinical experts working in this field. This thesis focuses on the views and experiences of people who have experienced hospitalisation for AECOPD to identify, from their perspective, what might help or hinder their ability to stay healthy and out of hospital. This perspective may help health professionals understand the gaps between public health messaging and how COPD patients manage their disease.

1.1 Background

Chronic obstructive pulmonary disease (COPD) is a disease caused by a complex interaction between long-term exposures to toxic or noxious gases and particles – such as those found in tobacco, biomass fuels and occupational air pollution – and genetic predisposition, hyper-responsive airways, and poor lung development in childhood (Global Initiative for Chronic Obstructive Lung Disease, 2019). COPD often begins in middle to later years and is characterised by progressively worsening symptoms of lung deterioration: breathlessness; fatigue; malnutrition; systemic inflammation; comorbidities; acute exacerbation; and eventually death (Farver-Vestergaard, Jacobsen, & Zachariae, 2015; Genao et al., 2015).

Severity of COPD is measured in part by declines in forced expiratory volume in one second (FEV_1). Higher exacerbation rates of COPD are associated with increased annual decline in FEV_1, increased airway inflammation, increased hospital admissions, and poorer health outcomes (Mantero et al., 2017). Reportedly 12-32% of patients relapse during the weeks immediately following hospitalisation and as many as 15% of patients die within the three months post-hospitalisation period (Mantero et al., 2017). Bacterial and viral respiratory tract infections make up the majority of AECOPD triggers, and humidity and air pollutants can contribute, but up to 30% of causes are unknown (Ko et al., 2016). Factors influencing a person's susceptibility to AECOPD, their likelihood of hospitalisation and their chances of recovery include age, sex, both global and respiratory muscle weakness, severity of disease, comorbidities, adherence to medication therapies, socioeconomic status, health-related quality of life and anxiety and depression scores (Mantero et al., 2017).

In New Zealand there are 12,000 hospital admissions per year due to AECOPD, costing $60 million annually – 70% of total COPD related health costs (Mantero et al., 2017; Milne & Beasley, 2015). Māori and Pasifika hospitalisation rates are significantly higher than for non-Māori and non-Pasifika (3.7 and 2.8 times higher respectively), with similar mortality rates are (2.2 and 1.9 times higher for Māori and Pasifika respectively) (Telfar & Zhang, 2016)

In 2018-2019, a study of a brief self-management intervention for people recently hospitalised for AECOPD was undertaken. This study, called the "*Being in control* of COPD" (TCOPD) study, was a 56-participant clinical feasibility study (HRC 17/521; Trial Registration no.: ACTRN12617000952347p). The TCOPD study used randomised controlled trial methods, to test the effectiveness of a brief, low-cost self-management intervention for people after an index admission for AECOPD. The intervention focused on a self-help workbook which was used to guide participants to think differently about their health condition, to reconsider their involvement in managing it, and to encourage them to proactively take control of their physical, mental, or emotional health. The intervention was delivered in a two-hour session by a research staff member, and the workbook was left with the participant. The primary outcome measure for this feasibility study was AECOPD rates over the following 12 months.

The study described in this thesis ran after the completion of the 12-month follow-up data collection phase of the TCOPD study and involved exploring the views and experiences of participants in this study regarding the causes of, and strategies to prevent, AECOPD. This included an exploration of the experience of the participants who had received the TCOPD intervention, but also explored their broader experiences of events and factors that influenced their ability to manage their health and stay out of hospital. Both participants in the intervention group and the control (usual care) group in the feasibility in the TCOPD study were invited to participate in this follow-up qualitative study.

1.2 Research aims

The question I set out to answer in this study was: *What do people with moderate to severe COPD believe contributes to repeat hospitalisations for AECOPD, and what do they believe keeps them out of hospital?*

This research explored the lifestyle and experiences of patients after an admission to hospital for an AECOPD. I aimed to describe the factors they believe contributed to rehospitalisation versus non-hospitalisation.

A secondary objective of this study was to explore, if possible, the experiences of participants who had been involved in the TCOPD study. Throughout the interviews, however, there was very little evidence that the TCOPD study had any impact on the participants who were recruited into this study. Evidence for this is that most who received the TCOPD intervention (5 of 12 ppts) could not remember being in the study and those who could remember (n=7) could not give information on the impact it had on them. As a result of the very low emphasis that the participants placed on the intervention it did not feature as a point of discussion for participants and is not explored in this research.

1.3 Definition of key terms

COPD is defined as a "progressive disease that affects the airways and/or alveoli, causing restriction to airflow." (Alison et al., 2017). COPD is characterised by severe shortness of breath, skeletal muscle dysfunction and significant morbidity and mortality. AECOPD is an acute exacerbation of COPD, which is characterised by a worsening of the symptoms of COPD, beyond normal day-to-day variations (Martineau et al., 2019). AECOPD usually includes excessive coughing, sputum, extreme shortness of breath, and can be accompanied by extreme anxiety. Episodes of AECOPD can be classified "moderate" or "severe". Moderate AECOPD episodes are those requiring treatment with oral corticosteroids or antibiotics, and severe AECOPD episodes as those requiring admission to hospital (Seemungal, Hurst, & Wedzicha, 2009)

1.4 My presence as a researcher

Before progressing with a study, it is It is essential for qualitative researchers to identify and reflect on their worldview and personal position regarding a research topic, as what a these bring to a study can have a direct influence on what data is collected and how it is interpreted (Charmaz, 2006; Mills, Bonner, & Francis, 2006). I have chosen this area of research because I have worked extensively with COPD patients in exercise rehabilitation settings in the past and have seen this lead to exceptional improvements in people's physical health and quality of life. This prompted my interest in working more with people who have COPD. I became involved as a research assistant collecting outcome data as part of the TCOPD study in 2018-2019. In this role I had the opportunity to listen to some often emotional and candid descriptions of participants' experiences of their life with COPD. I am an empathetic person and become emotionally involved in conversation with participants and have a strong desire to help them further.

My undergraduate degree and all my associated research have been based on quantitative sports science research, so undertaking a qualitative thesis has been a sharp learning curve for me. On the one hand this meant that I entered into this Master's research project with a solid understanding of scientific validity, which could be transferred to qualitative methods, but on the other hand I did not have a deep understanding of qualitative processes. I have been conscious throughout this thesis that I may be missing important aspects of the research process, but weekly conversations with my supervisor have filled in any gaps in my understanding. I feel sufficiently assured that I have completed this study to the best of my ability.

On a personal note, both my parents suffered COPD and my mother died of lung cancer. I am asthmatic and smoked for a number of years. I am now a free diver with excellent lung capacity and breath control, and use breathing techniques and breath holding a lot in my personal and professional life. It is an area of great interest to me. I am saddened by people's unavoidable loss of lung function once COPD develops, but more so, by the avoidable loss of physical function and quality of life which result from poor health literacy and hopelessness. Conversely, throughout my work on the TCOPD study I have been excited and inspired by some people's positive attitudes and full enjoyment of life despite their health condition. I wanted to explore and understand these experiences more, so I was excited to take up the opportunity to begin a Master's thesis on this topic when the opportunity arose.

1.5 Structure of thesis

In Chapter 2 (Background) I provide a detailed description of the prevalence and the financial and clinical relevance of AECOPD and its aetiology. This is followed with a narrative literature review of the studies that have aimed to identify causes of and reduce rehospitalisation rates for people with COPD. Chapter 3 (Methodology and Methods) explains the rationale behind my use of grounded theory as the qualitative methodology for this research, explains the leaning towards the Charmaz perspective of grounded theory and describes methods for this research. Chapter 4 (Results) presents the findings of this study, providing information on the main concepts and their relation to one another. Each concept that I identified is explored in detail, with examples of data from the interviews. Chapter 5 discusses the findings, how they fit with past research, and what they mean in an applied situation. This final chapter also addresses limitations of the study and provides suggestions for future research.

Chapter 2: Background

2.1 Introduction

This chapter provides an understanding of the medical and financial implications of COPD, an explanation of exacerbations of its symptoms and the impact that such exacerbations have, both financially and on disease progression. A narrative literature review outlines the latest research on interventions aimed at preventing rehospitalisation for exacerbations of COPD. The chapter then concludes with an explanation of the theoretical basis for the feasibility study from which the current study was developed.

2.2 Disease burden of COPD

It is estimated that COPD is responsible for approximately five percent of all deaths globally (Global Initiative for Chronic Obstructive Lung Disease, 2020). The World Health Organisation expects this figure to increase by 30% over the next 30 years, largely due to the aging population but also continued exposure to risk factors (Yang et al., 2017). In New Zealand, COPD is the fourth leading cause of death and was responsible for six percent of all deaths in 2009 (Milne & Beasley, 2015). Between 2007 and 2017 there was an increase of 7.1 % in premature deaths due to COPD, and an increase of 11.2 % in all deaths due to COPD (The Institute for Health Metrics and Evaluation, 2019).

The estimated prevalence of COPD in New Zealand is 200,000, with 14% of adults 40 years and older classified as having COPD (Alison, McKeough, et al., 2017; Barnard & Zhang, 2018). There are substantial ethnic, gender and age trends in COPD mortality and morbidity rates, with Māori males being the most susceptible. In 2017 there were 5,579 new cases of COPD reported, with the highest incidence of new cases in Māori (295.4 new cases per 100,000) and Pasifika (165.5 per 100,000), followed by non-Māori (100.8 per 100,000) and Asian (36.0 per 100,000)(Barnard & Zhang, 2018).

Māori show symptoms of COPD at a younger age compared with non-Māori (average onset for Māori being 62.5 years) and have the highest mortality rate of all ethnicities (107 per 100,000 per year) (Barnard & Zhang, 2018). The average age of onset for Pasifika people is 63.2 years, with a mortality rate of approximately 78.6 per 100,000 per year. Asian people have the second oldest average age onset (68.8 years) but the lowest mortality rate (30.7 per 100,000 per year), and non-Māori, non-Pasifika, and non-Asian people have the oldest onset (72.4 years) but the second highest mortality rate (81.9 per 100,000 per year). There is a slightly higher prevalence of COPD deaths in males (250 per 100,000 per year) compared with females (201 deaths per 100,000 per year) (Barnard & Zhang, 2018).

In 2009, COPD was estimated to cost New Zealand between $NZ103 million and $NZ192 million annually (Ministry of Health, 2013). One third of this cost was attributed to general practitioner consultations, community pharmaceuticals, and disability care, while two thirds comprised the cost of hospitalisation for AECOPD. New Zealand has one of the highest hospital admission rates for COPD among the countries contributing to the Organisation for Economic Co-operation and Development, with approximately 12,300 admissions per year. In the 2012/13 financial year, COPD admissions cost $NZ59.9 million (a mean cost of $NZ4,799 per admission) (Milne & Beasley, 2015).

Inequities around hospital admissions for COPD in New Zealand follow similar patterns as COPD disease rates, with Māori and Pacific peoples having the highest admission rates (4.4 and 3.6 times higher than non-Māori, non-Pacific New Zealanders respectively). Milne & Beasley's (2015) five-year data showed a higher rate of admission for males than females. However, a study of 2017 data by Barnard & Zhang (2018) shows very similar figures for both sexes (males: 1,469 per 100,000; females 1,435 per 100,000). According to these data, men aged 45-64 years had higher hospitalisation rates compared with women in the same age group (rate ratio 1.2), but there was a lower hospitalisation rate (rate ratio 0.93) for men compared with women in the 65+ age group. Both studies showed a high deprivation gradient, with COPD rates 5.11 times higher in the most deprived quintile compared to the least deprived quintile (Barnard & Zhang, 2018) . Studies have also shown that people living with COPD outside of urban areas have higher rates of hospitalisation than those living in cities (Brooke et al., 2017). Not only does hospitalisation for acute exacerbation of COPD (AECOPD) place a substantial financial burden on New Zealand health services, but it plays an important part in the progression of COPD. Higher exacerbation rates are an independent risk factor for treatment failure and are associated with: increased airway inflammation; increased annual decline in physiological lung function; further hospital admissions; poorer health outcomes; and increased mortality (Mantero et al., 2017). In the UK, approximately 11% of COPD patients admitted for AECOPD will die as a result of this exacerbation and this increases to 37% for those readmitted within 90 days (Mantero et al., 2017). Manatero et al. (2017) reported as many as 15% of patients die within the three months' post-hospitalisation period.

2.3 Exacerbations of COPD

Exacerbations of COPD occur when a person's symptoms worsen; the amount of phlegm increases and colour changes signify infection, breathing becomes increasingly difficult, fatigue sets in and anxiety often results. Respiratory tract infections, caused by virus and or bacteria, are responsible for more than 50% of AECOPD. It is estimated that exacerbations themselves may be responsible for up to 25% of the reduction in FEV_1 (Lange, 2009). Chronic mucus hypersecretion, which increases with escalating disease severity, may predispose patients to infection, creating a vicious cycle whereby one infection damages lung tissue and physiology, creating a vulnerability to future infections. In healthy lungs the airways are protected by a sophisticated defence system made up of mucociliary apparatus (mucus glands and cilia), macrophages, Immunoglobulin A, mucins and antimicrobial peptides. In COPD-affected lungs however, this defence system is dysfunctional, allowing bacteria to enter the lower respiratory tract and flourish, causing infection (Matta et al., 2018). Furthermore, with every exacerbation leading to hospitalisation patients are exposed to additional hospital-acquired infection and viruses (Sethi & Murphy, 2008).

Treatment of AECOPD typically involves pharmacological interventions and respiratory support. Management of stable COPD includes smoking cessation, flu vaccination, lifestyle and physical activity recommendations and self-management education - including risk factor management, inhaler techniques, breathlessness management, written action plans and comorbidity management. The aim of AECOPD treatment is to reduce symptoms and reduce risk of further exacerbations (Disease Global Initiative for Chronic Obstructive Lung, 2020)

2.4 The problem of rehospitalisation

One major problem in the management of COPD is the high rates of rehospitalisation following exacerbations. In New Zealand, it is estimated that 23% of those discharged from hospital after an initial episode of AECOPD are readmitted within 30 days (Milne & Beasley, 2015). Similar statistics are reported in the US, where early readmission rates (i.e. within 30 days) are estimated to be 20% (Barnard & Zhang, 2018). In fact, rehospitalisation rates have been considered so problematic in the US that the Centres for Medicare and Medicaid have implemented a programme whereby hospitals with excessive readmission rates are financially penalised (Shah, Press, Huisingh-Scheetz, & White, 2016). One suggested cause of this is poor-quality care, possibly due to a lack of published guidelines around COPD patient readmission prevention (Press et al., 2019). High readmissions rates are not confined to the US and New Zealand; similar numbers are reported worldwide. The UK currently reports AECOPD readmission rates of 19.2% (NHS Digital, 2020), Scotland has had an increase from 20.5% in 1996 to 24.5% in 2005 (Hakim, Garden, Jennings, & Dobler, 2018), and in New South Wales, Australia, 22% of AECOPD patients will be re-hospitalised within 30 days (Hakim et al., 2018). These figures do not take into account potential misdiagnoses which could add a further 4.9% (31 in 100,000 people) to readmission rates (Barnard & Zhang, 2018).

A number of clinical parameters are known to increase risk of early readmission. Some of these are non-modifiable, such as age, sex, socioeconomic status, pre-index comorbidities and disease severity (Mantero et al., 2017). Others however have varying degrees of potential for change. These include low body mass index (BMI), reduced physical capacity or fitness, global and respiratory muscle weakness, health related quality of life, anxiety and depression scores, perceived dyspnoea, adherence to medical therapy and follow-up (Mantero et al., 2017).

Health policy and funding issues are also thought to influence rehospitalisation rates. For instance, one US study showed that 30-day readmission rates in working-aged COPD patients who had employer-sponsored health insurance were as low as eight percent (Baker, Zou, & Su, 2013). In comparison, other US studies involving people with AECOPD who have their hospitalisation costs funded under a fee for service model, or who are uninsured beneficiaries, have reported readmission rates of 20-27% (Jencks, Williams, & Coleman, 2009; Sharma, Kuo, Freeman, Zhang, & Goodwin, 2010). It is important to note, however, that in such studies a number of parameters such as participant age differ, and so these types of comparisons have to be interpreted with some care. Sharma et al.'s (2010) study, for example, looked at readmission rates for adults aged 66 and older, whereas Baker et al.'s (2013) study involved individuals aged 40 to 65 years. Citing a study by Friedman & Basu (2004), which found a rate of rehospitalisation in 18 to 64 year olds to be 81%, Jencks et al. (2009) indicated that rehospitalisation rates are actually only weakly related to age, and that the absence of health insurance was a much higher predictor of rehospitalisation.

In the same study, which looked at data from 6,095 patients over a five-year period, Baker et al. (2013) found that approximately one third of early readmissions did not actually have COPD as their primary diagnosis. Comorbidities are often cited as a significant factor in early rehospitalisation, and congestive heart failure is a big player. In the Baker et al. (2013) study, congestive heart failure was associated with 25% of all early readmissions – a finding which was consistent with other similar studies (Lau, Siracuse, & Chamberlain, 2017; Shah, Press, Huisingh-Scheetz, & White, 2016). Coronary artery disease, pneumonia, pulmonary embolus, muscle wasting, depression, reduced fat-free mass, osteopenia, and chronic infections are all comorbidities commonly associated with COPD, each carries an increased risk of complications and these may be the primary cause of rehospitalisation (Duffy, Barnett, Civic, Mamary, & Criner, 2014). Interestingly, Baker et al.'s study (2013) found little association between diabetes mellitus and early rehospitalisation. They suggested this may have been because of the high contact that people with diabetes typically have with their health care provider, which may allow for early signs of AECOPD to be detected. This finding was supported by Wang et al., (2007) and McGhan et al., (2007), but a study by Ernesto and colleagues (2015) which collected data from 125 hospitalised patients with AECOPD over a 30-month period, found that diabetes, along with high levels of C-reactive protein and prior hospitalisation in the last 12 months, was an independent risk factor for rehospitalisation, and that the presence of all three could accurately predict early readmission (positive and negative predictive values of 1.000; 95% confidence interval (CI), 1.00–1.00)(Crisafulli, Torres, Huerta, Méndez, Guerrero, Martinez, Liapikou, Soler, 2015) . Overall however, all authors agree on the importance of addressing comorbidities both in hospital care and acute post hospital care in order to reduce early rehospitalisation (Baker et al., 2013; Crisafulli et al., 2015; Mantero et al., 2017a; McGhan et al., 2007).

2.5 Interventions for reducing rehospitalisation after AECOPD

The decision in the US to financially penalise hospitals that have high rehospitalisation rates prompted much investigation into how these numbers could be reduced. The majority of research in this area has come from the US and the UK and, although overseas the health care context differs from that in New Zealand, COPD has the same progression, aetiology, and similar epidemiology worldwide; thus some comparisons can still be made.

Research into reduction of hospitalisation for AECOPD has largely come from an extrinsic action point, that is, looking at external interventions, applied to people to either reduce AECOPD, or to aid people to better control COPD and avoid hospitalisation. Interventions have ranged from pulmonary rehabilitation, self-management programmes, tele-support programmes, mindfulness training, smoking cessation programmes, and health coaching, with a lot of overlap between these different approaches. Interventions have been provided in various settings, such as private homes, hospitals and community centres, and by various professionals: nurses, community health professionals, physiotherapists and respiratory specialists. Each of these interventions is discussed in more detail below, with reference to the most recent research in these areas. It needs to be noted that research on prevention of hospitalisation is limited to external interventions and scant research could be found that focused on prevention of hospitalisation from the perspective of people living with COPD.

2.5.1 Pulmonary rehabilitation

Pulmonary rehabilitation typically involves individual patient assessment, physical exercise, education, nutritional counselling and psychosocial support, with the intention of reducing COPD symptoms, re-establishing and improving functional ability, enhancing participation in everyday life, promoting autonomy and improving health related quality of life (Puhan, Cates, & Troosters, 2016; Seidel et al., 2012). While many interventions for COPD can be considered “rehabilitation” interventions as per the World Health Organisation’s definition of rehabilitation, the term “pulmonary rehabilitation” is used in the literature to reference to a particular programmes of intervention activities, i.e. “Any in-patient, out-patient, community-based or home-based rehabilitation programme of at least four weeks’ duration that included exercise therapy with or without any form of education and/or psychological support delivered to patients with exercise limitation attributable to COPD” (Mc Carthy et al., 2015). Current best evidence indicates that pulmonary rehabilitation can reduce hospital readmissions, particularly when initiated early post exacerbation (Spruit et al., 2013). This is not surprising given that pulmonary rehabilitation is associated with improvements in the areas of exercise tolerance, activity level, skeletal muscle function, COPD symptoms and health related quality of life (Puhan et al., 2016; Spruit et al., 2013).

In 2016, Puhan et al. (2016) conducted a Cochrane review to assess the effects of pulmonary rehabilitation on hospital readmissions. This review comprised 20 studies, including a total of 1477 participants. Eight of these studies (810 participants) measured hospital readmission data. Randomised controlled trials that compared pulmonary rehabilitation with conventional community care were included, providing the pulmonary rehabilitation included some form of physical exercise for a minimum number of sessions. The study revealed a great deal of diversity in length of pulmonary rehabilitation programmes, exercise protocols (number, intensity and type of sessions), type and administration of patient education and organisation and structure of delivery. This, combined with variable risk of bias, led to a high statistical heterogeneity ($I^2 = 77\%$) in the meta-analysis for this review regarding rehospitalisation rates. Despite this, the authors reported moderate quality evidence of a positive relationship between pulmonary rehabilitation and reductions in hospital readmission rates (pooled odds ratio (OR) 0.44, 95% CI 0.21 to 0.91). In addition, high quality evidence was reported that pulmonary rehabilitation also improved health-related quality of life and physical function in people with recent AECOPD. Pulmonary rehabilitation was found to result in a significant improvement on health-related quality of life as measured by the St. George Respiratory Questionnaire, above the minimal important difference (MID) of four points (mean difference (MD) -7.80; 95% CI -12.12 to -3.47) were found. Physical function is often measured by measuring the distance walked in six minutes (Six-minute walk test). In this review, performance on the six-minute walk test showed an MD of 62 meters (95% CI 38 to 86) between those who received pulmonary rehabilitation after AECOPD and those who did not (Puhan et al., 2016).

This review was followed up in 2018 with a systematic review and meta-analysis of 13 randomised controlled trials (801 participants), incorporating four additional papers not included in Puhan et al.’s original review (Ryrso et al., 2018). With tighter criteria, this review included papers reporting on supervised pulmonary rehabilitation programmes beginning within four weeks of AECOPD only. Again, authors reported, with moderate quality evidence, a reduction in hospital readmissions (six trials, 319 patients; relative risk (RR) 0.47; 95% CI 0.29 to 0.75) and an improvement in health-related quality of life and six-minute walk performance. In addition, a clinically significant reduction in mortality was found (four trials, RR 0.58; 95% CI 0.35 to 0.98), and in the longest follow up trials (3 trials, 127 patients; RR 0.55; 95% CI: 0.12 to 2.57) (Ryrso et al., 2018).

Unfortunately, despite the well-established benefits of pulmonary rehabilitation, both uptake and completion of programmes is low. In the United Kingdom less than 1.5% of AECOPD patients will complete a pulmonary rehabilitation programme (Keating et al., 2011), and in New Zealand this figure is less, sitting at one percent of patients (Levack, Weatherall, Reeve, & Mans, 2012). Reported barriers to pulmonary rehabilitation include poor access to transport and lack of perceived benefits. Current smokers and those with depression are most at risk of non-completion. Puhan et al. (2011) highlighted the fact that those with COPD who are motivated or sufficiently persuaded to attend and complete pulmonary rehabilitation are potentially a select group and therefore, while the intervention may be successful, it may not be for everybody.

2.5.2 Self-management programmes

Self-management of COPD refers to a patient’s ability to monitor their signs and symptoms, to take appropriate action, to adhere to medical advice and treatment, to maintain contact with health care providers, and to maintain psychosocial health (Effing et al., 2016). Self-management interventions include a wide range of components including action plans, health literacy education, coaching in problem solving and decision making, smoking cessation, tele-monitoring and goal setting. Unfortunately, there is no standardisation of self-management interventions and no global agreement on which components should be included. This adds an unavoidable degree of heterogeneity to study designs, making the analysis of the success of these programmes difficult.

Murphy et al. (2017) completed an overview of reviews on self-management interventions for COPD, which included 16 reviews, 165 randomised controlled trials, and 16,500 participants. Studies ranged from education and action plans, complex interventions with a focus on self-management, pulmonary rehabilitation and interventions delivered using telehealth. The outcome measures included health-related quality of life, health care utilization (hospitalisation and emergency department visits) and mortality. A quality assessment was carried out by two independent reviewers using the Revised Assessment of Multiple Systematic Reviews quality - assessment tool and evidence for each outcome measure was categorised as ‘strong,’ ‘moderate,’ or ‘limited’ based on the quality of the evidence and the statistical significance of the results.

In regard to education and action plans, the overview reported 26 unique randomised controlled trials, four Cochrane reviews which assessed: education, with or without action plans (Effing et al., 2007); action plans not including education (Turnock, Walters, Walters, & Wood-Baker, 2005), an update of the previous Cochrane review but including a brief patient education (Walters, Turnock, & Walters, 2010) and an assessment of patient-managed disease-specific education programmes (Tan, Chen, Zhang, Zhang, & Mei, 2012). Overall, limited evidence was found for health-related quality of life in all four reviews. Two, which focused on education, showed small but significant effects (Effing et al., 2007; Tan et al., 2012). Effing et al. (2007) and Tan et al. (2012) also reported a significant reduction in hospitalisations (evidence rated as strong). However, the two papers which were focused on action plans found no significant differences in hospitalisation rates (Turnock et al., 2005; Walters et al., 2010) (also strong evidence) (Murphy et al., 2017).

Complex interventions with a focus on self-management typically include multiple components such as education or rehabilitation, delivered by multiple administrators and in a variety of settings or using a variety of means such as technology. Seventy-seven unique randomised controlled trials were included in four review papers. Of these complex interventions, one showed significant improvements in health-related quality of life, with limited to moderate evidence (Zwerink et al., 2014). Two reported significant reductions in rehospitalisation with moderate evidence (Jordan et al., 2015; Zwerink et al., 2014), and one reported significant reductions in emergency department visits (Dickens et al., 2014), with evidence rated as moderate (Murphy et al., 2017). Neither of the three reviews that reported on mortality showed significant effects (Jordan et al., 2015; Kruis et al., 2011; Zwerink et al., 2014).

Four reviews of 38 unique randomised controlled trials were included in the section on telehealth. One of the two studies that included health-related quality of life showed limited evidence for positive results from home telemonitoring (Cruz, Brooks, & Marques, 2014). The three reviews that reported on hospitalisation all showed significant reductions, with limited to moderate evidence (Cruz et al., 2014; Kamei, Yamamoto, Kajii, Nakayama, & Kawakami, 2013; Lundell, Holmner, Rehn, Nyberg, & Wadell, 2015). Only two reviews reported on mortality and both showed no significant effect (Cruz et al., 2014; Kamei et al., 2013).

Only one review on pulmonary rehabilitation was included in this overview. That appears surprising but is due to the way Murphy et al. (2017) structured their overview. The review by McCarthy, Casey, Devane, Murphy, Murphy, & Lacasse, (2015) comprised 65 randomised controlled trials, each focused on pulmonary rehabilitation. With evidence rated strongly, significant positive effects were found for both health-related quality of life and exercise capacity, the only outcome measures included.

Finally, one review assessed an outreach (in home) nursing programme which helped people to use their treatments properly, and provided education about disease monitoring and coping strategies (Wong, Carson, & Smith, 2012). This paper reported small but significant improvements in health-related quality of life, but no significant reduction in hospitalisations, Murphy et al. (2017) rated the quality of evidence as limited.

Overall, the overview paper concluded that self-management programmes have a significant impact on health-related quality of life, whether delivered through education programmes or as a component of pulmonary rehabilitation. Of the self-management programmes, those that include telehealth showed the most meaningful reductions in rehospitalisation or emergency department visits, but there was no evidence to support self-management programmes having any impact on mortality (Murphy et al., 2017).

Some recent studies have been looking into the concept of self-efficacy with regard to self-management plans. Self-efficacy is a term that describes an individual’s belief in their ability to cope with a situation (Bandura 1977b, 1982, as cited in (O’ Leary, 1985). The theory purports that a person’s perception of their capability for a certain feat affects their motivation, thought patterns and their emotional reactions, ultimately regulating their self-motivation and behaviour. Perceived self-efficacy is believed to determine which behaviours will be attempted and which will be avoided, the amount of effort that will be dedicated to a task and the length of time one will persist when difficulties are encountered. People’s perceived ability to cope with a situation is also believed to affect the degree of anxiety they feel in stressful life situations (Blankstein, Flett, & Watson, 1992).

Bandura’s theory of self-efficacy has been applied to many areas of psychosocial functioning including depression and anxiety, motivation, achievement behaviour, sports and health behaviour (O’ Leary, 1985) and has made its way into disease management (Sousa, Zauszniewski, Musil, Price Lea, & Davis, 2005). In a critical review of this topic, Stellefson, Tennant, & Chaney, (2012) asserted that the purpose of COPD self-management education programmes is to enhance patient self-efficacy for managing symptoms. To assess the effectiveness of self-education programmes on self-efficacy Stellefson et al., (2012) reviewed seven peer-reviewed articles including three randomised controlled trials (n= 222), one secondary data analysis of a randomised controlled trial (n=103), one quasi-experimental trial (n=189), a two-group pre-test-post-test trial (n=59) and a multiple group pre-test-post-test trial (n=41). Each of these papers included self-efficacy measures of diagnosed COPD patients, over 40 years old, who had participated in self-management programmes. In Sellefson et al.’s (2012) review, six of the seven included studies which reported statistically significant improvements in self efficacy associated with taking part in self-management programmes. One of the most notable findings was reported in two studies that found increased confidence in managing breathlessness associated with physical exertion such as getting up out of a chair, climbing stairs or rushing to complete household tasks after completing self-management education programmes.

Besides the usual limitation of study heterogeneity, as well as particularly poor reporting methods, the review found lack of reporting of reliability measures in 57.1% of papers - an important limitation of the review was in the exclusion criteria. This review excluded those with multiple morbidities. This seriously affects the transferability of the findings as it is very common to have comorbidities alongside COPD.

Coming from quite the opposite perspective, Simpson & Jones (2013) carried out a literature review and exploratory descriptive survey to investigate effects of self-efficacy on COPD, specifically mood, breathlessness and exacerbations. Their survey was completed by 250 randomly selected participants across four general practices across Scotland. Participants all had moderate COPD (FEV_1= 50–79% predicted) and mean age was 69 years (range 53–86 years). Questions in the survey included a visual analogue scale which measures confidence in both recognising and treating an exacerbation, the Wigal COPD self-efficacy scale which measures patients' confidence in managing breathlessness in various situations, the Medical Research Council dyspnoea scale which measures breathlessness over a range of activities, and the hospital anxiety and depression scale. Results of this study found a positive association between higher self-efficacy and lower depression and anxiety rates, as well as lower measures of breathlessness ($P<0.5$ in all variables). Participants who said they were more confident at recognising and treating exacerbations had less anxiety, depression, and breathlessness. Interestingly, there was no difference in exacerbation rates between those with high or low self-efficacy levels. There has been little or no further research into the effects of self-efficacy on COPD management although it does appear to be associated with research into the effectiveness of self-management programmes and particularly in the areas of diabetes and stroke.

2.5.3 Exercise-based interventions

Physical inactivity is one of the key predictors for increased hospitalisation and all-cause mortality among COPD patients (Lahham, McDonald, & Holland, 2016). Unfortunately, physical inactivity is also very common. Research has shown that there is a marked reduction in the amount of time spent in physical activity and the intensity of exercise among COPD patients compared to their peers without COPD, regardless of the severity of their disease (Pitta et al., 2006). The decrease in functional and maximal exercise capacity that is both a by-product of the disease and a result of the reduced activity level means that any physical activity undertaken becomes more difficult and unpleasant. A downhill spiral ensues resulting in muscle wastage, reduction in strength and power and increased morbidity and mortality (Sun & Zhou, 2019). With that established, it is important to look to interventions that aim just to increase physical activity in this population, outside of the context of a full pulmonary rehabilitation programme.

Research into best practice in exercise protocols has been inconsistent and often involves small and inconclusive trials with poor reporting (Global Initiative for Chronic Obstructive Lung Disease, 2019; Lahham et al., 2016). To investigate which protocols actually increase physical activity levels in this population, Lahham, McDonald & Holland (2016) conducted a systematic review and meta-analysis of 37 exercise based randomised controlled trials. A total of 4,314 participants were included (mean FEV_1% predicted 50.5; standard deviation (SD) 10.4), and the primary outcome of interest was increased physical activity levels. The secondary outcomes in this systematic review were functional and maximal exercise capacity, health-related quality of life, dyspnoea and lung function variables. Randomised controlled trials were included if they compared physical activity with usual care, pulmonary rehabilitation with added physical activity and pulmonary rehabilitation alone, or two different physical activity interventions. The quality of included studies was rated fair to good using the PEDro quality scale, an 11-item scale used for assessing internal and external validity of clinical trials.

The results of the three studies (total 103 participants) that compared usual care with exercise training including Nordic walking, supervised exercise, and self-efficacy enhancing exercise (which emphasized meeting physical activity recommendations and then increasing intensity with time), showed that exercise training improved physical activity levels significantly more than usual care (effect size 0.84; 95% CI 0.44 to 1.25). Physical activity increases were measured either subjectively by questionnaires or objectively by accelerometers, pedometers or activity monitors. The MID for activity when using a pedometer is an increase of 599 steps. Of the 13 trials that used daily steps as their measure, only those that added activity counselling to pulmonary rehabilitation (n=4 studies including 140 participants) showed an estimated effect size exceeding the minimal important difference (MD 1,452 daily steps; 95% CI 549 to 2,356) - although even here the lower range for the 95% CI was below the MID. Five studies looked at the effects of nutritional and pharmaceutical interventions on physical activity and while authors reported a significant increase in physical activity when compared to control interventions, they noted that insufficient data and poor methodological quality meant that the pooled effect sizes data were unable to be calculated.

Consistent with previous critiques in this area, poor methodological reporting was allegedly common among trials in this review. A second limitation of this study was the heterogeneity of assessment time points and frequency of treatments, common in exercise trials. This meant that the authors were unable to pool all the data in the meta-analysis and calculate overall effects. The authors also point out that there is insufficient long-term follow up, so the sustainability of effects are not being captured. The key finding here shows us that including physical activity counselling in pulmonary rehabilitation may be the best way to significantly improve physical activity levels in this population. This could reverse the effects of inactivity, reducing hospitalisation and early mortality rates.

Some novel work in the area of exercise training has looked at interventions to make exercise more tolerable for those who find it challenging; for example, people with comorbidities that restrict movement or weight-bearing exercises. One example is whole-body vibration training, often used in athletes' and fitness rehabilitation centres, which aims to improve neuromuscular performance via stimulation and automatic contraction of skeletal muscles (Zhou et al., 2018). Whole-body vibration is produced through a base platform that the participant stands on, allowing a range of patterns and movements to be produced to suit the needs of the user. Whole-body vibration training has been employed using low-amplitude, low-frequency mechanical stimulation in COPD patients. Zhou et al. (2018) conducted a systematic review and meta-analysis, consisting of eight trials (356 participants, age 58 – 75 years), to examine the effects of whole-body vibration training on exercise capacity, pulmonary function, and quality of life in COPD patients. Based on stringent inclusion criteria, studies published between 2012 and 2017 were chosen and included whole-body vibration training versus physiotherapy (n=1 trial), calisthenics training (n=1 trial), conventional resistance training (n=1 trial) or no training (n=5). Besides lack of reporting on concealment of allocation in three trials and the inability to blind participants or study personnel to group allocation, the authors reported the methodological quality to be acceptable with a low risk of bias. This review found that compared to control interventions, whole-body vibration training improved six-minute walk distance above the MID of 35 m (weighted MD: 62.14 m; 95% CI: 48.12–76.16; P,0.001) and improved the participants' time taken to successfully complete five repetitions of the sit-to-stand test (weighted MD: -2.07 seconds; 95% CI: -4.00 to -0.05; P=0.04). These results suggest whole-body vibration training may be beneficial as an exercise training protocol for those living with COPD for whom exercise is limited by skeletal muscle weakness or other comorbidities. However, the authors warn, once again, that differences in training protocols as well as inconsistent control group interventions led to heterogeneity in outcomes, which adds uncertainty to interpretation of these findings.

2.5.4 Telehealth Interventions

Telemonitoring or telehealth programmes are a new development in the management of chronic health conditions and seem to have some success in managing AECOPD. Several recent reviews have found positive effects in favour of reducing hospital readmissions and improving some aspects of health-related quality of life. Telehealth typically involves some form of technology-based symptom monitoring which allows for early identification of deteriorating health. For example, Pedone, Chiurci, Scarlata & Incalzi (2013) used wrist bands to monitor heart rate, physical activity, body temperature, stress (galvanic skin response) and oxygen saturation, transmitting these data to a central monitoring system which was attended by a respiratory physician. De Toledo et al. (2006) built a complex protocol which allowed monitoring of biomedical parameters and symptoms, real time sharing of patient data, patient follow up prompts, access to patient records from any location, regular home visits by nurses and on demand patient access to video, phone and web-based health care case managers. Some interventions have also included an education component or access to patient education (Kamei et al., 2013).

The most recent review of telemonitoring was a 2019 systematic review and meta-analysis by Hong and Lee (2019), which included 27 randomised controlled trials and performed a subgroup analysis on patient severity as well as intervention type. Protocols included telemonitoring only (15 studies), integrated telemonitoring vs usual care (four studies) and integrated telemonitoring vs not pure control (defined as having some degree of COPD education or exercise (Hong & Lee, 2019, p. 3)(8 studies). Further analysis by patient severity categorised patients as severely ill (16 studies), moderately ill (eight studies) and non-disclosed (three studies). It is worth noting that the definition of ‘severe’ used in this study is different to that of the GOLD criteria (severe = $FEV_1 < 50\%$ vs severe = $FEV_1 < 30\%$ respectively) (Sharifabad, 2018). This review did not categorise the quality of the evidence and the self-reported quality assessment shows a high risk of selection bias in four papers and unclear allocation concealment and no blinding in most papers. Taking this into consideration, the meta-analysis showed positive results for telemonitoring, reducing emergency department visits (RR 0.63, 95% CI 0.55 to 0.72) and hospitalisations (RR 0.88, 95% CI 0.80 to 0.97). The subgroup analyses found a larger effect size for patients categorised as having severe compared to moderate severity COPD (RR 0.48, 95% CI 0.31–0.74 and RR 1.28, 95% CI 0.61–2.69 respectively) and similarly for hospitalisations (RR 0.92, 95% CI 0.82–1.02 and RR 1.24, 95% CI 0.57–2.70 respectively).

This review and meta-analysis complements the findings of two other reviews completed in the last two years, which also included components of telemonitoring as a part of their overall study. Murphy et al. (2017) included four randomised controlled trials on telehealth and found moderate to strong evidence (based on the Revised Assessment of Multi Systematic Reviews) for success in prevention of AECOPD rehospitalisation. Similarly, Yang et al., (2017) included eight studies, concluding that tele-monitoring significantly reduced all cause readmission over six to 12 months (RR, 0.78; 95% CI 0.58–0.88).

2.5.5 Mindfulness

Another new approach to improving health outcomes in the COPD population is the practice of mindfulness. Mindfulness is described as “a stress reduction practice that teaches awareness, appreciation, and non-judgmental acceptance of one’s present experience” (Victorson et al., 2015, p. 185). Victorson et al., (2015) also suggest that stress is “at the epicentre” of many behaviours that lead to unhealthy lifestyle choices such as poor food choice, smoking, excessive alcohol consumption and lack of exercise. Based on the understanding that anxiety and depression are rife among COPD patients, recent research has been investigating the use of mindfulness-based therapies to help to manage stress and anxiety and to lift mood. There is no literature on the effects of mindfulness on COPD re-hospitalisations, but there is some evidence that in COPD patients the fear of dyspnoea independently predicts emergency department visits (Abascal-Bolado & Benzo, 2016). Outcome measures in mindfulness-based research tend to include dyspnoea, anxiety, depression, quality of life, functional exercise capacity and nutritional status (Banth & Ardebil, 2015; Farver-Vestergaard et al., 2015).

Most of the research on mindfulness as a complementary therapy for COPD is focused on quantitative outcomes but there is a secondary body of qualitative research looking at is applicability and acceptability for both patients and health professionals.

One such qualitative study included face to face, semi structured interviews with 17 health care professionals and 15 COPD patients all attending pulmonary rehabilitation (Harrison, Lee, Goldstein, & Brooks, 2017). Participants described some lack of knowledge or uncertainty regarding their understanding of mindfulness, illustrated by statements such as “It’s hard to explain,” (Harrison et al., 2017, p. 338), and “Mindfulness? What’s mindfulness, first of all?” (Harrison et al., 2017, p. 339). This confusion was mimicked and magnified in health practitioners: “The relaxation techniques that we have with just slowing down your breathing, the stuff that we are already currently doing.” (Harrison et al., 2017, p. 339)

Participants did see the potential for mindfulness to play a role in disease management, illustrated by this participant’s view: “It [mindfulness] allows your body to … and mind to absorb all the things that you are supposed to do with the breathing.” (Harrison et al., 2017, p. 339). One participant expressed interest in using mindfulness as a pain management tool: “If I can use it, it would also make it a lot easier to try to control the pain.” (Harrison et al., 2017, p. 339). Most patients showed a willingness to participate in mindfulness-based training; however some were put off by the social stigma and negative preconceptions associated with mindfulness which were identified as the greatest barriers to attendance by both health practitioners and patients (Harrison et al., 2017).

Mindfulness techniques that showed the most potential for acceptance among the participants were meditation to music, breathing meditation - because of its relevance to breath control - and body scanning, which focuses on methodical relaxation of the body. Both health-care professionals and patients reported a preference for these methods because of their low levels of physicality, whereas there was the belief that interventions based on physical activity such as walking meditations or drumming would exacerbate breathlessness (Harrison, Lee, Janaudis-Ferreira, Goldstein, & Brooks, 2016)

The most recent systematic review on mindfulness in this population is a 2015 systematic review and meta-analysis that looked at chronic disease management, including cardiovascular disease, metabolic disorders, chronic pain, cancer, autoimmune, respiratory and neurologic conditions. This paper reported on outcome measures of anxiety and stress as well as examining the impact of study design issues. Only two respiratory papers were included, and only one of these used COPD as the study population, with the other investigating its influence on people with asthma.

The COPD study found no significant difference in the mindfulness based intervention (Mularski et al., 2009, as cited in Victorson et al., 2015), whereas the asthma study found significantly greater improvements in asthma-related quality of life, and a decrease in self-perceived stress levels at a 12 month follow-up (Pbert et al., 2012 as cited in Victorson et al., 2015).

Similarly a 2016 systematic review and meta-analysis was carried out by Harrison, Lee, Janaudis-Ferreira, Goldstein, & Brooks (2016), looking at the outcome measures of health-related quality of life, mindful awareness and stress in people with respiratory diagnosis. This review included the two papers previously reviewed and added two more, one a COPD study (Chan et al., 2015 as cited in Harrison et al., 2016) and one a respiratory failure study (Cox et al., 2014, as cited in Harrison et al., 2016). Papers were entered if: they included a mindful based therapy, a control group, participants were over 18 years old and had a diagnosed respiratory condition that caused dyspnoea, and outcome measures included quality of life and psychological morbidity. Like the previous study, this review paper also found no significant improvements in health-related quality of life (standard mean difference (SMD) -0.21; 95% CI -0.36 to 0.48), mindful awareness (SMD 0.09; 95% CI -0.34 to 0.52) or stress levels (SMD = -0.11; 95% CI -0.46 to 0.23).

In contrast to these outcomes, a systematic review by Farver-Vestergaard, Jacobsen, & Zachariae (2015) which looked at a range of cognitive and behavioural therapies found mindful-based approaches to be the only ones that improved physical outcomes of dyspnoea, exercise capacity, fatigue and lung function (g = 0.40; CI = 0.01-0.79; p = 0.042). This review included eight mindfulness-based randomised controlled trials, 12 studies of cognitive behavioural therapy and two other papers including analytical and behavioural therapy. Interestingly, authors reported that cognitive behavioural therapy had the most success in improving psychological outcomes such as anxiety and depression (g = 0.39, CI = 0.15–0.62; p = 0.001). However, as is common in COPD research, variation in study design, small sample sizes, population heterogeneity, inconsistent outcome measures and poor reporting, including a lack of risk of bias reporting, were evident in this systematic review.

Despite common limitations in study design there are some randomised controlled trials now showing positive results for the use of mindfulness-based therapies in helping to improve stress, anxiety, depression, fatigue, self-efficacy and quality of life in other chronic disease populations (Parswani, Sharma, & Ss, 2013; Pbert et al., 2011; Zangi et al., 2011). Unfortunately, this area is under-studied and its use is possibly being limited because of a lack of good research. Tian, Zhang, Li, Wu, & Li, (2019) are currently undertaking another systematic review looking at the outcomes of dyspnoea, anxiety and depression for COPD.

2.5.6 Health Coaching

The final psychosocial intervention to mention here is health coaching, which has been investigated in clinical settings (Benzo et al., 2016) and when delivered via telephone (Coventry et al., 2019). Health coaching aims to promote health behaviours and improve self-efficacy and self-management of chronic disease. Research on these types of interventions have again focused primarily on chronic disease management in general, but has produced little evidence of success in improving health behaviour, self-efficacy and health status so far (Dennis, Harris, Lloyd, Powell, & Zwar, 2013).

In a randomised-controlled trial involving 215 participants, Benzo et al. (2016) examined the effectiveness of a health coaching intervention based on motivational interviewing, with the addition of a written action plan to address episodes of AECOPD (the use of antibiotics and oral steroids) and brief exercise advice, and compared this to usual care. The health coach – a registered nurse or respiratory specialist – met with participants once in hospital, once for a two-hour clinical session and then followed up with phone calls. Details of the number, content or timing of the phone calls are omitted from the report, but it is noted that participants were encouraged to call the health coach any time they needed. The primary outcome measure was rehospitalisation rates, with health-related quality of life and physical activity level used as secondary measures. Data were collected at one, three, six and 12 months and indicated that the absolute reduction in risk of rehospitalisation in the intervention arm was significant at 11.6% (P = 0.03) at 3 months but (P = 0.24) at 12 months. The odds ratio for rehospitalisation in the intervention group compared with the control group was 0.37 (95% CI 0.15–0.91) at 3 months and 0.60 (95% CI 0.30–1.20) at 12 months. Disease specific quality of life improved in the intervention arm at both six and 12 months ($P<0.05$).

A qualitative study was conducted alongside a randomised controlled trial by Jolly et al. (2018) (as cited in Coventry et al., 2019). The original randomised controlled trial focused on outcomes of patient-managed telephone health coaching in people with mild COPD. Coventry et al. (2019) were interested in how, why and in what context those in the intervention arm engaged in self-management activities after completion of the study. From the responses of the 48 participants involved, the following three main concepts were identified which told the story of post-intervention exercise maintenance: motivation, mechanisms and maintenance.

Motivation focusses on the journey that participants have travelled, beginning with the initial diagnosis – which often comes as a shock and results in disbelief, particularly for those who have no idea that they may have a chronic lung disease. Participants talked through their often blunt and curt interactions with health professionals who commonly undermined or downplayed the patients' ability to improve their health status. Finally, participants talked about changing their own narrative and moving towards a more positive and proactive intention to manage their own condition and slow down their physical decline.

When talking about *mechanisms* for gaining control, the participants described their desire to become more physically active, and the issue became one of how to fit more physical activity into their lives with minimal disruption. Action planning for respiratory crisis was also considered important, but participants expressed a strong distaste for goal setting, either because they considered they were already completing the activities being asked of them, or because the concept of goal setting reminded them of setting targets at work.

The concept of *maintenance* represents the way that participants worked to maintain the new physical activity changes they implemented during the study. Participants talked about what factors helped or hindered them when it came to maintaining their new physical activity levels. Environmental conditions such as the weather were an important factor in determining adherence to exercise, but, particularly female participants who showed more of an appreciation for the health benefits of exercise would not let poor weather conditions deter them. Dog walking was considered a key resource for maintaining physical activity, whereas the pedometers used during the trial were rejected by many. Although participants wanted to remain physically active, they pushed back against the rigidity that they felt was represented by fitness trackers.

The learning that came from this qualitative study was that people with mild COPD were more inclined to focus on adopting a physically-active lifestyle than they were to focus on managing their respiratory symptoms. This was made easier for them by environmental factors such as good weather and pet dogs. There was considerable variation in people's ability to maintain physical activity, and this variation reflected the wider context of their everyday lives.

2.6 The theoretical basis for the TCOPD intervention

The TCOPD study was a feasibility study to explore the best methods required to test a novel self-management intervention for people admitted to hospital for AECOPD (HRC 17/521; Trial Registration no.: ACTRN12617000952347p). The TCOPD intervention was derived from a similarly-titled self-management approach that had been studied with people living with the effects of stroke (Fu, Weatherall, & McNaughton, 2017). "Taking Charge after Stroke" was based on the hypothesis that personal motivation, nurtured by enthusiastic staff and a positive outlook towards the future, was the key to the well-established success of stroke rehabilitation. The "Taking Charge after Stroke" intervention has been tested in two studies involving a total of 572 participants (Fu et al., 2020; Harwood et al., 2012). In both cases the intervention was delivered as an addition to community stroke rehabilitation, 2-16 weeks after acute stroke, and consisted of one or two brief (60 minute) sessions with a facilitator. During these sessions the facilitator guided participants through a workbook which included components of personal identity, purpose and hopes for the future, followed by optional areas for participants to work on, for example physical activity, mood, finances, supports, information, and stroke prevention. The booklet was structured to enable participants to break down goals into manageable steps and identify key support people.

Both "Taking Charge after Stroke" interventions had significant success, with the earlier study (n=139) (Harwood et al., 2012) showing improvements at 12 month in terms of improvement in quality of life and reduced dependency on carers. Participants who received the "Taking Charge after Stroke" intervention scoring 6 points higher (95% CI, 2.0 to 10.0) on the Physical Component Summary section of the SF-36 and were less likely to have a modified Rankin score of >2 (OR 0.42, 95% CI 0.2 to 0.89) compared a control group who received no additional intervention. The family carers of people in the "Taking Charge after Stroke" group also reported lower scores in the carer strain index compared to control participants (–1.5, 95% CI –2.8 to –0.1) (Harwood et al., 2012).

Similarly, in the second study, 388 randomised participants were grouped into three arms. Taking Charge One (TC1, n = 132) received the Taking Charge intervention one time, Taking Charge Two (TC2, n= 138) received the intervention twice, six weeks apart, and the control group (n=130) received usual care (Fu et al., 2020). Again, the results were compelling. Improvements were seen in the Physical Component Summary section of the SF-36, with both "Taking Charge" groups scoring 2.9 (95% CI 0.95 to 4.9, p=0.004) points higher than the control group at 12 months post intervention, and a dose effect was seen with the Physical Component Summary section scores increasing by 1.9 points (95% CI 0.8 to 3.1, p<0.001) in the group who received the additional Taking Charge session. Those in the intervention arms also had reduced odds of disability based on the modified Rankin Scale (TC1 & TC2 12% versus control 19.5%, OR 0.55, 95% CI 0.31 to 0.99, p=0.045).

The similarities between stroke rehabilitation and COPD rehabilitation were the driver behind developing the Taking Charge intervention to fit with COPD. Both stroke rehabilitation and pulmonary rehabilitation have shown exceptional success rates (Langhorne, 2013; McCarthy, Casey, Devane, Murphy, Murphy, Lacasse, et al., 2015). Both are complex interventions with multiple aspects and little evidence of which aspects of the intervention provides the greatest improvements. Both target behaviour change - which can easily be influenced by the relationship between the participant and the health professionals.

Hence, the *Taking Charge after Stroke* study was adapted, with minimal changes, to suit a COPD population. Maintaining the integrity of the study meant that the intervention remained low cost, person-centred and focused on promoting autonomy, purpose, mastery and connectedness, the fundamental components of Taking Charge. The TCOPD feasibility study was run over two years and involved 56 participants (male 22; female 34; average age 69.8 years (SD 10.7), Range 29 – 87 years; Māori 11; Pacific 6; Non- Māori, non-Pacific 39). Participants were randomised into an intervention arm (n= 28) who each received a two-hour Taking Charge session, and a control arm (n= 28). During the intervention, the researcher guided the participants through the Taking Charge workbook, encouraging participants to choose areas to work on that they felt were the most important to them. Researchers helped the participant work through the area as they learned how to use the book. On completion of the session, the book was left with the participant.

The TCOPD Study was a feasibility study developed in order to gather information to develop an appropriate study design for a future fully powered clinical trial. It was not intended to produce conclusive data on the effectiveness of the intervention; furthermore, results were not available at the time of completing this thesis. Therefore, I am unable to report information about its effectiveness of the TCOPD intervention here.

2.7 Summary

As discussed in this chapter, the health and economic burden of COPD is high and the need to reduce rehospitalisation for people at risk of AECOPD is great. We know already that more than half of all exacerbations are caused by virus or bacteria, and that following hospitalisation there is a decline in health status and an increased risk of rehospitalisation.

Several interventions have described clinical attempts to improve health status and reduce re-rehospitalisation in people with COPD. Pulmonary rehabilitation is recognised as one of the most successful prevention programmes available, showing improvements in important health indicators for those who take part. Unfortunately, however, uptake and completion of programmes is very low, both globally and nationally. The barriers to uptake and completion are complex, requiring a multi-faceted approach before the benefits of this intervention can be maximised.

Self-management programmes are another type of intervention that have some demonstrated success in reducing hospitalisations, but studies on self-management strategies tend to show such variation in interventions that it is hard to pinpoint which ones have the most success and in which populations. This same issue is found in exercise-based interventions, outside of the context of pulmonary rehabilitation. Again, these have shown great success in improving activity levels and decreasing hospitalisation, but trials and their reporting are inconsistent, making it hard to draw conclusions about which exercise protocols are the most, or the least, successful. What is known, however, is that physical activity counselling, when added to pulmonary rehabilitation, appears to contribute to significant increases in physical activity levels as well as reductions in rehospitalisation and early mortality.

Telehealth based interventions are relatively new and have shown some success in reducing emergency department visits and rehospitalisation. With a wide variety in the ways these interventions can be used to support self-management, telehealth is an area showing promise in decreasing rehospitalisation and improving health status. Mindfulness-based therapies have been investigated in COPD, not with the aim of reducing hospitalisation, but of decreasing associated anxiety and depression. Mixed and inconclusive results have been found in COPD research, but positive results have come from similar studies in asthma populations and in other chronic disease populations. A single qualitative paper showed that COPD patients were willing to take part in some aspects of mindfulness but there has been little research carried out in this area.

The final intervention described in this chapter has been health coaching, which has shown some success in improving health behaviours and health status in many populations, but with no evidence of efficacy from randomised controlled trials. The small amount of qualitative research available suggests that COPD patients prefer to focus on the positive act of improving their physically activity levels rather than on managing their respiratory symptoms. Ultimately it seems that there is a variety of interventions available, all with their own advantages and disadvantages, and as individuals with COPD are unique there may be no one size fits all approach to reducing hospitalisation and improving health status.

Throughout the process of this narrative literature review, no studies were found that explored the experiences of people at risk of hospitalisation for AECOPD regarding their perspectives on the factors that help or hinder their ability to maintain good health and keep out of hospital. The perspectives of people who have experience of AECOPD may provide valuable insights that have not previously been considered or prioritised by health professionals or rehabilitation researchers. The following chapter describes the methods used to conduct such a study for the purposes of this thesis.

Chapter 3: Methodology and Methods

3.1 Introduction

This chapter provides a rationale for the methods selected to address the aims of this research. It presents information on Constructivism and Symbolic Interactionism which are the background to my choice of approach, and then an explanation of why grounded theory was chosen to conduct this research. Following that is a detailed description of the methods used to carry out the study including participant recruitment, data collection, memo writing, and theoretical saturation and analysis. There is a brief note on the koha given to participants and areas which enhance scientific rigour that have not been mentioned under previous headings. The chapter concludes with detail of the ethical and cultural considerations that were given to the study.

3.2 Rationale for the selection of methodology and methods

There is plenty of quantitative data on the clinical factors associated with managing AECOPD (Crisafulli, Manco, & Torres, 2020; Laue, Reierth, & Melbye, 2015; Mantero et al., 2017). However, there is little understanding of the lived experiences of avoiding COPD exacerbations and the associated risk of hospitalisation from the perspective of the patient. AECOPD is a complex phenomenon which includes both physiological and psychosocial factors (Coventry, Gemmell, & Todd, 2011). In order to determine what factors contribute to COPD patients staying out of hospital, we need to employ a method of research that explores deeper into the “whys” and “hows” of the human experience as is found in qualitative research (Hollway, 2008)

It is becoming increasingly popular to use qualitative methodologies, particularly grounded theory, phenomenology and qualitative descriptive analysis, to inform evidence-based practices such as occupational therapy (Stanley & Nayar, 2014) and biomedical sciences (Lewin, Glenton, & Oxman, 2009), and in applied situations - those that use knowledge developed through research to inform policy, resolve situations and for other practical purposes (Nakkeeran & Zodpey, 2012). In carrying out research for this thesis, I aimed to understand the complex array of social, psychological and physiological factors that people living with COPD attribute to becoming hospitalised with their disease or overcoming the threat of illness and avoiding hospital. Therefore, a qualitative approach was required.

In choosing a methodology to approach this problem, I read extensively around the many different epistemologies and theoretical perspectives commonly employed in social research, and the methodologies and methods that come from these. The following is an outline of the rationale behind my decision to use a constructivist approach to grounded theory for this thesis.

3.2.1 Epistemology

The research described in this thesis is based on constructivist epistemology. Constructivism proposes that knowledge and meaningful reality are based on human practices and experiences that are created by a person through their interactions with the world, within a social context (Crotty, 1998). We give meaning to objects, such as money, grounded in the context of what it means to our society – in our social surroundings. Similarly, social status means nothing outside of the context of that society. It is a meaning constructed by interaction with the world. In this way the experience of COPD is also constructed. For example, to me, as a free diver, having limited access to air is a positive experience; to a person with COPD limitation of air is a very different experience. Similarly, the experience of breathlessness during exercise is normal and expected, but to someone with COPD, or to someone less accustomed to exercise, breathlessness is a dangerous side effect of a formidable activity.

Everybody's experience of COPD is different. Everybody's experience of medical services is different. For instance, when I have been in hospital in the past, I have felt safe; that I would recover because I was being looked after well. That is my experience, my beliefs. Others, based on their experience, may believe that hospital is a place you go to die. Hospitals may go against their cultural beliefs, or they may feel distrust of health professionals. What it means to a person to be hospitalised is constructed out of their own beliefs and experience, beliefs influenced by interactions with the world and its people, systems and objects, DNA and childhood teachings and experiences. Similarly, what it means to be sick, to be well, to experience COPD, its progression and its effects, is constructed by an individual's beliefs and their experience of the world. No two people's experiences of COPD are the same. Some people are barely affected by it, whereas others are completely debilitated. Two people may have the exact same results on a lung function test, and the same comorbidities, or lack of, yet have completely different experiences, in fact lung function is shown to be a poor predictor of physical function, health status or quality of life in people with COPD (Bentsen, Henriksen, Wentzel-Larsen, Hanestad, & Wahl, 2008; Hynninen, Breitve, Wiborg, Pallesen, & Nordhus, 2005). So, what is it that predicts function and quality of life? Constructivism assumes that research will, in the context of these different worldviews and experiences, seek to develop theories that help us to understand these phenomena.

A strong point of difference in Constructivist research is the role of the researcher. Constructivism emphasizes the relationship between the researcher and the participants and consciously acknowledges that data is constructed through the interactions between them (Mills et al., 2006). According with the tenets of constructivism the establishment of a relationship between the researcher and participants is crucial to developing good quality research. There is a naturally occurring power imbalance in the researcher/participant relationship, which initial relationship building can work to neutralise. The relationship is also crucial to creating a sense of reciprocity, whereby the researcher and the participants equally construct meaning from the participants' beliefs and experiences. Only after this relationship is established, and the researcher pronounces their role in the research, can participants' stories be written into a theory (Mills et al., 2006).

Another point of distinction between Charmaz's constructivist grounded theory and the beliefs of Glaser, Corbin and Strauss relates to the concept of theoretical sensitivity. Theoretical sensitivity refers to the ability to recognise data that is important to your theory (Chun Tie, Birks, & Francis, 2019). While Glaser argued that a researcher should go into a grounded theory study with no prior knowledge or pre-reading of the topic (Glaser, 1992) this research was a better fit with Charmaz (Charmaz, 2006) whose belief is that having some preconceptions about the topic may provide good starting points for your research. In this instance I had been working within the topic for two years, as well as having a personal interest and therefore it did not seem possible to go into the research with no preconceived knowledge or thinking. My prior reading was used to help me to understand what options are around for people to avoid hospitalisation, that is, what interventions have been tried and are in popular use. It also helped me engage in conversations with the study participants during interviews, knowing when to prompt participants for more information about their experiences and perspectives.

3.2.2 Theoretical perspective

Grounded theory as a method is based on symbolic interactionism as the underlying theoretical perspective. Symbolic interactionism proposes that our understandings of the world are created through language, with definitions and meanings of words arising from interactions between people in a society. Thomas (as cited in Mooney et al., 2007) argued that social reality is interpreted by people, in the context of their definition of the situation; there is no objective reality that exists outside of people's interpretation of it. This aligns with my own personal beliefs and fits the situation we face when asking multiple people about their experiences with the same condition, the same medical system and, presumably, similar resources available. Charles Cooley (as cited in Mooney, Knox, & Schacht, 2007) described what he calls the 'looking glass self'. In this view of symbolic interactionism, people develop their identity and sense of ‘self’ by interaction with society. The way an individual is treated shapes their perspective of themselves and how they behave in the world. Throughout my interviews for the TCOPD project, it was curious to note people’s different experiences of similar situations. The areas of who was responsible for managing their disease, the role of the medical professionals and the differences in the individual experiences of being in hospital were notably varied. Therefore, it fits to look at this study through the theoretical perspective of symbolic interactionism in order to investigate further what exactly it is that makes each person’s experience of hospitalisation, or not, so different.

3.2.3 Grounded theory

Grounded theory seeks to understand psychosocial processes where no current understanding exists (Charmaz, 2006). In this study I am looking for a deeper understanding of the experiences, beliefs and resulting actions of a group of individuals whose story, relating to this topic, has not been told. Specifically, what is the process that happens in the mind of an individual with COPD when illness threatens? What beliefs and assumptions do they have about themselves, their disease and their society that influence the choices they make? What are the beliefs they hold that keep them out of hospital, when many around them are repeatedly being hospitalised with the same disease?
Using a constructivist approach to grounded theory we are able to delve into people’s experiences, develop a deeper understanding of them, and construct theories that help us to understand them (Charmaz, 2006).

Charmaz’s constructivist approach to grounded theory acknowledges that the researcher enters the research, and each interview, with their own understandings, beliefs and opinions about the topic, and with this preconception, co-constructs the data with the participants (Mills et al., 2006). I find it difficult to argue against this assertion when research is carried out via a series of questions, albeit open-ended, but still directive in some manner. With this acknowledgement, we can go forward with the research to produce a rich descriptive narrative, tied together into a theory of human experience, with no false pretences.

3.3 Methods

3.3.1 Overview of the study method

Charmaz (1997) discusses a number of steps she considered important in carrying out a grounded theory study. While Charmaz explicitly emphasizes that “... the strength of grounded theory methodologies lies in their flexibility” (Charmaz, 2006, p.168) the following essential steps have been followed and are discussed in detail in this chapter: Ethics approval, Participant recruitment & theoretical sampling, data collection, memo-writing, theoretical saturation, coding and data analysis. These are followed by a note on the koha given to participants and attempts to ensure this study's scientific rigour.

3.3.2 Ethics committee approval

Participants for this study were originally recruited as part of the TCOPD study (HRC 17/CEN/122, see Appendices A to D for a copy of the original ethics committee approval, participant information sheet, consent form, and approval of the first annual ethics report). An amendment to this protocol to extend data collection at the 12 month follow-up for the purposes of this study was sought (Appendix E), and provisional approval given (Appendix F), but due to my primary supervisor misunderstanding the ethics committees' reporting requirements (see the report in Appendix G), this provisional approval was not completed until just before my thesis submission, and approved by the ethics committee retrospectively (Appendix H). Nonetheless, ethics committee approval has been given for publication of data from this study.

3.3.3 Participant recruitment

Participants were recruited from the TCOPD study cohort. All participants in the TCOPD study had been admitted to Capital and Coast DHB (C&CDHB) for acute exacerbation of COPD (AECOPD) between January 2017 and January 2018. To be eligible for the TCOPD study, and hence the study in this thesis, a diagnosis of COPD, confirmed by clinical history, was required. Exclusion criteria for the TCOPD study included contraindications for pulmonary rehabilitation such as advanced malignancies, unstable heart conditions, or active psychiatric disorders. There were no further exclusion criteria for this study.

Potential participants were told about this study during the 12-month data collection interview for the TCOPD study and invited to take part. All participants who were invited agreed willingly. I used purposeful sampling to select people to be involved in this study. I aimed to select people who came from a wide variety of different backgrounds based on gender, ethnicity, and severity of symptoms. Initially, I also aimed to invite participants who appeared particularly willing and enthusiastic to talk about their situation, based on my experience of working with them during the 12-month data collection period. I believed I would get richer data to begin with by interviewing those who were eager to tell me their story. I was also interested in getting perspectives from people who were hospitalised regularly and those who had minimal hospital admissions. As the study progressed, I used theoretical sampling to recruit people who might be best able to expand on or challenge some of the early categories that were identified in the preliminary analysis (Charmaz, 2006). For example, as the concept of having a positive attitude began to emerge from the initial data, I was interested to explore perspectives from participants who were not as 'bubbly' in their initial TCOPD interviews in order to further develop this theoretical category. This led to recruiting quieter, less outgoing participants. Similarly, early in the study I began to notice differences in the genders, particularly when it came to symptom awareness, and the concept of 'just not worrying' and hence I recruited more men into the study to explore this further.

One of the initial areas under investigation for this study was people's experience with the TCOPD study. When initially selecting people to be involved in this study, I was initially blinded to their group allocation in the TCOPD study. However, after the first eight participants, it became apparent that none of my participants had any recollection of the TCOPD intervention. I could not tell at this stage whether this was because the selected participants had not been in the intervention group for the TCOPD study or whether they had been and could not recall that intervention. At this stage my supervisor, who was not blinded to group allocation in the TCOPD study, checked the study identification number for the people I had spoken to, and purposefully selected additional names of people for me to follow up with in order to ensure equal representation of participants from the TCOPD intervention arm. I contacted four more participants from this list by telephone and each agreed to be part of the study.

3.3.4 Data collection

Interviews ranged for 45 to 90 minutes, and the duration of each interview was influenced by the participants' willingness to talk and their stamina. Following grounded theory methods, as analysis unfolded and concepts emerged, questions became more focused to elicit information about particular aspects of the theory, with a focus on process (Stanley & Nayar, 2014). Face-to-face, semi-structured interviews were the most suitable method for interviewing because being in the comfort of participants' homes, where I had already met them twice, gave them the sense of control and comfort that allowed them to open up and speak freely. Interviews were scheduled to take place in participants' homes. I called the participants the day before their scheduled interview to remind them about the interview and check that they were well enough to go through with it. It was common for participants in the TCOPD study to be rehospitalised at the time of a scheduled date collection appointment. All interviews were carried out at the participants' homes except for one participant who, on the day, was in hospital and did not expect to be returning home. With his permission I interviewed this participant in hospital.

Predetermined open-ended questions *were* used as prompts to initiate conversation about the participant's condition, their hospitalisation records, and their beliefs about what kept them well or stopped them recovering from an exacerbation. Examples of the main questions were: "How has your health been in the last year?" "What do you think contributed to this?" "Normally what steps do you take when you think you're going to get sick? E.g. sleep, good food, medications, stay home?" "Thinking back to when you've been sick, what things do you think contributed to, or made you sick? - what was happening at the time?" "Were there any times you thought you were going to get sick but you managed to pull through and avoid it? What helped?" (Appendix I). As the study continued and new ideas and concepts emerged, questions were added to investigate the concepts with other participants. An example was questioning around people's understanding of the disease, when and how they were diagnosed and how this affected their health management behaviours. Interviews were audio-recorded and transcribed by a third party, who signed a confidentiality agreement. The completed transcription was emailed to me via my personal email address.

In addition, I collated some data which had been collected as part of the TCOPD study. This data included participants' gender, age, living situation, number of episodes of moderate or severe AECOPD, disease-specific health status, and mental health at 12 months post index admission. Episodes of moderate AECOPD were defined as those requiring treatment with oral corticosteroids or antibiotics, but not hospitalisation and episodes of severe AECOPD were defined as those requiring admission to hospital (Seemungal et al., 2009). Disease-specific health status was measured with the Chronic COPD Questionnaire. This measure produces a total score from zero to six, with higher scores indicating poorer health. People with COPD who have a Chronic COPD Questionnaire score over three have been found to be three times more likely to die over a five year period than people with a score under one (Sundh, Janson, Lisspers, Montgomery, & Ställberg, 2012). Mental health was measured using the Hospital Anxiety and Depression Scale. The Hospital Anxiety and Depression Scale produces two scores: one for depression and one for anxiety. Both are scored on a scale from zero to 21, with scores above eight indicating possible 'caseness' for clinically significant anxiety or depression (Bjelland, Dahl, Haug, & Neckelmann, 2002).

Transcripts were stored securely on my personal password-protected computer. Emailed copies of transcripts were deleted. Interviews were stored on the password-protected tablet which was stored securely in the university office. No hard copies of transcripts were produced. On completion of the paper, all files will be stored on an external drive in a locked filing cabinet in the University of Otago's Wellington campus for five years, and all other copies of the data will be destroyed.

3.3.5 Data analysis

Data analysis commenced after I conducted the third interview using line-by-line coding to begin the development of initial codes (open coding). Data was coded in NVivo software (QSR International, Melbourne, Australia). From there, in line with the constant comparative method, further participants were recruited using purposeful sampling (Strauss, A., & Corbin, 1994). Coding continued throughout the interview process. It allows for common categories or gaps in the data to be identified and is believed to influence the direction of the interviews (Charmaz, 2006). This was the case as described above with the emergence of the category of diagnosis and disease management, as well as self-efficacy, which became a dominant concept halfway through the interviews.

3.3.6 Memo writing

Memos and diagramming were kept throughout the data collection stage, both immediately post interview and at other times when thoughts came to mind. These were used to assist in the development of a multi-dimensional understanding of the data and the development of theoretical concepts (Charmaz, 2006). Further analysis explored the relationships between codes to develop higher order concepts.

3.3.7 Theoretical saturation

After the initial two to three layers of coding patterns began to emerge in the data. These patterns were developed into categories using analytical features common in grounded theory research such as; memo writing, analysis, reflection, and discussion with my supervisors. After the ninth interview theoretical saturation was reached; no new data were emerging. I completed three further interviews to test the emerging themes and look for any new data (Charmaz, 1997).

3.3.8 Koha

Participants received a koha, by way of a $20 gift voucher, on completion of the interview.

3.3.9 Scientific rigour

Conversations with my supervisor continued weekly throughout the interview process and writing of this thesis. This arrangement ensured that any queries I had about data collection process, including ethical issues and issues concerning my own safety or that of the participants, were addressed or could be discussed, along with content issues including questions that I thought should be added, and when to push for further answers or to back off from a topic, for ethical or emotional safety reasons. All coding and conceptualisation was reviewed and discussed at these meetings. My supervisor coded transcripts to compare ideas and concepts. This gave a broader perspective of the data and enabled a deeper analysis.

3.4 Ethical and cultural considerations

Ethical approval for this project was extended through the TCOPD study (see Appendices A to H).

All participants signed consent forms (Appendix B) to take part in the initial TCOPD study, of which this accepted, by the ethics committee, as an extension. The information sheet/consent form explained the participants' right to withdraw at any stage, participants' rights to apply for ACC compensation if they felt they had been harmed by the study, participant anonymity by way of name change, and that all information and transcripts were stored on a password-protected computer.

All measures were taken to ensure planned ethical commitments were met. These included consultation with whānau when Māori or Pacific Island people were interviewed; in two cases this meant having family present throughout the interview as this was important to the participants. Observation of known Māori and Pasifika customs such as removing shoes at the door were observed. In accordance with my understanding of Māori and Pasifika cultures, introducing myself via my background first, followed by inquiring about participants' whakapapa preceded the introduction of the interview questions.

Ethical issues that arose were in regard to interview content. Although I suspected some participants might feel uncomfortable or distressed talking candidly about their disease and what it meant for them, this did not appear to be an issue; however in three cases participants talked about experiences they had had in their lives, such as during the war, that I thought were distressing. Similarly, in some instances participants showed deep sadness and regret when discussing factors that had contributed to their disease. Again, I checked if participants needed professional support, and all were content with their support networks and did not need immediate care. I discussed these incidences with my supervisor at our weekly meeting, and while they touched me on an emotional level, I felt privileged at being trusted with this information and at being a part of the participants' lives, rather than feeling any negative emotions.

There were no conflicts of interest. The study was not funded as it was a Master's Thesis. My personal interest in the topic were discussed and exposed as per constructivist grounded theory methods (Charmaz, 2006).

Chapter 4: Results

4.1 Introduction

In the results section I introduce the participants, summarising their demographic characteristics as well as relevant details about individual people's contexts. Next there is an overview of the main concepts, and discussion of additional factors which emerged from the findings. A visual representation is used to illustrate the interrelated nature of the main concepts. Each concept is presented with extracts from interviews as examples. Participants are given pseudonyms to support their anonymity.

4.2 Participant characteristics

A total of 12 participants were recruited from the TCOPD study. On average, the participants were 69.3 years old (SD 13.30 years). Six participants were female and six were male. Detailed demographics are reported in Table 4.1. One participant had a spouse present, who contributed significantly during the interview. While she was not officially a participant in this study, and therefore is not quoted in extracts reported in this chapter, her presence during the interview is noted in the reporting of these results where relevant.

The majority of participants in this study had experienced significant ongoing health problems in the 12 months since their initial hospital admission, when they had been first recruited to the TCOPD study. Ten of the 12 participants had experienced at least one moderate AECOPD in the 12 months following their index hospital admission. Half of the participants (6/12) had been hospitalised at least once for AECOPD in the 12 months following their index admission. On average the participants experienced 2.4 episodes (range zero to seven episodes) of moderate to severe AECOPD in the 12 months following their index admission. Only two of the 12 participants had experienced no moderate or severe episodes of AECOPD during this period.

The participants' Chronic COPD Questionnaire scores indicated that many had serious health consequences from COPD with five of the participants scoring above a three out of six on this scale. Only two participants scored above eight for either anxiety or depression on the Hospital Anxiety and Depression Scale, with the average scores being 3.8 for anxiety and 4.6 for depression. These low scores are not consistent with clinically-significant problems with anxiety or depression.

Table 4.1: Participants' characteristics (n=12)

Age (years)	Average 69.3 (SD 13.6); range 29 – 84
Gender	6 male, 6 female
Ethnicity	2 Māori, 3 Polynesian, 7 NZ European
Living status	4 living with spouse, 3 living alone, 3 living with family, 2 in hospital-level residential care
Smoking status	2 current smokers, 8 ex- smokers, 1 never smoked
Pack Years	Average 32.6 (SD 24.6); range 0.3 – 82.5
Body Mass Index	Average 27.82 (SD 4.96); range 19.2 to 36.2
On domiciliary oxygen	2 Yes, 10 No
Ever attended pulmonary rehabilitation	6 Yes, 6 No
TCOPD intervention arm	5 Yes, 7 No
Average number of moderate AECOPD events within 12 months of the index hospital admission	Average 1.8 (SD 2.3; median 1, range 0 to 7)
Number of severe AECOPD events within 12 months of the index hospital admission	Average 0.7 (SD 2.3; median 0, range 0 to 3)
Total Chronic COPD Questionnaire scores at 12 months	Average 2.7 (SD 1.5; median 2.4, range 0.4 to 5.2)
Hospital Anxiety and Depression Scale – Anxiety score at 12 month	Average 3.8 (SD 3.7; median 3.5; range 0 to 10)
Hospital Anxiety and Depression Scale – Depression score at 12 month	Average 4.6 (SD 1.8; median 4.0; range 1 to 8)

SD=standard deviation; COPD=chronic obstructive lung disease; TCOPD = "Taking Charge of COPD" study; AECOPD = acute exacerbation of chronic lung disease

4.3 Overview of the main concepts

Overall, most of the participants in this study felt that their actions and behaviours had a considerable impact on their health and wellbeing and contributed to prevention of further AECOPD. Three overlapping factors emerged from the interviews related to prevention of these exacerbations*:* 1) *Being Proactive*; 2) *Being Positive*; and 3) *Being in Control* (see Figure 4.1).

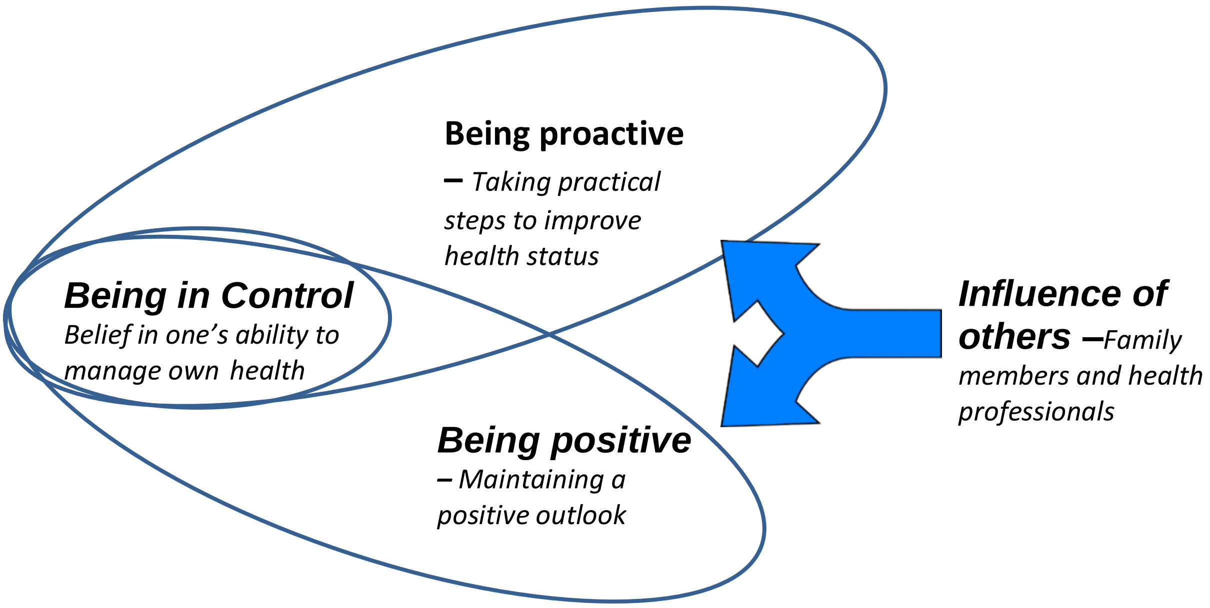

Figure 4.1 Overview of study findings

Being Proactive referred to all the practical steps participants took to manage their health and to ward off exacerbations. This concept relates to both an extensive list of actions participants took on a daily basis to maintain their health, and a more specific list of actions participants took when they felt a threat in the form of colds, flus or lung irritants. Three sub-categories can be identified in relation to these lists of actions. They are named *Health Maintenance, Avoiding Threats*, and *Fighting Back.*

Being Positive refers to thoughts and attitudes held by participants that they believed enhanced their health and decreased exacerbations, or, conversely, attitudes that participants believed were the source of poor health outcomes. Some participants differed in terms of how much emphasis they placed on elements of being positive versus being proactive. One participant for instance placed a lot more importance on being positive than on specifically thinking about and addressing his health problems associated with COPD. However, most participants talked about the importance of staying positive *and* taking an active control over their health.

Being in Control refers to the extent to which participants believed that they were in control of their health. All of these elements were interrelated. The participants' perceptions of how much in charge they were of their health related to their perspectives on how much they could be proactive and be positive. In many participants' experience, taking positive actions in favour of health led to improvements in health outcomes and decreased severity of exacerbations, and resulted in both positive attitudes and an increased belief in their ability to manage their own health. Likewise, having positive attitudes led participants towards taking positive actions, resulting in improved health outcomes and fostering the belief in their ability to self-manage.

Being Proactive, Being Positive, and Being in Control were also all influenced by other people in the participants' lives. Family members had a particularly important role to play in influencing these factors, with one participant being almost entirely dependent on a spouse to be able to have any control over his health. Health professionals were seldom mentioned by the participants as having a role in their response to COPD. The exception to this was the relationship that patients had with their general practitioners, and the degree to which these health professionals supported them to access additional medications during a period of AECOPD. Also of importance was how health professionals had engaged with the participant when first informing them of their COPD diagnosis and what this meant in their lives.

Finally, despite feeling in control of much of their lives and actions, some elements of AECOPD appeared to be inexplicable to the participants, and out of their control. Exacerbations could occur or worsen without warning, leaving the participants with some degree of uncertainty about how much influence they ultimately had over their health.

4.4 Being Proactive

For the participants in this study, taking control of their situation and taking positive actions to improve their health was a key component of taking charge over their COPD. Being proactive involved the participants taking practical steps to look after their health, rather than just responding passively to health events or problems after they occurred. The participants talked both about things they did on a daily basis to maintain optimal health and specific actions they took when they detected that a threat to their already fragile health was imminent.

This main concept comprises three categories: a) health maintenance, b) avoiding threats, and c) fighting back. In relation to each category, the participants described several actions they took to support their health. The amount of time, effort and thought put into doing this varied widely among participants, with some extremes in both directions.

Health maintenance

A small number of participants reported being strongly focused on health-promoting activities as a way of life. However, over half of participants said that they paid little or no attention to looking after their health. They did not consider that their daily routines were focused on health or that they took any specific actions to maintain their health. As one participant put it:

> I wake up in the morning, that's a good start. I probably – apart from multivitamins and not really – there's nothing I consciously think I should do that because it's healthy. – Christine

However, most participants had some practices that they followed, whether consciously or unconsciously, because they believed it was good for them. Actions that people took to look after their health fall into four categories: self-monitoring, exercise, nutrition, keeping warm and managing access to medications.

Self-monitoring

Self-monitoring happened in some way for most participants, but the method and the extent to which they self-monitored varied widely, with some monitoring symptoms almost obsessively, while others were just learning to notice important changes in their health. For three participants, regular self-monitoring allowed them to track their health and note if there were any changes that might be suggestive of an incoming bug or illness. This self-monitoring was a very conscious and precise task:

> I monitor myself here – see they just come and check this [Referring to a wrist digital blood pressure cuff]. They [nursing home staff] know damned well I check myself regularly. I look after myself a lot here they know that. - Peter

When I first interviewed Peter for the TCOPD study (three months after discharge from hospital for his initial admission for AECOPD), he was staying in shared accommodation where he reported there were thieves, drug addicts and smokers. He was very unwell and kept his medicines underneath his bed. When I came to interview him for this study, Peter was living in a nursing home where his drugs were controlled by staff, but where he could monitor his blood pressure, temperature and the humidity in the room 24 hours a day. Based on his blood pressure he would adjust the humidity by opening or closing the window.

Vera also had a methodical approach to monitoring her health. She kept a diary of her baseline physiological measurements and used this to monitor any changes which might signal that her health was under attack, requiring her to take action. She was keen to show me her daily records of her temperature, medication use, medical visit, diet and other health statistics.

> I monitor myself like every morning, I do my temperature, my oxygen level, my pulse and a peak flow and that's before I take any drugs. So that's the baseline for today. -

> Vera (showing her daily health records)

Despite having seven moderate exacerbations of COPD requiring additional medical treatment, Vera had no hospitalisations over the 12 months she was in the TCOPD study.

More common than this type of strict monitoring of physiological status was the tendency for participants to use subjective experience of symptoms to indicate when it was time to take action. These participants did not have an interest in monitoring their health so formally, but paid enough attention to notice changes in either the way they were feeling or the way their body was performing. Even among these participants there were varying levels of health monitoring. Typically, participants waited for obvious physical symptoms to indicate a worsening in their health status (e.g. increased phlegm, excessive shortness of breath or other symptoms of exacerbation) before they took any action:

> I felt the bugs coming. I spat up the first lot of phlegm and I thought I'll get straight onto the antibiotics. – Sheryl

A small number of participants did not notice illness coming on; just that suddenly they became unwell or unable to carry out their regular daily activities. A very headstrong and busy man, Gerald loved playing in his band and running his physically-active event supplies business. He seemed to be oblivious to his health and his wife took on the role of "home nurse", but when I asked about how he knew he was becoming unwell he replied:

> Some days if I do something physically - it could even be carrying a bag of firewood up the stairs for instance - you know, another day. Whoof, I've got to sit down. - Gerald

When asked to elaborate on his methods, Gerald described feeling more tired than usual during normal activities or having to rest more frequently than normal and this would indicate that he was not feeling well and needed to take his inhalers.

However, while most participants reported some level of self-monitoring, a small number reported that they did not pay any attention to their health at all. These participants reported that often the indicators of their health worsening were only apparent in hindsight, and identified too late for them to take action. These participants thought that they would often derive benefit from taking more proactive steps earlier. For instance, Emmett had experienced three severe exacerbations in the 12 months prior to his interview, and indicated normally he did not pay enough attention to his health:

> I just suddenly start getting a cold and the usual thing it's a cold, sore throat for a couple

> of days and someone’s put a rasp in your throat and then it just suddenly gets worse. Usually, my fault is possibly leaving it a bit late and taking the antibiotics and the prednisone. – Graham.

Emmett believed his health was declining and blamed his increasing exacerbations on this. It seemed the rate of decline was more rapid than he was prepared for and exacerbations could take him by surprise.

There was one participant who was on the extreme end of paying no attention to his health. Dennis was an active, happy-go-lucky man whose interest was purely in having a good time, having a laugh and enjoying himself. He enjoyed cooking but had no interest in his health at all. When talking about paying attention to his condition, Dennis explained that he had watched his brother die of lung cancer and as a result he chose to ignore issues relating to his own health:

> I’ve gone and stuck my head in the sand ... No, I don't think about these things [health-monitoring]. All I want to do is have a laugh – seriously, that’s all I want to do. Smile and laugh every day. - Dennis

In contrast to Emmett, Dennis was one of the two participants who had no moderate or severe exacerbations in the 12 months leading up to our interview.

Overall, there was considerable variation in the extent to which participants monitored their health. For some, proactive health monitoring was a core part of daily life. Other participants had a more casual attitude, but still monitored their health informally and took action when required. A few participants ignored their health status blatantly, either because they were not in the habit of paying it so much attention, or because they thought that obsessing about their health was bad for their mental wellbeing.

Exercise

Exercise was important to all participants but in different ways and for different reasons. While all participants saw exercise as vital to staying well, what constituted exercise, and how they believed it contributed to their health, varied among participants.

A small number of participants viewed exercise as having a direct effect on their functional ability and their ability to breathe. They saw exercise as its own activity, independent of everyday life, that needed its own time and space. These participants tended to stick rigidly to their exercise plans and saw them as a crucial part of their disease management. For instance, Cynthia who had not previously been physically active earlier in her life, now advocated for the exercises that she learned at pulmonary rehabilitation:

> I've got a course of exercises I do every other day. If I keep doing them, I find my lungs are a lot stronger and I have more energy and I can do more and I've also managed to stay out of hospital… now I'm determined I'm going to keep doing the exercises and just see, and so far it's making a difference so keep going. – Cynthia

A number of participants maintained physical activity on a daily basis but did not engage in what they considered "exercise" as a hobby or daily activity specifically. Dennis was a good example of this group: he was a very active man with a carpet laying business and a dog that he enjoyed walking, but he consciously chose not to do "exercise":

> I thought about exercise then I thought again… I mean I'm getting out of bed and going and doing things it's like walking the dog you know so it's not as if I'm a couch potato. I don't just sit around. You know if I've got no work on for a day, I'll be out in the workshop doing something. – Dennis

This group of participants talked about keeping fit, walking, in some instances swimming and going to exercise classes. Some played bowls or walked their dogs, but most of them did this because it was good for their general health, rather than because it was a requirement for their disease management. These participants kept themselves busy because they believed it was good for them, both physically and mentally. They found it difficult to separate the physical benefit of exercise from the mental health benefits, and talked about physical activities in terms of achievement:

> No, it's both. One, you feel more positive. Because you've achieved something. – Emmett

Some participants emphasised the social aspect of exercise more than the physical or mental aspects. For these participants exercise was a by-product of socialising, but the relationship was clearly intertwined:

> I don't know about the exercise because she [the dog] does more than I do. It's probably the fresh air, it's the social side of it because everybody talks to you. - Christine

Some participants were more motivated than others and, in general, displayed the same variation in motivation levels that might be found in healthy populations. Fitting exercise into busy schedules was an issue for several participants. Some busied themselves with social engagements, others with housework and normal daily activities and some participants were still working, but all of these participants prioritised exercise and found a way to make it work:

> Whenever we do swimming or exercise, we have to do it first thing in the morning otherwise you don't do it. So, we have to fit things in don't we. - Emmett

Most participants motivated themselves because they knew that exercise was good for them. Participants talked about pushing themselves even when they did not want to exercise because they knew that if they did not, they would feel worse or go backwards in their health. Most participants displayed a stoic attitude towards exercise. It was not a question of whether they would do it or how they felt about it, they simply would do it because they had to.

> Oh yeah I think it goes back to just going out every day for a walk whether you want to or not. – Christine

Some participants who struggled with motivation relied on the support of friends and family. Emmett for example, who appreciated the importance of exercise, often lacked the motivation or discipline to follow through with it each day. His wife often motivated him to get started but it seemed that once he began he would find his own motivation.

> Okay. Not having done [exercise] for a while I'll be struggling to do two minutes... But if I do it day in and day out by the end of a week, I'm comfortably doing two minutes. – Emmett

Only one participant was completely inactive, but this was due to her other comorbidities. As well as serious heart problems and an autoimmune disease, Vera had severe, inoperable arthritis. Although she knew she should exercise, her increasing pain levels stopped her. Another young participant, Gina, while occasionally active, was easily deterred by poor weather. Gina had serious comorbidities that would limit her walking when the weather was unsuitable:

> I just I keep meaning to, and then just not because I wake up in the morning and it will be windy like this and I don't want to do that. -Gina

A small number of participants believed that physical activity played a strong role in preventing severe, uncontrolled exacerbations. Three participants expressly associated lack of exercise with hospitalisations. Some talked about regretting being less active when they had the ability to do more:

> I think walking around and moving around all the time. I think that's the biggest …. if you sit on your arse all day, you know, …..[I've been doing] very little [exercise]. You

> know that’s where I went wrong, I realise that now, but now I realise that I should have gone up to the hospital and done the pulmonary care you know instead of lying on my bloody arse looking at the walls or whatever. – Hector

The majority of participants believed that exercise was an important factor in maintaining optimal health. A small number directly associated exercise with a decrease in exacerbations or, conversely, associated a lack of exercise with increased hospitalisation. These participants were primarily those who had been hospitalised more frequently.

Nutrition

A small number of participants identified nutrition as big factor in their personal health care. While this was not the first thing anyone identified when thinking about the actions they took to prevent exacerbations, the discussion during interviews frequently turned to the topic of nutrition eventually. Once the participants started discussing nutrition, it became obvious that some rated nutrition highly.

As for exercise, the importance attributed to nutrition varied among participants. At one end of the spectrum was Peter, who was an advocate for fruit in particular, and who discussed at length its benefits, and his belief that people were suffering because of the high price of fruit:

> You’d be surprised what fruit does for people they don’t realise it. They don’t realise it though they put the dollar and cent on it see because it’s so expensive, I say stuff everything else eat fruit because things have got so dear fruit is bloody dear now. – Peter

A more common belief among participants was a varied diet based on meat and vegetables was needed for good health. Gina, for instance, believed that she had become run down when she was eating poorly as a result of her bakery job. The participants with this view of nutrition did not tend to go out of their way to search for health-promoting foods, but common sense told them that eating a diet based on whole foods was good for them:

> I just try to eat like quite a lot of vegetables and fruit and like for meat dinner we always put extra vegetables into it and just like some more stuff like that. – Gina

An interesting comment came from Vera. Discussing how she believed leaving her ex-husband contributed to the improvement in her health, Vera spoke about the pleasure of cooking and eating as opposed to the unhappy way she had experienced this in the past. However, her focus was on the process of cooking and eating as opposed to the nutritional aspect of food per se.

> I can spoil myself now if I want to eat well… if I want to eat something I can go out and buy enough just for me and I can cook it the way I like it cooked and I can eat it the way I like to eat it and I enjoy it thoroughly. - Vera

This relaxed attitude towards food was common among participants, often reflecting the need to find a happy balance between being healthy and enjoying life:

> I think oh well what's the good of living if you can't have this and you can't have that. - Dennis

There was a variation in beliefs about nutrition that perhaps might be found in any sample of people, healthy or otherwise. In this study, the participants leaned towards a diet of meat and vegetables, with a small percentage showing more enthusiasm for food as a health promotion tool than others.

Avoiding threats

Despite their best attempts at health maintenance, all participants were still at risk of getting colds, flus, and exacerbations of their COPD symptoms, which could mean becoming very unwell and result in hospitalisation. In order to find out what actions people took to avoid exacerbations it was important first to discover what factors they believed were responsible for their exacerbations. Four areas were identified by the participants: 1) change in seasons, 2) colds and flus, 3) cigarette smoke and 4) cleanliness. For each of these areas participants had actions they took to avoid the threat of exacerbation and keep themselves safe. A small number of participants reported having no idea what caused their exacerbations.

Keeping warm

Temperature was a factor discussed by most participants, with an almost universal belief that being out in bad weather or having a cold home would be a risk factor for becoming unwell. However, the extent to which participants believed that keeping warm was important for their health varied, as did the extent to which they acted on this belief. For some participants it was just common sense that if it was cold you would be at risk but the vast majority of participants believed that cold environments, changes in temperature, or poor weather were almost entirely responsible for exacerbations of their COPD.

> I mean what happened last time was that I was still playing golf … and we didn't finish until virtually dark by which time it was freezing and the next minute I was back in hospital. – Emmett

For this group, keeping themselves and their homes warm was top priority. The cost of heating was a factor that influenced their willingness to warm their homes however, and some participants preferred to wear extra clothing and not use home heating:

> If the family are here I'd have the fire going but we don't have heat pumps you know, so I just put a jacket on, put a jersey on put another jersey on and so the cold doesn't affect us too much – Gerald

Whereas others believed heating the home was worth the cost.

> Yes. My power bill during the winter is probably three times what it is in summer…Well, you know, either I sit around here and freeze or I have my warm coat and blankets and everything on that's ridiculous. – Bill

For some participants keeping out of the cold was so important that they sacrificed sporting activities, recreation, and visiting family members in order to stay warm.

> Cathy was threatening that you know, if you don't get the heat up and look after yourself, I'm not coming around you know [Discussing visiting his mother in law]. – Emmett

The drop in temperature associated with autumn and winter was one aspect that all participants agreed provoked exacerbations. For most this was obvious, and they regularly took steps to avoid the elements in these seasons, such as wearing warm clothing, heating their homes and staying out of the weather. However, for a handful of participants, it took some thinking before it dawned on them that the change of season put them at risk:

> Yes. Actually, change of season is actually, I mean that's when lots of old people die too, change of season. But that's most probably what it is. – Sheryl

Avoiding infections

With the change in season came colds, flus and other infections that many participants were aware of and avoided. The participants talked simply of staying away from people who were sick. This did not appear to be a problem to anybody, and it had become a normal part of life. There was no talk of friends, family or participants themselves struggling with this either physically or emotionally, and everyone had ways of meeting their needs for shopping and other every-day tasks. Participants simply knew that if an associate was sick, they should stay away.

> Well just trying to keep away from where the bugs are, if I hear somebody coughing down the road I'll go and lock myself somewhere away you know. Yes, that was it. Keep away from them. – Hector

One participant talked, not about avoiding others, but about her friends and family avoiding her when they had colds and flus.

> Like if my other sisters that don't live with us is that [sick] they'll just not, try not to come around or my sister's kids will like, just stay away from me. - Gina

No other participants mentioned this and not all participants felt so strongly about avoiding infections. Some did not mention it at all, and others were quite blasé about it: Picking up bug was just a part of life.

> Well, I would have picked it up from somebody. I mean flu germs get around. If there's something going around … and you'll be against it it's very hard to avoid it because you can't see it. So, it could have been anywhere, supermarket, club, anywhere, it could have been in here. – Bill

Avoiding Smoke

Although 11 out of the 12 participants were ex-smokers only two participants expressed concern about being around cigarette smoke. For these two, cigarette smoke was the number one cause, they believed, of worsening COPD symptoms and they worked actively to avoid being around it.

> Oh, I'm not near anybody smoking that's one thing … and being away from smoke that's the biggest thing for me. If I see anybody smoking, I'll head the other way even now. – Peter

Conversely, Sheryl also believed that cigarette smoke increased her risk of exacerbation, but this did not stop her from indulging in a cigarette if she was sufficiently tempted. One of her friends whom she had recently cared for after he suffered a heart attack was staying with her, and Sheryl acknowledged that being with him encouraged her to smoke. She talked about ways to stop smoking and was investigating vaping. Sheryl put her decision to smoke down to feeling depressed:

> Actually, this time when I bought the packet, I was a bit down and I don't get down, but I was getting a bit depressed. And maybe that's what made me buy them or whatever I don't know. - Sheryl

One other participant continued to smoke with no regard to the impact of this on his health. Dennis believed that good luck and having a positive attitude was enough to keep him well and he had a very blasé approach to his health. Neither Sheryl nor Dennis had had a severe exacerbation in the 12 months prior to the interview, although Sheryl had had three mild exacerbations.

Cleanliness

An interesting belief that came through strongly in two participants' interviews was the concept of keeping a clean environment. Hector talked about the dust from his heat pump in his Housing New Zealand home being an irritant and causing him to get sick. He was certain that this was a significant contributor to his hospitalisation, and he was unable to maintain it himself.

> *A.H: When you came into hospital last time what do you think caused you to get sick then?*
>
> Hector: With the heater.
>
> *A.H: Oh the heater, yep.*
>
> Hector: As I say if you don't clean your filters, they're not going to clean themselves and the last time we cleaned them when my daughter came around and cleaned them she showed me the gunk we've got on them, heaps of gunk on them. -Hector

Peter, who had a small single room in a rest home, believed that keeping clean and tidy was key to his health and wellbeing. Peter took charge of his health by monitoring his own symptoms and adjusting his environment appropriately, and as a result he felt fully in control of his health.

> I take care of myself; I clean everything. Cleanliness is very high for me no matter what I do, no it's try and look after myself like anybody should do. – Peter

Fighting back

When the participants did detect that their health condition was worsening, they took active steps to combat the exacerbation. All had different attitudes towards it. Some saw it as a personal challenge that they wanted to conquer, others were more inclined to be gentle on themselves and work with their body, while still others felt they had no control over the situation and would inevitably succumb to the sickness when it struck.

Access to medication

The primary way of fighting an exacerbation, which all participants agreed on, was having access to, and taking medication when they needed it. All participants had a ‘back pocket prescription’ for antibiotics and in some cases, steroids. The term ‘back pocket prescription’ was used to describe a prescription given by the general practitioner COPD patients keep at home ready to use at the first sign of an infection. The idea behind this is to attack the infection early on and prevent its spread, giving the patient a better chance of avoiding a full-scale infection. This required a certain amount of self-monitoring by participants – a task that some were more inclined to take responsibility for than others. Drivers for deciding when to take this additional medication differed between participants. Some took antibiotics as soon as symptoms presented, because they believed firmly that this was their best chance to avoid ending up in hospital. For instance, when asked why she believed had not been hospitalised for over a year, Christine explained:

> Why? Because my doctor’s given me 40 Amoxil just to keep in my back pocket in case I need them. So as soon as I cough start taking them. - Christine

In a small number of cases participants were not aware of their worsening symptoms and as a result took the medications when it was too late. Emmett and Gerald, for example, often did not detect the seriousness of their symptoms until it was too late. In both cases, Gerald and Emmett’s wives reportedly asked their husbands to take the antibiotics when they first noticed excessive breathlessness, or cold-like symptoms, but the men refused. Emmett put this down to stupidity:

> Yes stupidity. Yeah. No, I mean I think, oh, it’s just a cold. – Emmett

At their interviews, both men were beginning to question their decision making in this regard:

> Yes, recognise all these things and work on them, act upon them ... It’s going to take a while for me to get to that. - Gerald

Among the participants in this study, leaving the decision to take additional medication until the last moment was more common among men than women. One man had not been sick in the 12 months prior to the interview so had not needed medications, but three of the remaining five men admitted to taking the medications only when their symptoms had become very serious:

> No, I felt really sick. I thought I’d better go out there and get something done. – Bill

With one exception, all the women and two of the men took the antibiotics and steroids as soon as they saw symptoms. Cynthia, however, felt that she was sick of taking medication and wanted to fight off the exacerbation herself.

> I was a bit tired of taking all these steroids, so the last flare up was a real nasty cold and I didn't go to the doctor at all. I'm trying to get my body to fight for itself. And I've just got over it myself so I'm actually very rapt because I managed to get over a flare up. - Cynthia

Cynthia talked enthusiastically about how pleased she was to have succeeded in fighting the cold off herself. Techniques she believed helped her included: pure stubbornness and determination, lemon and honey drinks, continuing her normal routine as much as she felt she could, allowing herself extra rest, and self-monitoring of her peak flow and oxygen saturation. If her oxygen saturation dropped below 92%, Cynthia said she would have gone to the doctor. No other participants reported making such a conscious effort as this to fight an exacerbation as this.

Home remedies

Three of the female participants talked about making special tonics of ginger, lemon or manuka honey to assist their immune system to fight off colds and flus. Each of them was certain that their tonic was crucial in warding off sickness.

> I've got ginger up there and grate it, pour boiling water over it and lemon grate that as well and put it through the sieve and lashings of honey in it and drink lots of that drink every night…. a couple of Panadol and a nice hot drink. It seems to get you there. - Cynthia

Most participants talked about losing their appetite when they become unwell. For Sheryl, years of managing her diabetes prepared her for this and she knew she had to eat, so she would force herself to even if it was a small meal. Vera premade meals and froze them in preparation for when she became unwell because she understood the importance of eating even if she didn't feel like it.

> And I'll put it in the deep freeze and then when I'm sick or not feeling like cooking or whatever you'd be surprised what's in my deep freeze. - Vera

There were no further claims to specific nutrition supplements or aids. Most participants, in fact, claimed they made no effort to use food to help their fight against exacerbations.

Resting and routine

Finally, the participants often talked about resting more and taking it easy when they felt they were becoming unwell:

> Probably just like try and rest for a while or go to bed earlier. - Emily

However, they also discussed the importance of maintaining a semblance of their usual routine when sick. This was to do with feeling normal, and the idea that if you put on your sick clothes, you become sick. Some participants believed that too much variation in their routines could cause them to give in to an illness, but, to an extent, ignoring symptoms and carrying on as normal was reported as a good way of fighting exacerbations.

> Yes do my everyday thing. I'll go out and feed the birds, I'll hang the washing out, I won't, I'll do everything I normally do even though I feel sick I'll make myself do it. Probably I won't be able to do the gardening, or maybe I won't get out and look in the letterbox, it's quite a walk up and down those stairs, but I'll do everything else I normally do whether I drag myself around I will do it. - Cynthia

This idea of maintaining a healthy mentality was shared among most participants. They did not want to be unwell, or think of themselves as unwell, even when they were. Most of the participants were determined to get on with their lives and not stop living because of the disease.

Not all participants paid attention to their health but those who did had a range of beliefs on how best to look after their health on a day-to-day basis, as well as how to ward off infection when it threatened. The actions that participants took were not wildly different from each other and were actions that were not surprising to see in this generation in this country. While participants displayed a considerable variance in the amount of time and effort they put into looking after their bodies, no extreme actions or beliefs were revealed through these interviews.

Influence of the Taking Charge of COPD study

Five participants in this study had been in the intervention arm of the TCOPD study. Three of these participants remembered being in it and two did not. Those who did remember having the intervention all had very different experiences. One participant remembered a strong message from the staff member who delivered the intervention but did not remember the intervention itself.

> No, I don't remember anything about the book, but I remember being told that I should join a singing group. – Christine

Another participant thought that the intervention was a waste of time and was upset because he'd been expecting information more tailored to his situation.

> There wasn't, I don't remember much stuff on how to manage the condition … Well, say,

> kind of informally [I wanted information on] what I need to do, more the things I needed to do to alleviate that happening again, because I certainly don't want it to happen again. - Dennis

The third participant who remembered the intervention had a positive experience with it but, despite her best intentions it did not seem to have any impact on her behaviour. Gina made plans to go to COPD rehabilitation classes and wanted to go walking so that she had something to report back on at the next meeting; however, those plans did not come to fruition.

> I thought about going to one of those COPD meeting things [pulmonary rehabilitation] but I haven't. – Gina

All participants tried hard to remember whether they had been the intervention, and some who were not in the intervention remembered being in it. Some participants in the control group mistook the data collection phase of the study for the intervention. One participant who had been in the intervention arm became confused as she talked about it, concluding it must not have happened. One very interesting case was that of Bill. Bill had no recollection of having the intervention, yet he had joined a COPD choir as a result of the researcher who delivered the intervention visiting him both in hospital and at his home.

> The first I knew about all these things [COPD] I think must have been when [the researcher] contacted me in the hospital and came to see me and yeah and she was also the one who introduced me to SYLO [Choir for those living with COPD]. – Bill

Bill had been a regular member of the choir since but did not have any memory of having participated in the study intervention.

4.5 Being positive

Having a positive attitude and staying focused on enjoying life was seen by most participants as crucial to their wellness. This impacted on general health and wellbeing, avoiding the negative consequence of triggers to illness and fighting back during exacerbation. Thus, the importance of being positive was threaded throughout all discussion of strategies to be proactive, making it difficult to integrate or separate the two concepts. However, all participants agreed that attitude or frame of mind affected their health in some way, although the degree to which participants believed this varied slightly, as did the degree to which participants were aware of this belief. Some of the participants considered themselves to be naturally optimistic people and believed that their attitude had a direct impact on their physical health. These participants expressed very clearly that their lack of recent hospitalisations was primarily the result of maintaining a positive attitude. There was no attempt to explain this phenomenon, it was simply a strong and clear message:

> I know exactly what keeps me well – it's the frame of mind; the positiveness. - Sheryl

Another group of participants made a conscious decision to take an optimistic outlook towards both their health and life in general. They chose to downplay their illness. Although they knew they had one or more diseases they felt that focusing on their good health and other positive aspects of their lives reduced the impact of their disease.

> I think I haven't got anything wrong with me. I know, I know I have, but I don't accept it. It sounds silly … I mean content is your health. You work it out that that is your health. If you're content you haven't got anything wrong with you. – Vera

Vera had a practical explanation for how mood reduced hospitalisations, which was shared to some extent by all participants. Vera reported that if she allowed her mood to become too low she would neglect looking after herself, and then her health would suffer further:

> Yes. Because when I'm feeling down like that I do not cook myself proper meals and I don't look after myself. - Vera

The idea that having a negative attitude, disposition or stress influenced your susceptibility to exacerbations was widespread among the participants. For some this was a more outright belief than it was for others.

> I've actually thought myself into spiralling down at times I think I have. I thought oh no I'm going to start feeling bad, oh jeez and I think I've actually talked myself into it. – Dennis

Interestingly, one male participant shared his belief that holding onto anger or resentment also contributed to illness. This came up when discussing in what ways Bill believed a positive attitude helped to improve health:

> I don't get upset about things, I don't get angry about things, I don't bear a grudge, so all of these things that play on your mind and people have anger management and that sort of thing, I think all these things get people down. All of these different things I sort of think contributes to one's own life and one's own wellbeing. - Bill

Two participants talked extensively about how their health had improved since leaving unhappy relationships and both believed that this had largely to do with stress:

> After I left my husband and came right with that everything [ill health] disappeared. So what’s that telling you? - Sheryl

Both these participants claimed that stress was no longer an issue for them. Both had manufactured their lives so that they were as stress free as possible. They both talked about doing what they wanted when they wanted and enjoying themselves.

More specifically regarding exacerbations, some participants talked about stress causing them to panic during an exacerbation which would make their symptoms worse. They knew this could be a problem but did not report having good strategies for managing to control feelings of panic. This was such a strong phenomenon that simply the arrival of an ambulance could be enough to reduce the panic, and the breathlessness:

> You know you’ve got the panic under control when you get to that stage trying to get the breath down and then you realise that it’s not getting down as much as or as far as what you want it or whatever and that will bring the panic back … but the time you don’t panic is when you see the ambulance guys. – Sheryl

Participants placed such importance on maintaining a positive outlook that when asked what advice they would give to others living with COPD several stated that their best advice would be to stop worrying, not letting stress affect them, and keep a positive attitude.

> Stop worrying that’s the biggest one is not worrying because that’s the killer, the worrying is the most. - Peter

Some participants had very practical techniques for maintaining a positive outlook on life. Physical exercise and breathing exercises which focused on stress management were common. A small group of participants talked about the importance of keeping busy when worrisome thoughts threatened their happiness. For some this meant reading – Sheryl had an extensive book collection that she talked very fondly of – and others found things around the house to busy themselves with. Over half of participants talked about consciously avoiding negative thoughts.

> I mean like yesterday I was sat and I thought I don't feel good and I thought no I’ve got to get up and do something, take my mind off it. Because [my daughter-in-law] said, ‘You certainly wash all the towels every day.’ And I thought ‘well I’ve got to do something’. - Trudy

It was common for participants to talk about focusing on the positive aspects of their lives rather than the negative, and in this respect being aware that there were always people worse off in the world. This advice was offered to others living with COPD.

> Yeah, stay positive and always think there's someone worse off than you are rather than, oh boy, why did I have to get this stuff you know, it's bad enough having it but don't dwell on it, don't brood on it. - Cynthia

Other participants talked about accepting and dealing with things as they came rather than wasting time worrying about them. This was particularly common among the men in this study.

> If you can change things then you get out and do it, you don't think about it. But if you know certain things that's happening and you can't change it, you can't do anything about it, there's no point in worrying about it. – Bill

Socialising was talked about by a lot of people in terms of how they maintain a positive outlook. Most of this was talking to or seeing friends and family. One participant talked a lot about the benefit she gained from walking her dog, but on further discussion it became apparent that it was the social aspect of dog walking that she felt she benefited from rather than physical aspects of the activity. Similarly, another participant spoke very favourably of a choir for people living with COPD that he had joined. This choir provided an important opportunity for social connection, specifically socialising with people who had similar health problems really made him happy.

> It's the social side, they're all in the same boat, you're all in the same sort of problems.- Bill

Interestingly, a number of participants attributed their positive outlook to having a couple of alcoholic beverages each night. Five participants, three men and two women agreed that enjoying the things they liked, such as nice food and alcohol, in moderation was good for their spirits and hence their health.

> The main thing is to do what you can do and don't overdo it. When I'm well I just do whatever I like. Maybe have a few drinks most nights. - Sheryl

Keeping a positive frame of mind and avoiding worry or stress was of such importance to participants that most in this study had manipulated their lives to ensure there was minimal stress and maximal enjoyment. All participants saw some relationship between attitude and wellness, whether that was an outright belief that mental wellbeing causes physical wellbeing and conversely, stress causes illness, or a more subtle, and possibly less conscious belief, all participants had developed strategies to maximise their mental wellbeing and minimise mental or emotional distress.

4.6 Being in Control

Participants were asked whether they felt they had control over their health and the answers were fairly evenly split, with just under half of participants saying that they felt that they were in control of their health and a similar number believing they had little to no control. There was more evidence of the varying degrees of self-belief buried within less explicit narratives. The expression of being in control was different for all participants.

For some, being in control meant paying attention to their bodies and knowing whether a disruption to their health was manageable on their own or whether it needed medical attention. This demonstrated the participants' trust, not only in their bodies' capabilities, but also in their ability to make that judgement call. Some participants followed this practice strongly and monitored their health daily, paying attention when something felt wrong. From there they would make the decision about whether to go to the general practitioner or whether they could manage the issue themselves.

> Well, I know first of all I get chesty, then I wake up with headaches and cough, cough, cough, cough, so I go and have a hot bath, steam, coughing as much as possible, I do all these things for myself, increase my inhalers, all else failing I ring the GP [General Practitioner]. – Cynthia

One participant talked about being hospitalised for symptoms of COPD quite frequently until they found she had a pulmonary embolism. She said that after she learned what the problem was she had been able to manage it and had not been hospitalised since. This participant felt strongly that she had control over her health.

> So even COPD, I've got that under control. – Cynthia

For some participants, the sense that they were in control of their health came through as a determination to fight off colds and flus. Some participants believed there was nothing the doctors could do for them that they could not do themselves, and some believed firmly in their bodies' ability to heal itself:

> I have a method of sort of saying, hey, it's going to go away, it's not serious and it eventually does go away if you keep sort of telling it to you know. - Gerald

Not all of the participants who believed they were in control of their health had such a strong belief in their own healing ability, but many did share this determination to fight as best they could. Fighting the bugs for some meant resting and eating well; for some it meant adjusting their environment to suit their needs. Such was the case for Peter, who adjusted the humidity in his room as his breathing became more difficult. But for others, it was purely a stubborn refusal to get sick. All the participants who believed they were in control of their health shared a self-identified trait of stubbornness. Various terms such as “pig headed”, “bloody minded” and “stubborn” were used regularly to describe participants’ attitudes in general as well as their attitudes towards their health:

> So, I think my attitude is that you know as I said before I’m very stubborn and bloody minded if you like to call it that, I just refuse to give in. – Bill

While this group of participants used their determination to fight off bugs and stay well, another small group turned the same stubbornness against loved ones or medical professionals.
These participants did not like to be told what to do, particularly when it came to restricting activities they enjoyed, wearing certain clothing such as hats or scarves, taking medication or seeking medical attention:

> …a couple of days later my wife said should you go to hospital and I said ‘like hell.’ - Gerald

Those participants who considered themselves stubborn also talked about debating or negotiating with their general practitioners and hospital staff regarding the interventions they should (or should not) receive. Gerald had a severe AECOPD for a few days before a family birthday. Hospital staff wanted to keep him in over the weekend but Gerald, determined to get home, negotiated with staff, stating it was easy for him to come back to the hospital if his symptoms returned. Eventually the staff agreed to discharge him in time for the weekend.

Another participant demonstrated being in control in the way that she dealt with her general practitioners. Early on in her COPD journey Vera’s young general practitioner shared with her that he was inexperienced with respiratory disease and was unsure how to help her. Vera took charge of the situation and convinced him to phone her respiratory specialist:

> [The respiratory specialist] invited him to a seminar he was going to and by the time I left they were as thick as thieves and that’s good because the GP [general practitioner] now has a broad base of knowledge on respiratory diseases that he didn’t have before - Vera

Vera felt strongly that people these days went to a general practitioner too readily. She believed that, rather than listening to their own bodies, most people relied on general practitioners to do the thinking for them, and she did not approve of this. Vera had an open and reciprocal relationship with her new general practitioner whereby she would go and tell him her symptoms and what she thought she needed. The general practitioner would listen, discuss and negotiate respectfully. Vera claimed:

> He's taken a while to get used to me because he's not used to somebody who listens to their body and also who has enough brains … Yes, it's taken me three years, but I've finally broken him in. - Vera

Regardless of which direction their obstinance took, all participants with a stubborn disposition felt that they were in control of their health. Being in control was also associated with participants having a sense of confidence that was not confined only to health. This belief infiltrated multiple aspects of the participants' lives and was demonstrated in the actions they took, decisions they made, and tasks they attempted. Cynthia, for example, had decided to go on a diet and lose weight over the summer and when asked if she thought she could achieve this she replied:

> I'll do it, oh yeah, yes. Definitely…yes. Yep, I don't procrastinate if I think I'm going to do something I don't think about it I go and do it. That's just me. - Cynthia

Similarly, Peter talked about the way he controlled his behaviour in a heavy drinking environment:

> Oh yeah. A lot of people when they start drinking they forget they can have reaction and that's when they get in trouble. If they drink it like this it's not too bad but if they drink like this you know ... I was in the navy nine years and I never ever got drunk. – Peter

Peter, now living in a rest home, found himself restless and frustrated at being confined to the small space, but, rather than let the feelings take over him he took charge of the situation and found things to enjoy including feeding the birds, for which he snuck extra toast from the kitchen at breakfast.

The propensity to take charge of their situation was demonstrated to some degree by most participants but not all. Three participants said they believed they had no control over their health at all and this belief extended to other areas of their lives. These participants appeared to have little knowledge of their condition, little interest in knowing more, a high degree of dependence on others, and a firm belief in luck having a major influence on their health status at any point in time.

One such participant, Hector was in hospital at the time of the interview. He weighed approximately 40kg and was shortly to be transferred to another hospital. Hector did not expect to leave the hospital alive. His answer to the question of feeling in control of his health was simple:

> No, I don’t, to be honest. – Hector

Hector expressed deep regret for not taking the actions he believed, in hindsight, would have helped him improve his health. These included quitting smoking earlier, exercise and pulmonary rehabilitation classes, yet he could not think of any advice he would give to others with COPD besides stop smoking.

Dennis also felt he had no control over his health. As a child his mother had taught him that he was a very lucky person and it seemed that Dennis held onto this belief throughout his life. As a result Dennis felt that health, or lack of it, came down to good or bad fortune:

> Honestly, no of course I don’t … No I’ve got no control over my health … I don't know what it is, perhaps it is just luck of the draw. – Dennis

Dennis took no action to keep himself well; his answer was to keep a positive attitude which he reported maintaining with alcohol, Prozac and other drugs.

The third participant who felt she had no control over her health was Trudy. Trudy had had a very traumatic life, starting as a child in Europe during World War II. Trudy talked about events that had happened throughout her life that led her to develop agoraphobia. She relied heavily on her son, whom she lived with, and would regularly end up hospitalised for severe episodes of AECOPD when he went away for work trips. When faced with a stressful situation, health-related or otherwise, Trudy’s answer was distraction rather than addressing the problem:

> I mean like yesterday I was sat, and I thought I don't feel good, and I thought no I’ve got to get up and do something, take my mind off it. – Trudy

Trudy trusted medical staff completely and relied solely on them for all her essential health care. She did not give any indication of attempting any strategies to take care of her own health.

Those participants who had no sense of control over their health also appeared to have a lowered propensity for proactive healthcare behaviours. Many who felt they had no control over their health shared that they did not really know what caused them to get sick. In their opinion exacerbations arose from forces or influences outside of their control, and so there was little they could do to prevent them from occurring.

> It just seems to come up on you, well you pick up a bug obviously or whatever from somewhere and just the start of that and with having the cord that just seems to grow. - Cheryl

Some guessed, when probed, that their health condition and exacerbations of it, was mostly down to bad luck, while others said they never thought about what caused it. Most participants, however, despite how little they knew about the causes of their disease, did express an interest in learning how to manage it. Those who had attended pulmonary rehabilitation greatly appreciated what they had learned in this regard:

> It's very true. That's why I think they get us to do these exercise programmes because they know that that strengthens your body – not only strengthens your muscles; it strengthens your lungs and if your lungs are strengthened, you can breathe better and you can do more. – Cynthia

Of those who had not attended pulmonary rehabilitation, one regretted his stubbornness, which, he admitted, was the reason for his lack of attendance, and the other five learned what they felt they needed to from their general practitioners or the Internet.

> No, I found out for myself not through the GP [general Practitioner], no. No way. Lucky I've got the Internet. – Cynthia

There appeared to be some relationship between feeling in charge of one's health and taking proactive steps to maintain good health. Feeling in charge of health often involved a certain degree of stubbornness which was either helpful, when it was aimed at beating exacerbations or forging a good relationship with medical staff, or it worked against participants as in cases where participants refused to listen to good advice from friends and family. There was a strong relationship between participants feeling in charge of their lives in general and feeling in charge of their health.

4.7 Influence of others

The social context of health management was not explored in detail in this study; however, it is impossible to remove the social context from any type of beliefs or behaviour. As is discussed throughout the results above, many of the participants' beliefs and behaviours were influenced by family and upbringing, and by those around them in their present day. Even the participants from this study who lived alone had outside influences. Significant others and health care workers were spoken about most often. Outside influences could be both positive and negative. In some instances, these influences could cause participants to undertake unhealthy behaviours, such as was the case with Sheryl who smoked when she was around a close friend, and in other cases it was a positive influence on their behaviour.

Significant others

Most participants appeared to take responsibility for their own health, but in some instances there was a significant other person impacting on their health behaviours. Participants who lived with a spouse or family member who lived very close to a relative were more likely to be influenced by these people. In some cases, this influence was fairly subtle and suggestive. For instance, Gina declared that she had not looked after herself very well in the past. She had recently started making changes to this and paying attention to her health more, but had done so primarily because she was beginning to realise the stress it put on her mother when she became sick:

> So that’s part of the reason I started to go to the doctor more because I don't want her to get all stressed. – Gina

In some cases, there was a far more direct link between behaviour and the influence of others. This was particularly evident when it came to behaviours that the significant other believed were good for the participant’s health. Whether or not the participant agreed was sometimes contentious, but it seemed the significant other always won out in the end. In some instances, it was a minor matter, such as Trudy’s sister insisting that she wore a scarf. In other cases, the significant other could be much more in charge of the participant’s health than the participant was themselves. In two cases, a married male participant’s health behaviour was largely controlled by their wives. Emmett’s activities – golf and exercise – and clothing choices were strongly dictated by his wife:

> I’ve now got berets; a hat, and woe betide if I go outside without me hat on. – Emmett

Another married male participant, Gerald, made it clear that his health care was entirely his wife’s job, and he had no interest in learning about medication or even paying attention to his symptoms:

> Yep, yep. Well that’s her job. Yeah, yeah well she’s the one who sort of says, ‘hey there’s something wrong, something wrong.’ – Gerald

On further discussion, Gerald reported that he believed his exacerbation arose in part because his wife ‘nagged’ him so much about his health – that he had learned to ‘tune out’ and had stopped paying attention, resulting in his health condition get worse than it would have otherwise, to the point that Gerald’s wife had threatened to get their son to take him to hospital if he did not go by himself.

Although it appeared in this example that Gerald had abandoned all responsibility for his health, this was not entirely the case. He had his own system that he used to manage his health, which was quite different to the plan his wife had for managing his symptoms. When talking about the 'official' plan written by Gerald's wife and general practitioner, Gerald did not express much buy-in:

> Oh yes, yep, yep. It's all written out for me da da da, you know. – Gerald

Gerald spoke of refusing to take the medication when his wife told him to and of having his own way of identifying when he was unwell and managing his symptoms. This generally meant resting and taking his inhalers. Although Gerald thought he was controlling his behaviours, his wife still was in charge of when he took medication and when he sought the help of health professionals.

Health professionals

The role of health professionals was of interest because all participants interacted with multiple health professionals on a regular basis, however the amount of influence that the health professionals had varied among participants. There were a few at either end of the spectrum, but most were reasonably indifferent.

At one end of the spectrum were the participants who followed the doctors' orders to the letter, with little or no independent decision-making. Usually, these people talked about not being interested in health-related topics and found it easier to let the medical professionals do their jobs. They did demonstrate a high amount of trust in their health professionals:

> People say what are you taking. I say I have no idea. I don't care. They just tell me to take it and I take it you know, if they give me poison, I'll take it yeah okay. – Gerald

At the other end of the spectrum were participants who preferred to make their own decisions or work in a partnership with the health professionals. This was not out of a lack of respect for health professionals, but rather a belief in their own ability to look after their health.

> They [hospitals] don't do anything for me that I couldn't do at home other than once I needed fluid drip. – Cynthia

Those in the middle did not talk about their general practitioner or other medical professionals except to mention that they had a back-pocket prescription or that they saw their general practitioner regularly.

Receiving the COPD diagnosis

The manner in which participants were given their COPD diagnosis, and by whom, may have had a significant impact in their understanding of the disease and in their belief in their ability to control its progression. Most participants had no recollection of being diagnosed with COPD or being told what that meant.

For the youngest participant, Gina, the first she knew about COPD was when a specialist was talking to her after an exacerbation. Gina recalled thinking that she must have already been told about the condition, but she had no recollection of such a conversation.

> Yes, I remember he was like talking about it, like, I already knew and I was going have I been told this? I was like listening at the time … I've got like big blank spaces in my memory, but I guess that's good because no one wants to remember the hospital. – Gina

The remaining participants were either certain they had never been told they had COPD or they had no memory of it. One participant had completed a lung function test at the general practitioner and was sent home with inhalers and a diagnosis of COPD but no further instruction on how to manage the condition or what to expect as it progressed.

Of the 12 participants in this study, only one recalled having the disease and its severity explained to her. Trudy was in Auckland when she went into hospital with severe breathlessness:

> I remember when I was up in Auckland. I had it up there and there was an old couple sat in the waiting room and this man was breathing and he was sort of whistling and it was a Russian doctor that was taking over from the doctor and then I went in so she told me, she said 'did you see that old man that came in?' So I said 'yes.' So she said 'you're going to be like that.' She said there's no actual cure for it. – Trudy

This approach did not give Trudy any increased sense of control over her health, nor did she express any emotion around the way it affected her, however she had already discussed many other significant changes and distressing situations in her life, so perhaps this did not feel any more significant.

No participants expressed any distress by the lack of clear diagnosis or explanation and seemed content to go forward and get more information as they needed it. Most participants preferred to get their health care information from their general practitioner than from anywhere else.

The social context of people’s lives played an important part of their disease management. Family, friends and significant others had the strongest influence on their behaviour, and this could have either a positive or negative effect, encouraging health promoting behaviour or encouraging rebellious behaviour. The majority of participants had the necessary interactions with health professionals, but they did not consider health professionals to have a strong influence over their lives; however the way participants learned about their disease may have impacted their attitude to it.

Chapter 5: Discussion

Participants in this study believed that there were a number of things that helped them avoid exacerbations. Those things ranged from regular daily or weekly activities such as self-monitoring, some form of exercise, eating well and keeping a positive attitude, to specific actions that they took when they believed they were at risk of an exacerbation such as keeping warm, avoiding people with colds or flus, avoiding cigarette smoke and other irritants, and keeping themselves and their environment clean. Two actions participants believed helped if symptoms of exacerbation increased were, firstly, resting while maintaining some degree of their normal routine, and secondly, taking home remedies such as lemon and honey drinks. Overall, the two universal beliefs held among participants were that taking medication and having a positive outlook, with minimal stress or worry, were crucial to avoiding exacerbations.

Most participants obtained information on how to manage their health from their general practitioner, practice nurse or pulmonary rehabilitation staff. However, many still displayed a lack of health literacy, relying on what might be considered general health knowledge to direct their personal care behaviours.

Public health guidelines for people living with COPD involve strategies for disease management including how to avoid and manage exacerbations. These include smoking cessation, having a written action plan, staying active, maintaining healthy body weight, improving breathing techniques, attending pulmonary rehabilitation, getting regular flu vaccinations, correct use of medication and keeping a warm, dry home (Asthma & Respiratory Foundation, 2020; Health Navigator, 2020)
The participants in this study were generally aware of all of these strategies, and which ones they followed seemed to be based on whatever they deemed most important, most achievable and the most likely to work. These beliefs were influenced by multiple factors: upbringing, cultural or familial customs, self -efficacy, health literacy and the impact of significant others.

Interestingly, there were some important actions that participants took to reduce their COPD exacerbations which do not appear to be emphasised as much in mainstream healthcare recommendations for avoiding AECOPD. For instance, maintaining a positive outlook, engaging in satisfying social activities and avoiding infections and irritants were areas that participants strongly believed reduced their risk of exacerbation. These all have some merit but are under-emphasised in professional guidelines (Criner et al., 2015; Global Initiative for Chronic Obstructive Lung Disease, 2019; National Institute for HealthCare and Excellence, 2018).

For example, avoiding infections and irritants may seem like common sense, but not all participants mentioned this when talking about how they avoided exacerbations. This suggests that it may be worth reviewing what information is included on this topic in public health guidelines.

Having a good social network, which included family, friends, interest groups and appropriate exercise groups, was very important to the participants, and while they did not overtly state that this was a factor that decreased their exacerbations, it was either a catalyst for exercise or a tool used for maintaining a positive attitude, both of which they did consider to be significant in decreasing exacerbations. The importance of a social support in COPD management fits with the current literature, including research by Arne et al., (2011) in which social support almost doubled the likelihood of better health and improved quality of life in of 1,475 Swedish COPD patients (OR 2.0695 % CI 1.38 to 3.07).

Maintaining a positive outlook and avoiding worry was of great importance to almost all participants in this study. Participants saw this as one of the key factors in avoiding exacerbations and maintaining optimal health. The health benefits of a positive outlook is supported by literature (Sun & Zhou, 2019) and has demonstrated improvements in health promoting behaviours and functional ability as well as quality of life and delayed disease progression (Hynninen et al., 2005), yet neither mental or emotional health are included in public health messaging about preventing AECOPD.

5.1 The importance of having a positive outlook

Maintaining a positive outlook, reducing worry, and focusing attention on the positive aspects of their lives was universally agreed on by participants as crucial to maintaining good health. Whether they were naturally optimistic and this came easily, or they had to choose positive thinking each day, or they used methods of distraction from negative thoughts, almost all participants acknowledged that their mood, outlook on life, and their reaction to stress had a direct effect on their health. Perhaps as a result of this, or perhaps coincidentally, participants did not report suffering from depression, and for the most part were adamant they did not get down or depressed. Indeed, the participants' Hospital Depression and Anxiety Scores indicated that the majority of the people in this study did not have any particularly significant problems with depression or anxiety. Only two participants scored above the threshold of eight on this scale, indicating 'caseness' for anxiety or depression (Bjelland et al., 2002). This is surprising as it is regularly reported that COPD patients are prone to depression and anxiety (Fearn et al., 2017). It is possible that selection bias within the methods used to identify people for this study contributed to this low rate of self-reported depression in this sample of participants. In particular, the TCOPD study had a high rate of participant attrition at the 12 month data collection period, with 39% (22/56) of the original 56 participants being unable to contribute to the study at this time point (five died, six actively withdrew, five were uncontactable, and six were too unwell to contribute to data collection), reflecting the severity of illness that people with AECOPD present within hospital in general (unpublished data from the TCOPD study). The remaining participants who were available for data collection at 12 months are less representative of the general population of people admitted to hospital with AECOPD simply because they were alive, relatively well, and willing to discuss their experiences of COPD.

Nonetheless, there is a known relationship between mental wellbeing and health in general for people with COPD. Hynninen et al. (2005) discussed, in depth, the relationship between psychosocial health and COPD in their literature review. While the reports of low depression in the present study do not fit with the figures reported in their review, their work does help to understand the importance participants place on positivity and how the concepts of *maintaining a positive attitude* and *being proactive* fit together in this study.

In their review, Hynninen et al. (2005) investigated the relationship between emotional state and physical health in COPD patients. Looking at a variety of outcome measures, Hynninen et al. included 81 papers in their review, eight of which looked directly at the relationship between emotional state and physical functioning of COPD patients. Seven of these studies reported a strong positive relationship between the two variables. One study in the review, which used five different scales to look at mental state and physical functioning in 43 male participants, found that emotional state contributed more to the variance in functional status than either disease severity or medical burden (Kim et al., 2000). What was notable about this study was that rather than using an exercise-based test to measure functional state, which can be common in COPD research (Hernandes et al., 2011). Kim et al. used the SF-36 which gives a broad account of self-care activities such as bathing, dressing, exercise, and socialising. Kim et al. (2000) considered this a limitation of the study, but for the purpose of comparison to the results found in the present study it is more relatable than an exercise-based test.

Another study included in the review by Hynninen et al. (2005) was a nine-year longitudinal study which examined the relationship between emotional state, living alone, and life span in 157 participants with severe COPD, who were going onto long-term oxygen therapy (Crockett, Cranston, Moss, & Alpers, 2002). Based on measurements of depression, anxiety and restlessness in the chronic respiratory disease questionnaire, Crockett et al. found that females with a higher rating on the emotional section of the chronic respiratory disease questionnaire (indicating a more positive mood state) lived longer than those females who rated lower on the same questionnaire, even after controlling for psychological risk factors (50.8 vs. 29.5 months respectively, log rank test p =0.004). The risk of death for female participants decreased by six percent for every one-point increase in the emotional function scores. This was not the same for male participants for whom little to no effect was found. The main predictor of life span for males was partial pressure of oxygen, a measure of lung function.

General practitioners in a study in the same review considered the impact of mood state so significant that that they used patients' ratings of panic and fear on the Minnesota Multiphasic Personality Inventor scales (which assesses personality traits and psychopathology) to judge the severity of COPD rather than independent pulmonary function tests (Heller & Dirks, 1978 as cited in Hynninen et al., 2005). The potential strength of this relationship could be seen in the present study and was illustrated specifically by the participant, Cynthia, who appeared to avoid rehospitalisation through sheer determination.

While almost all participants in the present study emphasised the importance of a positive outlook, only one attempted to explain the complex relationship between mood and health. Gail stated that when she started becoming unwell her energy and her mood both declined, and if she allowed her mood to continue going downhill, she would become too depressed to look after herself. This association between mental and physical care is echoed in research by Yıldırım, Asılar, Bakar, & Demir (2013) in which the mean scores for anxiety and depression (based on the Hospital Anxiety and Depression Scale, the Quality of Life Assessment and the Appraisal of Self-care Agency Scale) increased as the scores for self-care agency decreased, and conversely, as the means scores for quality of life increased so did the mean scores for self-care agency (n= 135, moderate to severe COPD). Self-care agency refers to the combination of skills, motivation and emotional capacity to care for one's self (Gast et al., 1989). Going back to Hynninen et al.'s (2005) review, a number of studies in that review also reported on this relationship between poor mood state and poor self-care. One paper found that impairment of daily activities was associated with emotional state more so than disease severity (Beck, Scott, Teague, Perez & Brown, 1988, as cited in Hynninen et al., 2005), and another small study (n=28) by Moore & Zebb (1998), looking at the effects of anxiety and depression on functional status, reported a positive correlation between the two, even after controlling for the effects of dyspnoea.

This evidence above supports the participants' belief that maintaining a positive outlook was vital to their ability to ward off exacerbations of COPD. Although they generally did not discuss why this was so important, the belief in the importance of a positive outlook was more universally agreed on than any other with regard to AECOPD prevention, with the exception of medication. While most participants did not consciously understand how maintaining a positive outlook affected their health, it seemed to be a built-in mechanism that helped participants cope with their disease and encouraged them towards proactively looking after their health.

5.2 The relationship between being in control and being proactive

One of the areas of interest in this study was the degree to which participants felt that they were in charge of their health. There were mixed results with approximately half of participants feeling that they had control over their health, and half feeling that they did not. Some participants were very passionate about being in charge, not just of their health, but other areas of their lives as well and this was demonstrated in statements such as: "If I think I'm going to do something, I don't think it, I go and do it. That's just me." (Heather)

In general, participants who felt that they had control over their health took active steps to look after themselves, such as self-monitoring, preparing meals in advance and exercising. These results echoed those found by Kaşikçi & Alberto (2007), whose survey of 200 Turkish participants with COPD found that self-efficacy and disease management behaviour (r=0.186; p=0.01) were very strongly related. However, there appears to be relatively little research on the role of self-efficacy in helping people manage moderate to severe COPD. For example, I was able to identify only a small number of studies on the relationship between self-efficacy and self-care behaviours in COPD, albeit by conducting a detailed but non-systematic search. Two reviews on self-care in COPD - a critical review by Stellefson, Tennant, & Chaney (2012) and a Cochrane review (Howcroft, Walters, & Walters, 2016) – reference only seven studies that have examined some aspect of self-efficacy and self-management. In comparison, when I searched for papers on self-efficacy and health-care behaviour in general there was an abundant return of literature on self-efficacy in diabetes management (Al-Khawaldeh, Al-Hassan, & Froelicher, 2012; Sousa et al., 2005), stroke management (Fryer, Luker, McDonnell, & Hillier, 2016), arthritis (Anderson, Zimmerman, Caplan, & Michaud, 2011) and physical activity in chronic disease (Tung et al., 2014), all of which reported a positive relationship between efficacy and self-care behaviour.

One particular paper that stood out because of its explanation of the relationship was that by Sousa et al. (2005). Reporting on diabetes management, Sousa et al. (2005) suggested that in order to consistently and successfully perform self-care behaviours, people with diabetes must have both the belief in their ability to manage their condition and the skills, motivation and emotional capacity to do so. This model of self-care was first developed by Sousa, Zauszniewski, Musil, McDonald, & Milligan's, (2004). The research model, which combines Bandura's theory on self-efficacy (Bandura, 1997) and Oram's theory on self-agency (Gast et al., 1989), purports that in order to effectively and consistently perform self-care behaviours, self-efficacy and self-care agency are required. Sousa called this early model of self- care the *Enhance-Behaviour-Performance model*. I am drawn to this model because it is remarkably similar to the reports of experiences of participants in this study - whereby the first concept, *Being Proactive* talks about performing self-care behaviours, the second concept *Being positive* has similarities to self-care agency in terms of motivation and emotional capacity, and the third concept of *being in control* refers to self-efficacy, or the deep underlying belief that the individual can effect change in their health status. If one of those components were missing, the self-care behaviour would, according to the participants, decrease.

5.3 The role of relationships in staying well

5.3.1 Significant others

Relationships played a significant role in the journey with COPD for participants in this study. In some cases, relationships with a spouse or family member promoted self-care behaviour such as exercise, keeping warm or seeking medical attention, although at times these relationships had caused stress and reduced the participants' perceived ability to look after their own health. It has been noted that research on the effects of social support on self-care behaviours in COPD is very limited (Barton, Effing, & Cafarella, 2015; Chen, Fan, Belza, Pike, & Nguyen, 2017). Chen et al. (2017) carried secondary analysis of data from a two-year longitudinal study, examining data from 282 participants. The study looked at the impact of structural (marital and living status) and functional (functions provided by a social network) social support on physical activity levels, pulmonary rehabilitation attendance, smoking status, influenza or pneumococcal vaccinations, and adherence to medication. Overall, their results showed a strong association between living with others and higher levels of physical activity, with an increase of 900 steps per day (95% CI 373 to 1,433; P = 0.001) in those that lived with others. This increase in physical activity was not however found to be associated with functional social support. This is interesting because in the present study those who lived alone spoke of the need for functional social support being their main driver for participation in physical activity, this was not the case for people who lived with others, who were either internally motivated or motivated by a significant other. It is noteworthy however that the participants who lived alone still used exercise as a social tool at times when their structured exercise or recreational activities were planned. This could contribute to a reduced physical activity level in people living alone and could increase if more social activities were structured during the week. In concurrence with Chen et al.'s (2017) study, all of the participants in the present study who lived alone indicated that they did not have the ability, whether that was motivation or physical capacity to exercise outside of that.

Chen et al. (2017) also found a significant increase in the likelihood of participation in pulmonary rehabilitation in those who lived with a spouse or caregiver (OR 11.03; 95% CI 1.93–62.97; P=0.01). There was no obvious association between participation in pulmonary rehabilitation and living status in the present study. In Chen et al.'s (2017) study those living with others were slightly less inclined to smoke (OR, 0.99; 95%CI, 0.98–1.00; P = 0.03) and slightly more likely to receive the pneumococcal vaccination (OR, 1.02; 95% CI, 1.00–1.03; P = 0.02), but there was no association between social support and influenza vaccination or adherence to medication. In the present study, it was evident in two cases that family members were crucial to medication adherence – both cases were men, where this significant relationship role was provided by their wives.

In their literature review, Chen et al. (2017) reported on two further papers which also reported positive effects of social structures. Kaşikçi & Alberto (2007) reported significant positive effects of family support on self-care behaviour (r = 0.302; p = 0.01) and Xiaolian et al. (2002) showed a positive association between perception of family support and perceived adequacy of self-care behaviour.
I was only able to find only one further paper on this topic, which was not reported on by Chen et al. (2017). This report was a 12-week, single blind, randomised-control trial that investigated the effect of involving family members in pulmonary rehabilitation (Marques et al., 2015). The results of this 42-family study were fairly understated, but one significant result was an improvement in coping skills in both COPD patients (P=0.048) and family members (P = 0.004). However, there were no significant improvements for COPD patients in their other outcome measures of sexual relationships or psychological distress, although they were seen in the families of the intervention group. It is possible, however, given the sample size, that this study was underpowered to detect important clinical differences, however.

It is clear that there is a strong need for more research on the effects of social support on COPD management. There are two aspects to this. Firstly, based on the results of published studies and those emerging from the present study, the role of friends, family and social networks may have the potential to positively influence the self-care behaviours of people with COPD, but there is insufficient research to enable any specific recommendations. Secondly, I could not find any research that presented the potential negative effects of relationships on self-care. This was seen as potentially occurring on three occasions in the present study. Two participants described relationship stresses that could have contributed to poorer self-care and one participant described a relationship that contributed to her being more likely to smoke. While it may be common sense that stress or bad behaviour can have negative health consequences, if relationships are a big part of these outcomes, then that should be acknowledged and addressed in COPD management plans.

Additionally, although no cultural issues arose throughout data collection in this study, it is important to note that the social context of health care may be even more important when it comes to working with Māori and Pacific populations. Because community and family are so much more involved in a person's health care than they are in a Pākehā context, it would be essential to work together with the whānau or community to promote any behaviour change (Mark & Lyons, 2010).

5.3.2 Health care practitioners

The relationship with the general practitioner is also very important with regard to health outcomes. While many had little to say about health care professionals, those in this study who did talk about them described having comfortable relationships and a high level of trust. This was largely demonstrated by the fact that the majority of participants preferred to go to their general practitioner for information about COPD and how to manage it. Even in cases where participants felt more confident managing their own health, they kept their general practitioner involved, either by having them as a step in their health-care plan or by discussing, and even debating with the general practitioner how to deal with a situation. The ability to debate with a health care provider demonstrates a high level of trust, both in oneself and in the relationship. These results support previous studies which have found that relationships that support good communication between patients and their health care providers resulted in both improved quality of care, and improved confidence in dealing with breathlessness (Slatore et al., 2010). In this study, the trusted patient-general practitioner relationship also meant that participants felt comfortable to approach their general practitioner for medications at any point in their COPD journey, whether that meant keeping a "back-pocket prescription" or approaching the general practitioner after an exacerbation had begun. This was crucial, because as we see demonstrated in this study, having access to medication was both a key factor in reducing AECOPD and in the participants having a sense of control over their health.

Interestingly, Pinnock et al. (2011), in their research on the perspectives of patients, informal and formal caregivers, on living and dying with COPD, there was suggestion that the formal carer/clinician particularly those who have been with the patient for a long time, may share the participants passive acceptance of their health condition. , and in my role as a Clinical Exercise Physiologist I can see how this is possible. Perhaps this is reflected by the lack of acknowledgement of the GPs in this study.

Perhaps the GPs “just go along with” the patients’ acceptance of the disease and don’t push them towards lifestyle change, don’t discuss the severity of the condition, don’t “rock the boat,” and perhaps this is why GPs are so unremarkable in the data for this study – except in the situations of participants who, themselves, rock the boat, demanding extra attention.

5.4 Gender roles

This research project was not a study on gender roles in the management of COPD, so it is wise to be cautious about overgeneralising from the data gathered. However, the stories shared by participants appear to reveal an influence of gender or marital roles for a number of people. In currently married couples, by and large, looking after both parties’ health was described as being the job of the woman, with some men showing little or no interest in their own healthcare.

Research into gender differences in COPD has largely focused on epidemiology. Men of a younger age group appear to be more prone to rehospitalisation than women of the same age, and males in general have a higher rate of death due to COPD (Barnard & Zhang, 2018). This data may reflect what is represented in this study, with males being less inclined to manage their own health. Of all the male participants in this study, only one had a strict self-monitoring process and action plan, and in this case he was well supported by rest home staff. It is also worth noting that men in this study were more inclined to look back at their behaviour with regret than women, whereas the women appeared more forward-thinking regarding planning for their healthcare.

There is little research into gender differences in COPD diagnosis and management (Camp & Goring, 2007) but research by Martinez et al. (2012) showed some important differences which, although interesting, contrast with the finding in the present study. Females in Martinez et al.’s (2012) 568-person survey, reported having more trouble getting an appointment with the general practitioner than men did, and expressed more dissatisfaction with the amount of time spent with their general practitioner. Gender bias from practitioners was also reported in a paper by Aryal, Diaz-Guzman, & Mannino (2013). Although it is not seen in this study, this potential gender bias in health care is worthwhile examining further in a New Zealand context. If it does exist it may affect the way patients go forward to manage their own health.

5.5 Delivery of the COPD diagnosis

The majority of participants in this study had no recollection of being told they had COPD. For most of them, in the absence of a diagnosis, they just came to understand that they had this disease and were required to manage it. This contrasts with findings in a qualitative review by Coventry et al (2019) who reported on participants' feeling shock and disbelief at being given the diagnosis of COPD. How a diagnosis is delivered is important to consider because it impacts on the weight that people put on their disease or how seriously they take it. This may alter the way people with COPD look after themselves.

One factor that may influence participants' recollection of receiving a diagnosis is timing. The participants in this study had little recollection of anything that happened around the days and weeks after their exacerbation. Most could recall what happened leading up to their AECOPD resulting in hospitalisation, but from there onwards the participants' memories of events were very limited. If diagnoses are given during this hospitalisation period, the participants would be no more likely to remember this than other things that had happened to them. Alternatively, the participants may not have remembered being given a diagnosis of COPD in hospital because this was not ever discussed with them.

Another point to consider is who provided the diagnosis. Coventry et al. (2019) discussed the impact of early interactions with healthcare providers on patients' experiences of receiving a COPD diagnosis. In their study, participants were left feeling disempowered and hopeless after the diagnosis was delivered. In contrast, a paper by Gately, Rogers, & Sanders (2007) suggested that people's responses to receiving a diagnosis was influenced more by their existing coping strategies and prior experiences with health services than by how the diagnosis was delivered. It is likely that both the delivery of the diagnosis and internal factors influence how a patient responds to a diagnosis of COPD, but this is an area that is under-researched. Future studies could provide insight into ways of delivering the diagnosis that might enhance a person's inclination towards self- care.

Whether, and when COPD should be diagnosed is a contentious issue, mostly due to unacceptably high rates of misdiagnosis (Enright & Fragoso, 2020; Spero, Bayasi, Beaudry, Barber, & Khorfan, 2017). Incorrect positive diagnosis of COPD too often leads to overuse of medication which is both costly and comes with significant adverse effects (Enright & Fragoso, 2020). Furthermore, diagnosing COPD without thorough investigation into what else could be causing the symptoms may mean that serious conditions, with similar symptoms, such as ischemic heart disease congestive heart failure, subglottic stenosis, and pulmonary hypertension are going untreated (Enright & Fragoso, 2020).

Questions around the clinical value of diagnosing early-stage COPD are also being asked. In older persons, comorbidities, adverse effects of existing medication and simple deconditioning provoke similar symptoms to COPD. Enright & Fragoso (2020) argue that the main symptom, poor exercise tolerance should be treated, more directly, with exercise rather than adding more medications.

Enright & Fragoso (2020) also suggest that because spirometry testing does not predict progression to clinically significant ($p<0.5$) COPD in current smokers, detection and treatment of pre, mild or early COPD, is pointless.

These arguments have led to recommendations that Primary care practitioners do not diagnose treat COPD without two or more positive spirometry tests and that these are carried out by pulmonary specialists in properly equipped facilities (*COPD-X Australian and New Zealand guidelines for the diagnosis and management of chronic obstructive pulmonary disease: 2017 update*, 2019; Enright & Fragoso, 2020). Nevertheless, the people in this study did not have mild COPD but COPD that was sufficiently severe to cause multiple hospitalisations. Therefore, allowing patients to have an accurate understanding of their condition may be important.

5.6 Strengths and limitations/considerations

This qualitative study had a number of strengths which worked in its favour to help produce rich and profound data. The first of these is the result of the study being initiated from the TCOPD study. This enriched the study both from the position of the participants and from my position as a researcher. Firstly, patients were enrolled in the TCOPD study because of a recent AECOPD. This meant that in some cases, when I interviewed the participants, the memories of their behaviour leading up to the exacerbation may have been fresh in their minds and they were more readily able to recall them. Furthermore, the fact that participants had already spoken twice about their condition (during prior data collection periods in the TCOPD study) meant that these memories were kept fresh and primed the participants to speak more readily about them.

From a participant perspective, this factor, that I had already interviewed them twice and established a good rapport, gave me, as a researcher, credibility, affording comfortable, open and honest conversations which resulted in extensive data collection to the point where participants were telling me things they had never expressed before. In the same vein, another strength that I brought to this study was my personal experience with COPD. Both of my parents lived with COPD, and as being a moderate asthmatic myself, I have had experiences that afforded me empathy with these participants – an attribute which further supported the building of rapport and the ease with which participants expressed their opinions.

There were both strengths and limitations in the participant demographics, which affect how these results can be transferred into the wider population. One positive was an even split between men and women, which offers a broad representation of the challenges, opinions and experiences of both genders.

With a sample size of 12, I was able to take time to gather a full data set and did so until theoretical saturation. However, this represents only a small number of COPD patients and it is possible that other people from other populations might introduce beliefs or experiences of dealing with exacerbations of COPD that were not covered in this small sample. Similarly, this study recruited only those who had been hospitalised for severe AECOPD. There may be a population in New Zealand who are effectively managing their COPD at home or in primary care. That population could provide useful insights into self-management strategies.

Further regarding the transferability of results, all participants but one were over 53 years old, and 10 of the 12 were retired or not working. This gives a certain amount of homogeneity to their daily living situations and hence to their experiences. There is, again, a large population of people aged 45 to 65 years, still of working age, who are living with COPD. It is possible that this population may have very different experiences of managing their disease. They may also have different drivers, such as work and social expectations that influence their inclination towards health management in a way that is different from those who are not working. Conversely this population may have increased time, social and work pressures which affect their ability to adopt a positive attitude.

A further and important limitation of this study is the under-representation of Māori. Only two of the 12 participants were Māori. Given how over-represented Māori are in COPD statistics, this small number brings into question how transferable these results are to a Māori population.

The use of purposive sampling is a normal part of grounded theory research, but it does have its limitations. Participants chosen for this study were not only those who, for physical and/or mental health reasons, had remained available throughout the TCOPD study, but those who were also open and eager to talk. This could have skewed the sample towards those with a more open or positive outlook; it is possible that those who were quieter and less ready to offer their opinions had a very different experience of AECOPD. Similarly, the self-selection nature of this sampling carries the same risk of biasing towards those more interested in offering their experiences.

5.7 Recommendations for future studies

This study has explored the thoughts and experiences of people with AECOPD about what help or hinders them to avoid rehospitalisation, but there is a lot more information needed if we are to truly understand what causes severe AECOPD and rehospitalisation, and therefore to reduce rehospitalisations in the New Zealand COPD population. To begin with, participants in this study were mainly of the same age and had similar lifestyles. While the average age of first hospitalisation ranges from 63 years old (Māori) to 73.7 Years (non- Māori, non-Pacific) there may still be important insights to gain from a younger, working population, or, at the very least, it would be interesting to look at whether there are more factors than just age that contribute to the increase in disease severity. These issues could be investigated through a similar qualitative study aimed at 40- to 65-year-old working populations living with moderate COPD.

It was a strength of this study to have an even gender split, with the study data raising questions about differences in the way each gender manages their health. Future studies could usefully investigate the different ways that people of different gender take charge of their health. For instance, how do people of different genders view health maintenance? What is the influence of gender identity on a person's sense of responsibility to manage their own or their partner’s health? At what point do the different genders choose to take medications or to go to hospital? Future research on issues like these could be used to develop a tailored approach to self-management to men and women with COPD.

Although almost half of the participant groups in this study was non-European, only two were Māori. In order to get truly representative Māori data, this study, or one similar could be run, focusing specifically on the experiences of Māori with COPD. Such a study would be best conducted using Kaupapa Māori methods, by Māori researchers (Walker, Eketone, & Gibbs, 2006). This would open avenues to understanding the issues facing Māori people with moderate to severe COPD and may help to reduce the inequalities in hospitalisation rates.

How people were given the diagnosis of COPD is touched on only briefly in this study. However, the fact that most participants did not recall this potentially important step in their COPD journey leads to the recommendation that more clinical trials investigate what impact, if any, could be achieved by different ways of communicating a COPD diagnosis and the timing of this information. Such a study could look at the effect of more proactive approaches to diagnosis on the way people go forward to take care of their health, and on rehospitalisation rates and health care behaviours.

5.8 Implications for clinical practice

The findings from this research have implications for health professionals who work with people with COPD at all stages, from initial diagnosis, education and rehabilitation to treatment and management of exacerbations. Given that the participants identified a number of factors that they believe reduced their risk of severe COPD exacerbation which are not included in public health messaging, it is recommended that a working group consisting of health professionals and people living with COPD be established to inform health policy and clinical practice, in particular on what components of care should be included in such messaging. Given that COPD is the fourth leading cause of death in New Zealand (Milne & Beasley, 2015), and that exacerbations are a source of advancing disease progression, there is much more that we, as a health profession could be doing to reduce exacerbation rates and to improve individuals' agency for managing their own health. More attention needs to go into looking at what works and providing practical options to the COPD population.

To begin, this study identified that people commonly do not have any recollection of receiving a COPD diagnosis. Whether this affects the way they go forward to look after their health or not is not clear, but we have learned from previous studies (Coventry et al., 2019) that it does have the potential to cause feelings of disempowerment and hopelessness if approached incorrectly. Presumably then, there is the potential to promote feelings of empowerment and efficacy within this interaction. All interactions with medical and health personnel have the potential to promote self-efficacy, which we have seen here, is crucial to initiating self-care behaviour, at every step of the way. Perhaps there is a need for training around how to develop the building self-efficacy into practice for general practitioners, nurses and rehabilitation staff.

Pulmonary rehabilitation is demonstrated to be one of the most successful preventers of AECOPD yet less than one percent of New Zealanders with COPD have completed a full course (Levack et al., 2012), despite the availability of these statistics. If we know that the barriers are transport and lack of perceived benefits, and we now know that patients prefer to get their information from their general practitioner, and generally have a good relationship with them, then we can begin to make a change here by addressing the barrier of perceived benefits. General practitioners could be upselling the benefits of pulmonary rehabilitation, in a positive light, with a focus on the improvements to breathing and functional ability which participants in this study, and others (Coventry et al., 2019) have indicated are important to them. Finally, being aware of the individual preferences, needs, and drivers of each person who presents with COPD or an exacerbation of it is crucial, not only to provide effective medical treatment, education and advice, but also to addressing the psychosocial factors that could develop each individual, influencing their self-efficacy and driving them to managing their condition more effectively.

5.9 My learnings from undertaking the study

I went into this study looking to learn what people living with COPD believe are the causes of their exacerbations, what they believe causes their exacerbations to become so bad they end up hospitalised and how they believe they can prevent this. I learned many answers to these questions, but more importantly I learned how people who have COPD live full, rich, meaningful lives despite this corrosive condition. The answers to the two questions were the same.

After working on the TCOPD study I believed I had good insights into the lives of people living with COPD and was in a good position to start memo writing. Looking back at my first memo (Appendix J), one of my assumptions was "… all people with COPD" are depressed. However, I have found that while the disease - and common comorbidities – may predispose someone towards depression, it may also have the opposite effect whereby people develop a determination to enjoy the rest of their lives. I was so inspired by the joy and the keenness to enjoy life that I saw in a number of participants that my preconceptions of what it is like to live with COPD have been completely transformed.

Another early assumption that I held going into the study was that: "Not enough people know that taking antibiotics early keeps them out of hospital." This assumption was also contradicted in my study. Everyone knew about the need to take antibiotics early, but not everyone recognised the signs that it was time to start taking them. Again, during my work in the TCOPD study I saw that people who did not believe they had any control over their health appeared to be less likely to be proactive, because they did not believe being proactive would make a difference. My investigation confirmed this view and I believe it would be fair to say that those who had a higher level of self-efficacy were also more inclined to get on and enjoy life than to allow depression to take over, although further research is needed to test these ideas.

On another note, I was very disappointed (but, given my own experiences with loved ones in hospital, not surprised) to learn that the COPD diagnosis is often missing from a person's journey through the health system. I suspect this would have a significant impact on the choices people make in regard to management of the disease, attendance at pulmonary rehabilitation and lifestyle choices, and I would like to see this changed.

Finally, I went into the study looking for things that people had in common, but in doing so learned that everyone is very different. While there were commonalities, there was so much diversity among this population, as there is among any population, that trying to develop or force a one size fits all approach to COPD management would seem futile. I learned again that I love research, and that there is an unending need for more of it. There are too many rabbit holes unexplored. I also learned the pain and the joy of undertaking a qualitative Master's thesis. I learned how to think, question, process, write and repeat until I could not do so anymore. Now, I finally feel I am ready to start a Master's degree! Learning is a lifelong journey.

5.10: Conclusion

Chronic Obstructive Pulmonary disease and exacerbations of its symptoms has a severe financial impact on the New Zealand health system and a deleterious medical impact on the 200,000 in New Zealanders it is estimated to affect. We have a substantial understanding of the biological processes behind COPD exacerbations, but this study was concerned with investigating both causes and prevention from the perspective of those who experience them. Specifically, I was interested in the relationship between the physiological and psychological processes that happen prior to an exacerbation of COPD, the inherent beliefs and assumptions held by individuals and how these influence patients' management of the condition.

Using Grounded theory, the stories of 12 people with moderate to severe COPD were analysed and three main concepts emerged. Supported by a growing body of previous research the concept *being in control* was at the heart of people's actions and attitudes. The extent to which people took charge of their health outcomes was strongly influenced by their degree of self-efficacy and had an equally strong influence over their health-care behaviour. Participants understood the clinical guidelines for managing COPD and adopted those that fit within their belief system. These practices fell into the second category of *Being Proactive* and reflected the practical steps that people took to manage their condition. The final concept – *Being Positive* – reminds us that people's attitudes have a substantial impact on their health. The importance of adopting or maintaining a positive outlook was both unmistakable and complex. A clear relationship exists between poor spirits and loss of health care motivation, but that does not entirely explain the weight of importance that *being positive* has on prevention of AECOPD. People's behaviours, beliefs and attitudes are influenced to some degree by loved ones, and there is potential for this influence to be harnessed and to assist in the development and implementation of health care plans.

It used to be thought that treatment for AECOPD should be purely determined by clinicians, but this study has shown that patients' own assessments of what treatments benefit them should be taken into account. This work is the first of its kind and has shed some light on how those with COPD actually manage it, and how the recommended guidelines fit within this reality. Going forward with the understanding that self–efficacy, a positive attitude and relationships have a strong impact on the practical steps that prevent AECOPD, we, as the doctors, nurses, physiologists, physiotherapists and other health professionals who work alongside COPD have an opportunity, if not a responsibility, to better promote and realise the potential benefits of this new, expanded approach.

Glossary

Caseness: A term used to define a score on measures of anxiety and depression high enough to be classed as a clinical case (Public Health England, 2020).

Chronic Obstructive Pulmonary Disease: (COPD) A treatable and preventable, but ultimately terminal lung disease which is usually caused by exposure to noxious gasses or particles and influenced by existing factors such as abnormal lung development. COPD is characterised by respiratory symptoms, airflow limitation, fatigue and weight loss and often accompanied by one or more comorbidities (Disease Global Initiative for Chronic Obstructive Lung, 2020).

Constructivism: A theoretical perspective that suggests that knowledge, meaning and reality come to be based on our interactions with the world (Crotty, 1998).

Theoretical saturation: The point in data collection when no new or relevant information emerges with respect to the newly constructed theory (Hollway, 2008, p. 195).

Epistemology: A philosophical study of the nature, origin, and limits of human knowledge.(Crotty, 1998; Martinich & Stroll, 2020).

Exacerbation: Periods of acute worsening of respiratory symptoms (Disease Global Initiative for Chronic Obstructive Lung, 2020, p. 4).

Grounded Theory: A systematic, inductive, and comparative approach for conducting qualitative research for the purpose of constructing a theory (Charmaz, 2006).

Health Literacy: Having a level of knowledge, personal skills and confidence to take action to improve health by changing lifestyles and living conditions (Nutbeam, 1986, p. 10).

Intervention: A preventative or therapeutic measure intended to create change (Midgley, 2000).

Moderate exacerbation of COPD: Acute increase in respiratory symptoms requiring treatment with oral corticosteroids or antibiotics, but not requiring hospitalisation (Seemungal et al., 2009).

Purposive sampling: A non-random participant selection tool by which the researcher decides what needs to be known and sets out to find people who can and are willing to provide the information by virtue of knowledge or experience (Tongco, 2007).

Rehabilitation: A set of interventions delivered to people experiencing limitations in every day functioning due to ageing or health conditions, including chronic diseases or disorders, injuries or traumas. Rehabilitation is a highly person-centred health strategy that may be delivered either through specialised rehabilitation programmes (commonly for people with complex needs), or integrated into other health programmes and services, for example, primary health care, mental health, vision and hearing programmes (World Health Organization, 2019).

Self-care agency The capabilities of an individual that allow them to initiate and persevere in self-care activities (Gast et al., 1989).

Self-Efficacy: A person's belief in his or her capacity to deal with any given task or situation (Maddux, 1995; Sousa et al., 2004).

Severe exacerbation of COPD: Acute increase in respiratory symptoms requiring admission to hospital (Seemungal et al., 2009).

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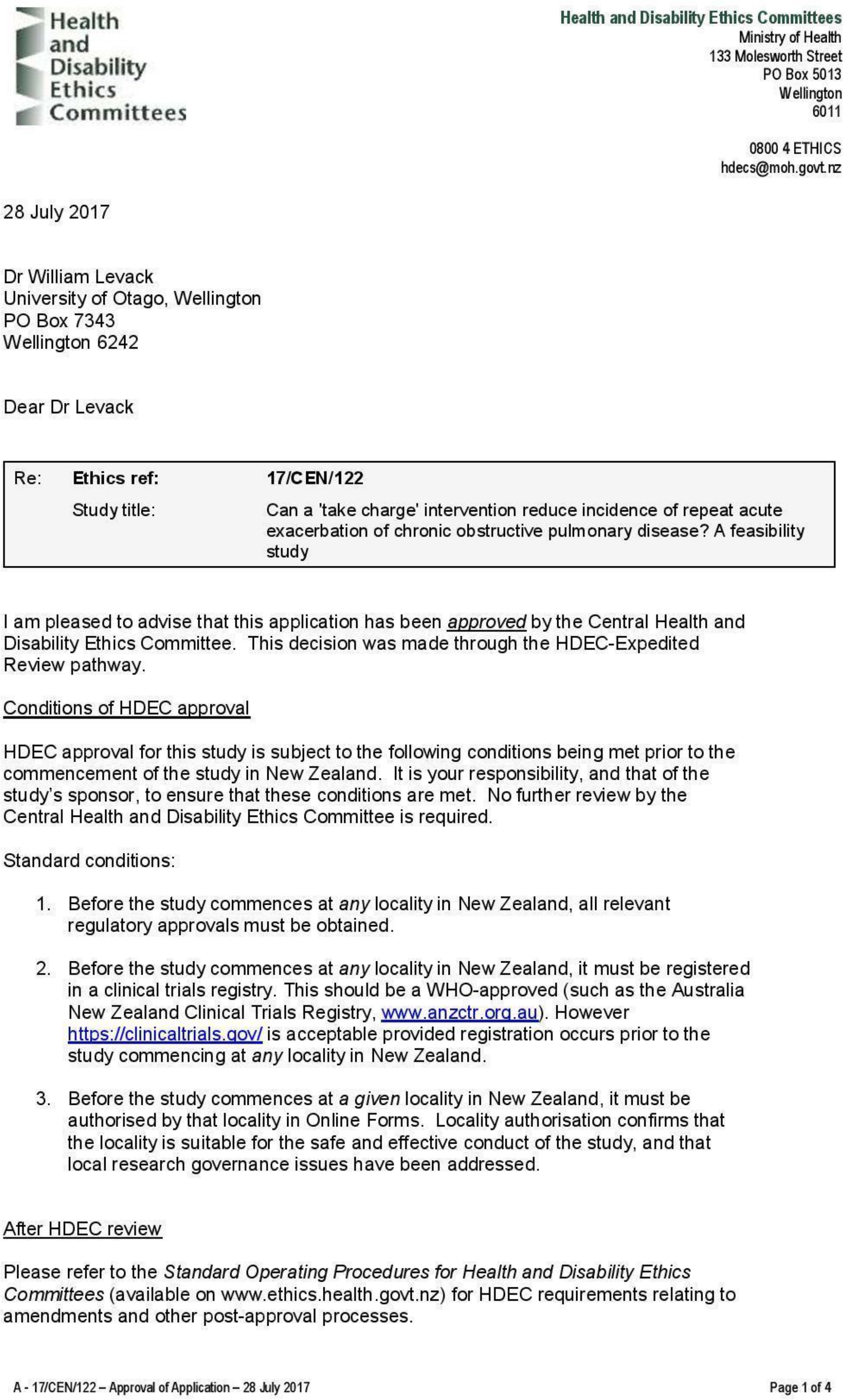
Appendix A: Original ethics committee approval



Health
and
Disability
Ethics
Committees

Health and Disability Ethics Committees
Ministry of Health
133 Molesworth Street
PO Box 5013
Wellington
6011

0800 4 ETHICS
hdecs@moh.govt.nz

28 July 2017

Dr William Levack
University of Otago, Wellington
PO Box 7343
Wellington 6242

Dear Dr Levack

Re:	**Ethics ref:**	**17/CEN/122**
	Study title:	Can a 'take charge' intervention reduce incidence of repeat acute exacerbation of chronic obstructive pulmonary disease? A feasibility study

I am pleased to advise that this application has been *approved* by the Central Health and Disability Ethics Committee. This decision was made through the HDEC-Expedited Review pathway.

Conditions of HDEC approval

HDEC approval for this study is subject to the following conditions being met prior to the commencement of the study in New Zealand. It is your responsibility, and that of the study's sponsor, to ensure that these conditions are met. No further review by the Central Health and Disability Ethics Committee is required.

Standard conditions:

1. Before the study commences at *any* locality in New Zealand, all relevant regulatory approvals must be obtained.
2. Before the study commences at *any* locality in New Zealand, it must be registered in a clinical trials registry. This should be a WHO-approved (such as the Australia New Zealand Clinical Trials Registry, www.anzctr.org.au). However https://clinicaltrials.gov/ is acceptable provided registration occurs prior to the study commencing at *any* locality in New Zealand.
3. Before the study commences at *a given* locality in New Zealand, it must be authorised by that locality in Online Forms. Locality authorisation confirms that the locality is suitable for the safe and effective conduct of the study, and that local research governance issues have been addressed.

After HDEC review

Please refer to the *Standard Operating Procedures for Health and Disability Ethics Committees* (available on www.ethics.health.govt.nz) for HDEC requirements relating to amendments and other post-approval processes.

Your **next progress report** is due by **27 July 2018.**

Participant access to ACC

The Central Health and Disability Ethics Committee is satisfied that your study is not a clinical trial that is to be conducted principally for the benefit of the manufacturer or distributor of the medicine or item being trialled. Participants injured as a result of treatment received as part of your study may therefore be eligible for publicly-funded compensation through the Accident Compensation Corporation (ACC).

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,

Mrs Helen Walker
Chairperson
Central Health and Disability Ethics Committee

Encl: appendix A: documents submitted
appendix B: statement of compliance and list of members

Appendix B: Participant information sheet

Study title: Taking charge of chronic obstructive lung disease (COPD)	
Locality: Capital & Coast DHB	Ethics committee ref.: 17/CEN/122
Lead investigator: Dr William Levack	Contact phone number: 021 918 627

We invite you to take part in a study about helping people take charge of their chronic obstructive lung disease. Through this study, we aim to help people stay healthy and out of hospital. Some people also call chronic obstructive lung disease:

- Chronic obstructive pulmonary disease (or COPD),
- Chronic bronchitis,
- Emphysema, or
- Bronchiectasis.

Whether or not you take part in this study is your choice. If you don't want to take part, you don't have to give a reason. It won't affect the care you get. If you do want to take part now, but change your mind later, you can pull out of the study at any time.

This Participant Information Sheet will help you decide if you'd like to take part. It tells you:

- Why we are doing the study
- What it involves for you
- What the benefits and risks to you might be, and
- What happens after the study ends.

We will go through this information with you and answer any questions you have. You do not have to decide today whether you will join the study. Before you decide, you may want to talk about the study with other people. You can talk to family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part, we will ask you to sign a Consent Form. This is on the last page of this document. We will give you a copy of both the Participant Information Sheet and the Consent Form to keep.

This document is 7 pages long, including the Consent Form. Please make sure you have read and understood all pages.

WHAT IS THE PURPOSE/KAUPAPA OF THE STUDY?

People who have COPD can get a worsening of their lung problems. Some people can end up in hospital as a result. Some may have to go to hospital many times, which is no fun. In fact 1 in 5 people with COPD who leave hospital for lung problems will be back in hospital again within 12 months[1]. The aim of this study is to help people with COPD take charge of their health to stay well and stay out of hospital. This study will run from July 2017 to July 2019.

WHAT IS THE STUDY TESTING?

We are testing the effect of one "Take Charge" session on people's health and their use of helpful health services. People can be involved in this study if they are in hospital because of problems with COPD. We aim to invite people to join the study while they are still in hospital. A trained research assistant will deliver the "Take Charge" session in people's homes about two weeks after they leave hospital. The "Take Charge" session takes approximately 90 minutes. It involves providing people with training to help them pick areas of their health and wellbeing that they want to work on and develop their own plans to address these.

To test this "Take Charge" session, we plan to compare the health outcomes of people who got this programme to other people who did not get it. Please note: all people in the study will get all the usual healthcare services for people who go to hospital for problems with COPD. The "Take Charge" session is in addition to usual care. To avoid affecting the results of this study accidentally, we will randomly assign people to the "Take Charge" session or comparison group. If you join this study, you have an equal chance of being in the "Take Charge" group or in the comparison group.

WHAT IS IMPORTANT ABOUT THIS STUDY FOR MĀORI?

While COPD affects people of all cultures, it is more of a problem for Māori. Māori are more likely to have COPD than non-Māori people. Māori also tend to be twenty years younger than non-Māori people when they first get COPD[2]. They go to hospital four times more often than non-Māori with COPD.[1] We also know that hospitals not do always feel like safe spaces for Māori.

We have worked hard to make our study as safe, useful and meaningful for Māori as it is for non-Māori. We have two Māori health researchers on our team: Dr Tristram Ingham and Bernadette Jones. Dr Ingham and Ms Jones will advise on cultural matters during the study. In the development of this study we consulted with Ngāi Tahu Consultation Committee (at University of Otago) and with local Māori health providers.

The "Take Charge" session is family/whānau centred. Your family members are welcome to join in with this part of the study. We also aim to have Māori research assistants available to deliver the "Take Charge" session to Māori participants. The "Take Charge" session is based on a similar programme that was made for Māori and Pacific peoples with stroke, found to be successful in the past.[3] At the end of the study, we will hold a hui to provide feedback to the community about the study. We will send you an invite to this hui.

WHAT IS IMPORTANT ABOUT THIS STUDY FOR PACIFIC PEOPLES?

As for Māori, COPD is more of a problem for Pacific peoples than for non-Pacific people. Pacific peoples also have more hospital admissions for problems with COPD. They get COPD at a younger age than non-Pacific people. To make this study useful to Pacific peoples, we aim to have a Pacifica research assistant available to work with Pacific peoples. Again, the "Take Charge" session is family-centred, so family members are welcome to join in. We are talking with the Pacific Health Director at Capital & Coast District Health Board (Wellington) during this study to make sure the study stays relevant to Pacific peoples. Pacific peoples will also be welcome to join our hui at the end of the study to hear about our findings.

WHO CHECKS THAT THE STUDY IS RUN CORRECTLY AND SAFELY?

The Health & Disability Ethics Committee of New Zealand (http://ethics.health.govt.nz/) has provided ethical approval for this study. There are details at the end of this Participant Information Sheet on how to contact this ethics committee if you have any questions or concerns about this study.

WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

If you agree to join this study, we will ask you to participate in one initial visit where we collect information (while you are in hospital), then in three other visits in your home (or other place of your choosing) over a year. See below for more about each of these visits:

Initial hospital visit:

We will ask you give us with some information about yourself at the start of the study (e.g. age; ethnicity; other health problems). We also would like to measure your height and weight. We expect this to take about 30-40 minutes.

First home visit:

If you are randomly chosen for the "Take Charge" session, you will also be asked to participate in a 90 minute visit in your home (or other place of your choosing) about two weeks after you leave hospital. A research assistant will work with you (and your family if you choose) to help you develop a plan to improve your health and wellbeing.

We will also ask a few people in the "Take Charge" group if we can video the "Take Charge" session. This is optional. We wish to do this so we can check that the research assistants are delivering the "Take Charge" session as we intend.

Second and third home visits:

For the second and third home visits, we will ask to visit you 3 months and 12 months after hospital. At these visits, we will ask you answer some questions about your health and wellbeing. These questions will take about 30-40 minutes of your time. We can come to your home for these visits or another place you choose.

At the 3-month visit, we will also ask a few people to participate in an interview about their experiences of the study. We will ask these people what worked well and where we could improve in the future. These interviews are likely to be 15-30 minutes long. We will ask if we can record them so we don't miss anything important you tell us.

Other information:

We also would like to collect some information from your hospital records. We would like to know about your past lung tests and use of hospital and GP services over the year. This does not required any extra time from you. We just need your permission to look at your patient records in hospital and at your GP clinic.

WHAT ARE THE POSSIBLE BENEFITS AND RISKS OF THIS STUDY?

We do not believe that you will be at any risk from joining this study. The "Take Charge" session is about helping you be more active in improving your health. It is also about making the most of health services that are already open to you. Both the people in the "Take Charge" group and comparison group will get all the healthcare services that they would have otherwise usually been provided.

The benefit of join this study is that it might help you improve health and wellbeing. This may possibly help you avoid future hospital admissions for lung problems. Joining this study will also help improve knowledge about what things keep people with COPD healthy, well, and out of hospital. We will share findings from this study with other health professionals at national meetings in New Zealand. We will write about the study in medical journals.

WHO PAYS FOR THE STUDY?

The Health Research Council of New Zealand funds this study. You will not have to pay any money to be in the study. We will provide a $20 gift voucher for each home visit as a small way of thanking you for your help with the study.

WHAT IF SOMETHING GOES WRONG?

If you were injured in this study, which is highly unlikely, you would be eligible **to apply** for compensation from ACC. This is the same as if you got an injury in an accident at work or home. This does not mean that ACC will automatically accept your claim. You will have to lodge a claim with ACC, which may take some time to assess. If your claim is accepted, you will get funding to assist in your recovery.

If you have private health or life insurance, you may wish to check with your insurer that taking part in this study won't affect your cover.

WHAT ARE MY RIGHTS?

This study is voluntary. This means that you are free to choose if you wish to join it.

If you do agree to join this study, you are welcome to withdraw from the whole study or part of it at any time. You do not have to give a reason to withdraw. You will not be disadvantaged if you do.

You have the right to access all information we gather about you in this study.

You will be told of any new information about good or bad effects related to the study that become available during the study, if these have a chance of impacting on your health.

You have the right to privacy and confidentiality. We will anonymise your personal information in the study. This means we will remove your name and other identifying information from all study data before we analyse or present it. We will store all your personal information securely in a locked filing cabinet and password-protected computers during the course of the study. You will not be personally identifiable in any publication of information arising from this study.

WHAT HAPPENS AFTER THE STUDY OR IF I CHANGE MY MIND?

If you withdraw from this study or if you complete the study, you will continue to get usual health services from your healthcare providers and hospital.

We are required to keep the study records for 10 years after the end of the study. We will keep these records in a locked filing cabinet in the University of Otago building in Wellington. After 10 years, we will destroy the stored study records. We plan to publish the findings from this study in medical journals. We will also present them at medical meetings to share the knowledge arising from this study.

We will provide a written summary of the study findings to all participants at the end of the study (July 2019). We will also invite you to attend a hui where we will share our findings with the people involved.

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

If you have any questions, concerns or complaints about the study at any stage, you can contact:

William Levack (Associate Professor of Rehabilitation)

Address: Department of Medicine, University of Otago Wellington (on the Wellington Hospital campus), PO Box 7343, Mein Street, Newtown, Wellington 6242.

Phone: 021 918 627 (mobile) or 04 918 6279 (direct dial)

Email: william.levack@otago.ac.nz

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050
Fax: 0800 2 SUPPORT (0800 2787 7678)
Email: advocacy@hdc.org.nz

For Māori health support please contact:

Bernadette Jones (Registered nurse & Research Fellow in Hauora Māori)

Phone: 027 600 3868 (mobile) or 04 918 6845 (direct dial)

Email: bernadette.jones@otago.ac.nz

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS

Email: hdecs@moh.govt.nz

1. Milne RJ, Beasley R. Hospital admissions for chronic obstructive pulmonary disease in New Zealand. *New Zealand Medical Journal* 2015;128(1408):1175-8716.

2. TMG Associates Ltd. Literature Review: Respiratory Health for Maori. Wellington: The Asthma and Respiratory Foundation of New Zealand (Inc.), 2009.

3. Harwood M, Weatherall M, Talemaitoga A, et al. Taking charge after stroke: promoting self-directed rehabilitation to improve quality of life – a randomized controlled trial. *Clinical Rehabilitation* 2011;26(6):493-501.

Appendix C: Consent form

Study title: Taking charge of chronic obstructive lung disease (COPD)

Please tick to indicate you consent to the following.

I have read, or have had read to me in my first language, and I understand the Participant Information Sheet.		
I have been given sufficient time to consider whether or not to participate in this study.		
I have had the opportunity to use a legal representative, whānau/ family support or a friend to help me ask questions and understand the study if I wanted.		
I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.		
I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my medical care.		
I consent to the research staff collecting and processing my information, including information about my health.		
If I decide to withdraw from the study, I agree that the information collected about me up to the point when I withdraw may continue to be processed.	Yes ☐	No ☐
I consent to my GP or current provider being informed about my participation in the study and of any significant results obtained during the study.	Yes ☐	No ☐
I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.		
I understand the compensation provisions in case of injury during the study.		
I know who to contact if I have any questions about the study in general.		
I understand my responsibilities as a study participant.		
I wish to receive a summary of the results from the study.	Yes ☐	No ☐

Declaration by participant:

I hereby consent to take part in this study.

Participant's name:

Signature:
Date:

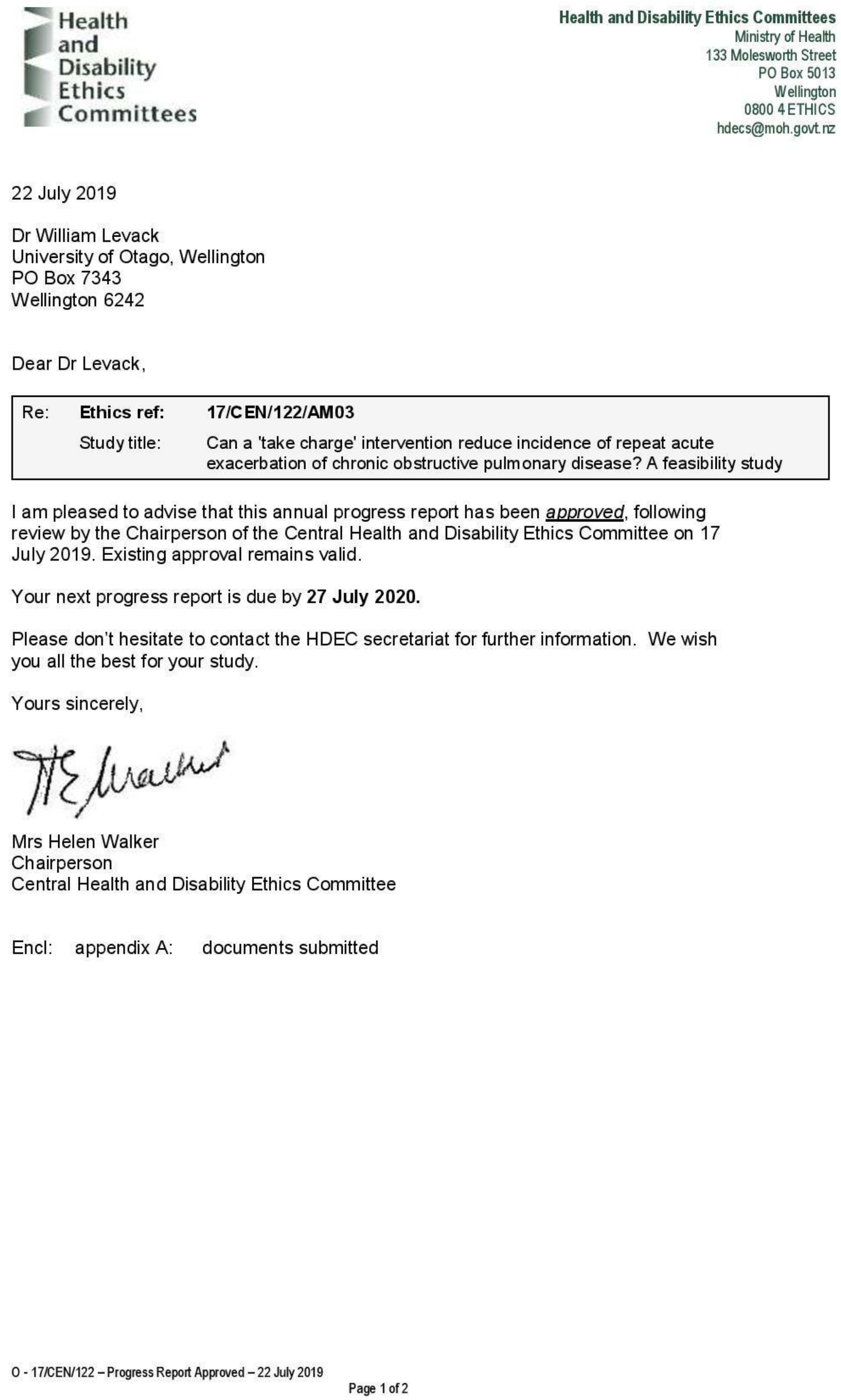
Declaration by member of research team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name:	
Signature:	Date:

Appendix D: Approval of annual report to ethics committee



Health and Disability Ethics Committees

Health and Disability Ethics Committees
Ministry of Health
133 Molesworth Street
PO Box 5013
Wellington
0800 4 ETHICS
hdecs@moh.govt.nz

22 July 2019

Dr William Levack
University of Otago, Wellington
PO Box 7343
Wellington 6242

Dear Dr Levack,

Re:	**Ethics ref:**	**17/CEN/122/AM03**
	Study title:	Can a 'take charge' intervention reduce incidence of repeat acute exacerbation of chronic obstructive pulmonary disease? A feasibility study

I am pleased to advise that this annual progress report has been *approved*, following review by the Chairperson of the Central Health and Disability Ethics Committee on 17 July 2019. Existing approval remains valid.

Your next progress report is due by **27 July 2020.**

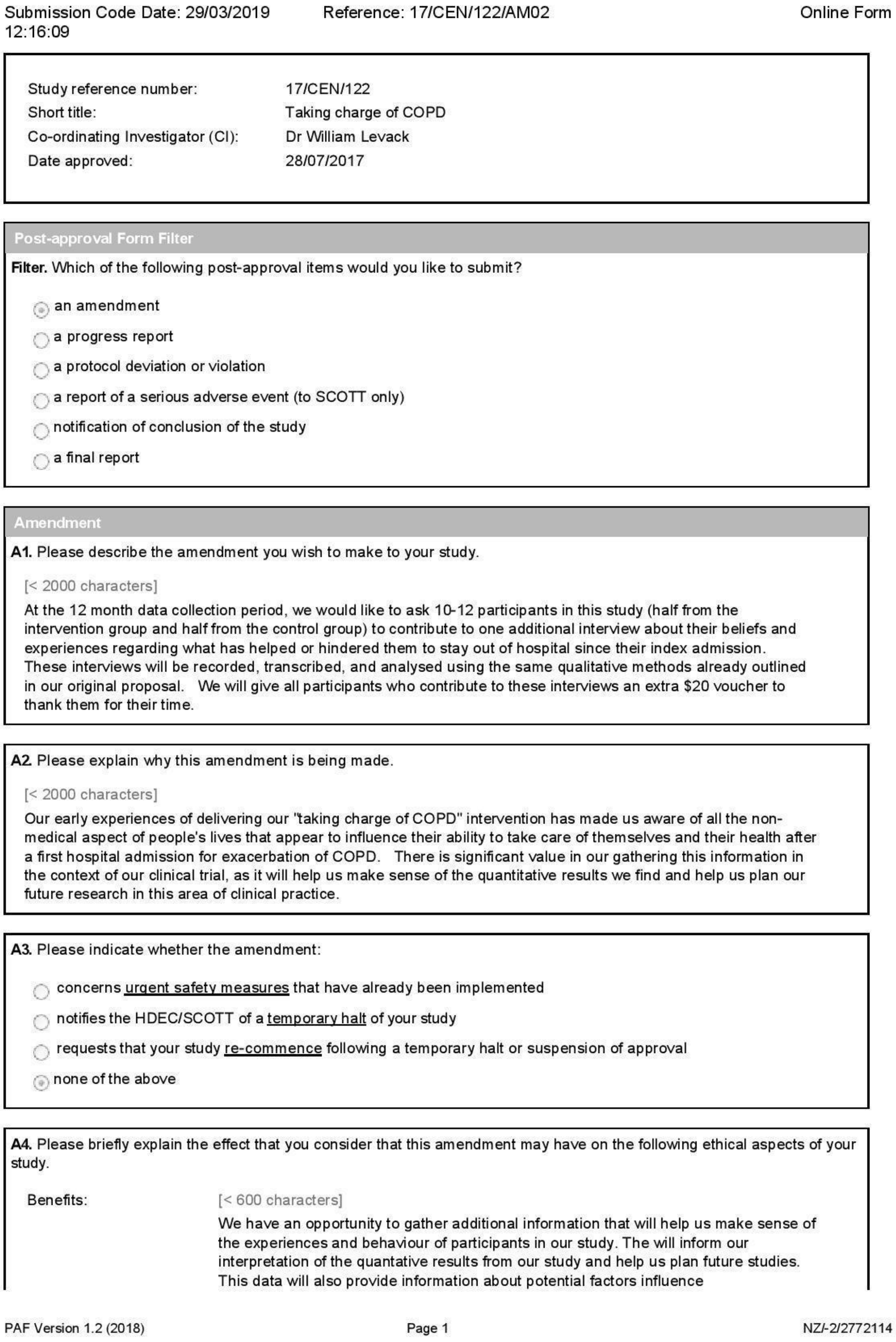
Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,

Mrs Helen Walker
Chairperson
Central Health and Disability Ethics Committee

Encl: appendix A: documents submitted

Appendix E: Request for amendment to ethics



Submission Code Date: 29/03/2019 12:16:09 Reference: 17/CEN/122/AM02 Online Form

Study reference number:	17/CEN/122
Short title:	Taking charge of COPD
Co-ordinating Investigator (CI):	Dr William Levack
Date approved:	28/07/2017

Post-approval Form Filter

Filter. Which of the following post-approval items would you like to submit?

● an amendment

○ a progress report

○ a protocol deviation or violation

○ a report of a serious adverse event (to SCOTT only)

○ notification of conclusion of the study

○ a final report

Amendment

A1. Please describe the amendment you wish to make to your study.

[< 2000 characters]

At the 12 month data collection period, we would like to ask 10-12 participants in this study (half from the intervention group and half from the control group) to contribute to one additional interview about their beliefs and experiences regarding what has helped or hindered them to stay out of hospital since their index admission. These interviews will be recorded, transcribed, and analysed using the same qualitative methods already outlined in our original proposal. We will give all participants who contribute to these interviews an extra $20 voucher to thank them for their time.

A2. Please explain why this amendment is being made.

[< 2000 characters]

Our early experiences of delivering our "taking charge of COPD" intervention has made us aware of all the non-medical aspect of people's lives that appear to influence their ability to take care of themselves and their health after a first hospital admission for exacerbation of COPD. There is significant value in our gathering this information in the context of our clinical trial, as it will help us make sense of the quantitative results we find and help us plan our future research in this area of clinical practice.

A3. Please indicate whether the amendment:

○ concerns urgent safety measures that have already been implemented

○ notifies the HDEC/SCOTT of a temporary halt of your study

○ requests that your study re-commence following a temporary halt or suspension of approval

● none of the above

A4. Please briefly explain the effect that you consider that this amendment may have on the following ethical aspects of your study.

Benefits: [< 600 characters]

We have an opportunity to gather additional information that will help us make sense of the experiences and behaviour of participants in our study. The will inform our interpretation of the quantative results from our study and help us plan future studies. This data will also provide information about potential factors influence

PAF Version 1.2 (2018) Page 1 NZ/-2/2772114

	rehospitalisation after an initial exacerbation of COPD.
Risks:	[< 600 characters] We are aware of no additional risk to participants arising from this addition to our protocol. Participants are welcome to accept or decline participation in this additional stage of data collection as their discretion. We are not asking any new people to join the study.
Respect for persons and populations:	[< 600 characters] We have already gained permission from our participants to interview them and to record their interviews - we are just seeking permission to add one more period of interview data collection to our study protocol. Participants will be able to decline to participate in these interviews or decline to answer any questions that they do not wish to answer without any consequences to them. These rights have already been documented in the participants information sheet and consent form, but we will reiterate them before any additional data collection.
Fairness:	[< 600 characters] All participants will be treated equally in this part of the study.

A5. *Only substantial amendments, as defined in section 11 of the Standard Operating Procedures for HDECs, need to be submitted to HDECs.*

Is this amendment substantial?

○ Yes

● No

A6. Please explain your answer above

[< 1200 characters]

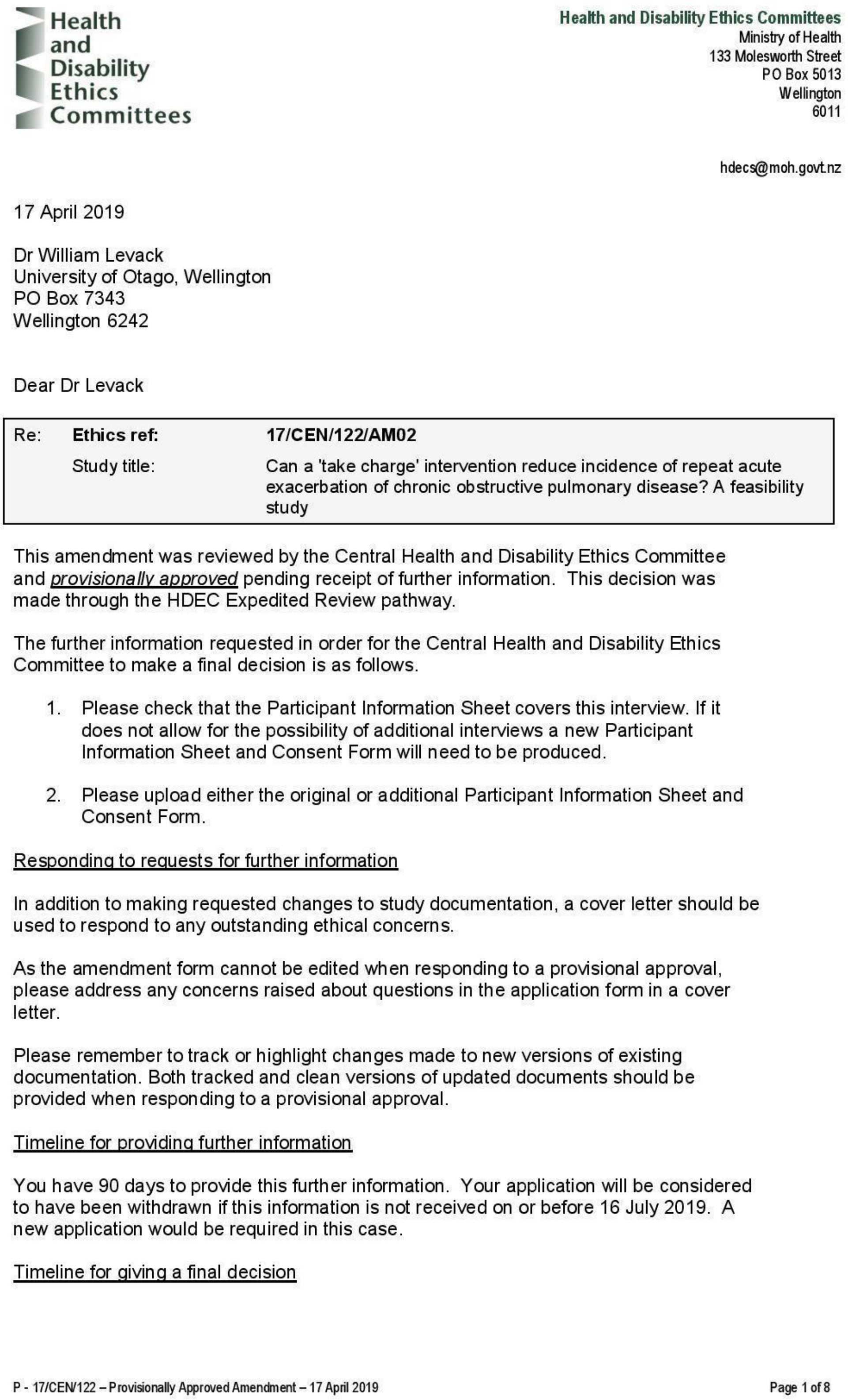
We are seeking to extend qualitative data collection of a similar nature to that which we have already had approved (at the 3 month data collection period) for study participants.

A7. Please provide the current number of NZ participants affected by this amendment.

12

Please upload amended versions of all relevant study documents in the "Documents" tab.

Appendix F: Provisional approval of protocol amendment



Health and Disability Ethics Committees
Ministry of Health
133 Molesworth Street
PO Box 5013
Wellington
6011

hdecs@moh.govt.nz

17 April 2019

Dr William Levack
University of Otago, Wellington
PO Box 7343
Wellington 6242

Dear Dr Levack

Re:	**Ethics ref:**	**17/CEN/122/AM02**
	Study title:	Can a 'take charge' intervention reduce incidence of repeat acute exacerbation of chronic obstructive pulmonary disease? A feasibility study

This amendment was reviewed by the Central Health and Disability Ethics Committee and *provisionally approved* pending receipt of further information. This decision was made through the HDEC Expedited Review pathway.

The further information requested in order for the Central Health and Disability Ethics Committee to make a final decision is as follows.

1. Please check that the Participant Information Sheet covers this interview. If it does not allow for the possibility of additional interviews a new Participant Information Sheet and Consent Form will need to be produced.
2. Please upload either the original or additional Participant Information Sheet and Consent Form.

Responding to requests for further information

In addition to making requested changes to study documentation, a cover letter should be used to respond to any outstanding ethical concerns.

As the amendment form cannot be edited when responding to a provisional approval, please address any concerns raised about questions in the application form in a cover letter.

Please remember to track or highlight changes made to new versions of existing documentation. Both tracked and clean versions of updated documents should be provided when responding to a provisional approval.

Timeline for providing further information

You have 90 days to provide this further information. Your application will be considered to have been withdrawn if this information is not received on or before 16 July 2019. A new application would be required in this case.

Timeline for giving a final decision

The 15-day clock within which a final decision must be made on this study is suspended as of the date of this letter. This clock, on which -9 days remain, will restart on the date on which **all** of the further information requested above is received by the Central Health and Disability Ethics Committee.

How to respond to a Provisional Approval for post approval submissions

You will need to submit your new or amended documents through Online Forms.

New versions of existing documents:

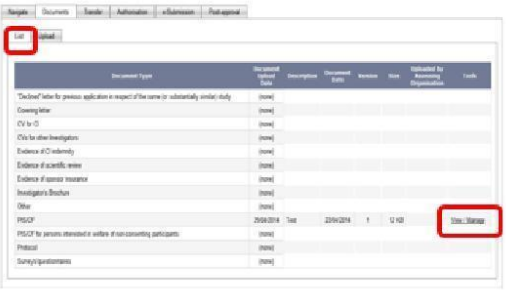
Steps **Screenshots**

1. Select the corresponding PAF for this submission.
2. Go to the Documents Tab to upload the revised documentation requested by the secretariat

Click here to begin completing/reviewing the form or clic

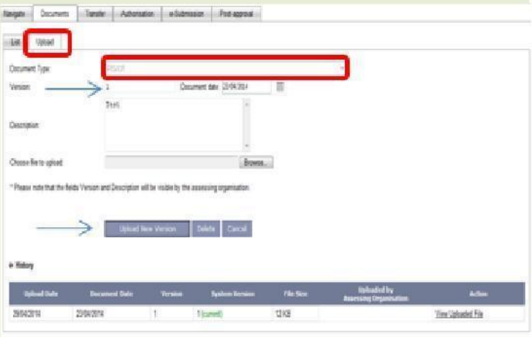
3. To update versions of documents, go to the List tab. Select View/Manage to upload a newer version of the document.

- For example you can upload new versions of the PIS/CF
- Remember to track changes.



4. When you click View/Manage for a particular document it will take you to the upload tab for that document.

- Update the version number and document date.
- Browse to find the new version of the file.
- Click 'Upload New Version'
- Once the upload is complete the history will populate with the new version.

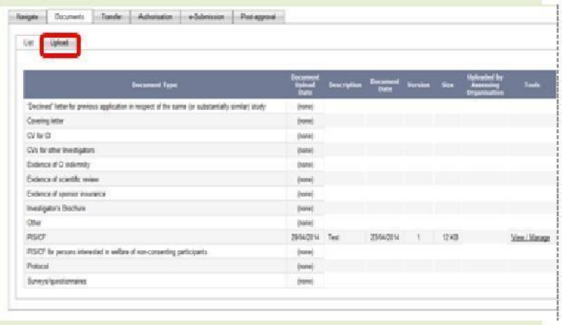


New documents:

Steps **Screenshots**

5. For New documents, go to the upload tab.

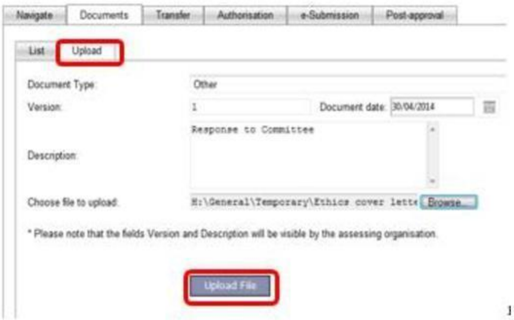
- For example you can upload a word document responding to questions raised by the Committee.



Document Type	Document Upload Date	Description	Document Date	Version	Size	Uploaded by Assessing Organisation	Tools
'Declined' letter for previous application in respect of the same (or substantially similar) study	(none)						
Covering letter	(none)						
CV for CI	(none)						
CVs for other Investigators	(none)						
Evidence of CI indemnity	(none)						
Evidence of scientific review	(none)						
Evidence of sponsor insurance	(none)						
Investigator's Brochure	(none)						
Other	(none)						
PIS/CF	29/04/2014	Test	23/04/2014	1	12 KB		View / Manage
PIS/CF for persons interested in welfare of non-consenting participants	(none)						
Protocol	(none)						
Surveys/questionnaires	(none)						

6. Select the document type. Add a version number, document date and add a description if required.

Browse your computer to find the new file and select Upload File.

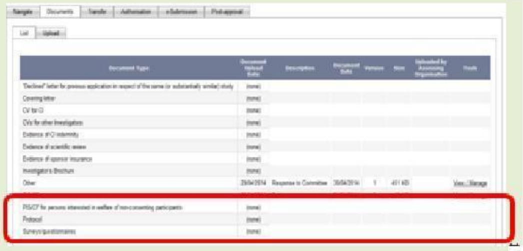


Document Type: Other
Version: 1 Document date: 30/04/2014
Description: Response to Committee
Choose file to upload: H:\General\Temporary\Ethics cover lette

* Please note that the fields Version and Description will be visible by the assessing organisation.

7. The new document will now be uploaded and visible on the List Tab.

Before submitting check to see all your documents are on the List tab and are displaying the correct version and document date.



Document Type	Document Upload Date	Description	Document Date	Version	Size	Uploaded by Assessing Organisation	Tools
'Declined' letter for previous application in respect of the same (or substantially similar) study	(none)						
Covering letter	(none)						
CV for CI	(none)						
CVs for other Investigators	(none)						
Evidence of CI indemnity	(none)						
Evidence of scientific review	(none)						
Evidence of sponsor insurance	(none)						
Investigator's Brochure	(none)						
Other	29/04/2014	Response to Committee	30/04/2014	1	451 kB		View / Manage
PIS/CF for persons interested in welfare of non-consenting participants	(none)						
Protocol	(none)						
Surveys/questionnaires	(none)						

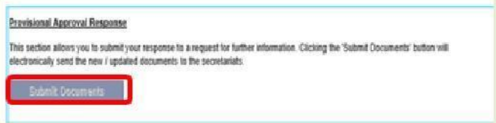
To submit:

8. Once you have uploaded all new documents or updated all existing documents click the E-Submissions tab.

9. Scroll down until you see ‘Provisional Approval Response’.

This button will only be able to be used when you have received a ‘Provisional Approval’ letter.

Please note: only click submit once.


Provisional Approval Response

This section allows you to submit your response to a request for further information. Clicking the 'Submit Documents' button will electronically send the new / updated documents to the secretariats.

Please don’t hesitate to contact the HDEC secretariat if you have any queries. We look forward to receiving your response.

Yours sincerely,

Mrs Helen Walker
Chairperson
Central Health and Disability Ethics Committee

Encl: appendix A: documents submitted
appendix B: statement of compliance and list of members

Appendix A
Documents submitted

Document	Version	Date
Post Approval Form	AM02	29 March 2019

Appendix B
Statement of compliance and list of members

Statement of compliance

The Central Health and Disability Ethics Committee:

- is constituted in accordance with its Terms of Reference
- operates in accordance with the *Standard Operating Procedures for Health and Disability Ethics Committees*, and with the principles of international good clinical practice (GCP)
- is approved by the Health Research Council of New Zealand's Ethics Committee for the purposes of section 25(1)(c) of the Health Research Council Act 1990
- is registered (number 00008712) with the US Department of Health and Human Services' Office for Human Research Protection (OHRP).

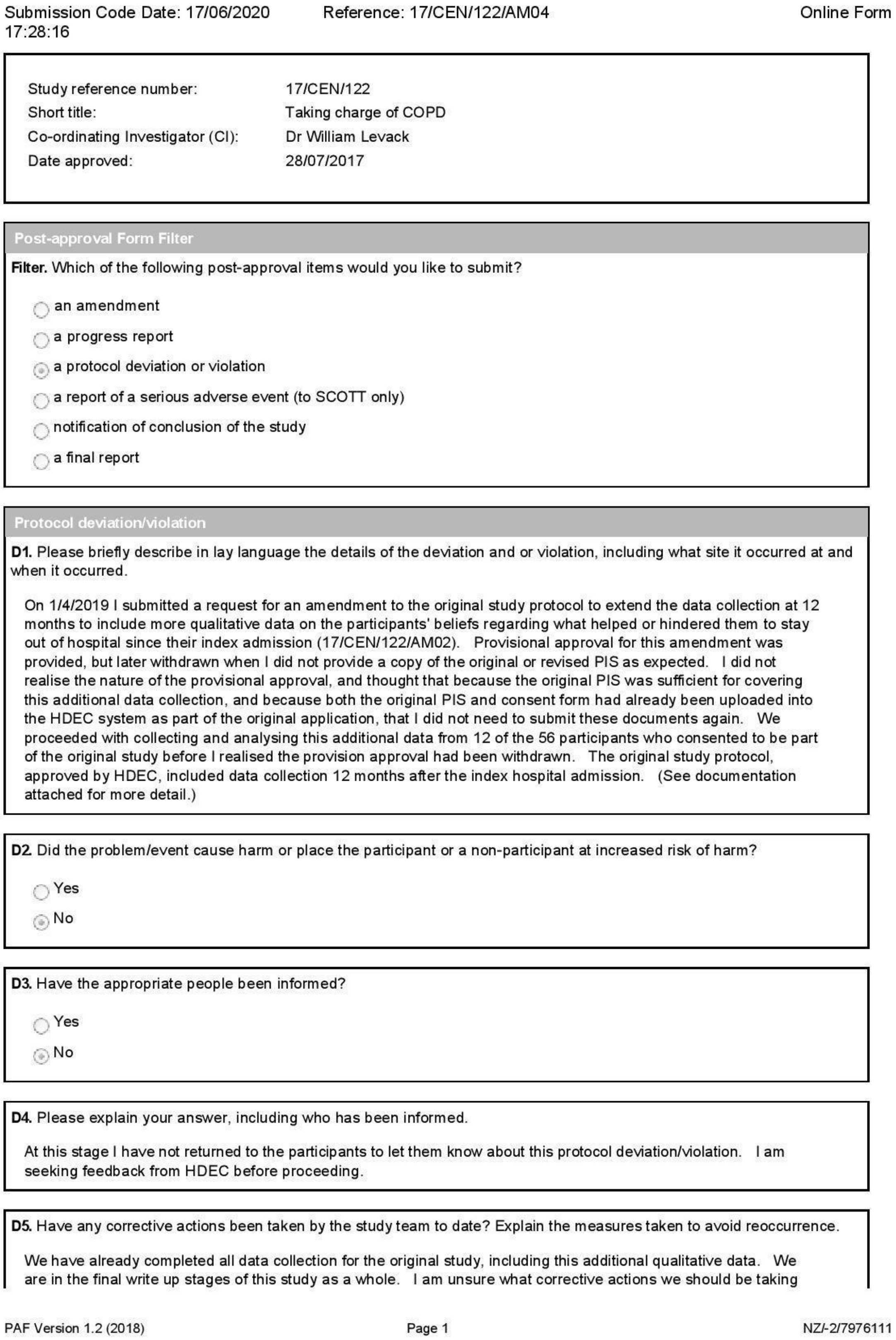
List of members

Name	*Category*	*Appointed*	*Term Expires*	*Present on 31/12/2019?*	*Declaration of interest?*
Mrs Helen Walker	Lay (consumer/community perspectives)	01/07/2015	01/07/2018	Yes	No
Dr Peter Gallagher	Non-lay (health/disability service provision)	30/07/2015	30/07/2018	No	No
Mrs Sandy Gill	Lay (consumer/community perspectives)	30/07/2015	30/07/2018	No	No
Dr Patries Herst	Non-lay (intervention studies)	27/10/2015	27/10/2018	No	No
Dr Dean Quinn	Non-lay (intervention studies)	27/10/2015	27/10/2018	No	No
Dr Cordelia Thomas	Lay (the law)	20/05/2017	20/05/2020	No	No

Unless members resign, vacate or are removed from their office, every member of HDEC shall continue in office until their successor comes into office (HDEC Terms of Reference)

http://www.ethics.health.govt.nz

Appendix G: Report on protocol violation/deviation



Submission Code Date: 17/06/2020 17:28:16 Reference: 17/CEN/122/AM04 Online Form

Study reference number:	17/CEN/122
Short title:	Taking charge of COPD
Co-ordinating Investigator (CI):	Dr William Levack
Date approved:	28/07/2017

Post-approval Form Filter

Filter. Which of the following post-approval items would you like to submit?

○ an amendment
○ a progress report
● a protocol deviation or violation
○ a report of a serious adverse event (to SCOTT only)
○ notification of conclusion of the study
○ a final report

Protocol deviation/violation

D1. Please briefly describe in lay language the details of the deviation and or violation, including what site it occurred at and when it occurred.

On 1/4/2019 I submitted a request for an amendment to the original study protocol to extend the data collection at 12 months to include more qualitative data on the participants' beliefs regarding what helped or hindered them to stay out of hospital since their index admission (17/CEN/122/AM02). Provisional approval for this amendment was provided, but later withdrawn when I did not provide a copy of the original or revised PIS as expected. I did not realise the nature of the provisional approval, and thought that because the original PIS was sufficient for covering this additional data collection, and because both the original PIS and consent form had already been uploaded into the HDEC system as part of the original application, that I did not need to submit these documents again. We proceeded with collecting and analysing this additional data from 12 of the 56 participants who consented to be part of the original study before I realised the provision approval had been withdrawn. The original study protocol, approved by HDEC, included data collection 12 months after the index hospital admission. (See documentation attached for more detail.)

D2. Did the problem/event cause harm or place the participant or a non-participant at increased risk of harm?

○ Yes
● No

D3. Have the appropriate people been informed?

○ Yes
● No

D4. Please explain your answer, including who has been informed.

At this stage I have not returned to the participants to let them know about this protocol deviation/violation. I am seeking feedback from HDEC before proceeding.

D5. Have any corrective actions been taken by the study team to date? Explain the measures taken to avoid reoccurrence.

We have already completed all data collection for the original study, including this additional qualitative data. We are in the final write up stages of this study as a whole. I am unsure what corrective actions we should be taking

PAF Version 1.2 (2018) Page 1 NZ/-2/7976111 from here. Advice from HDEC would be appreciated before proceeding.

D6. Should the research plan (and/or Sponsor's protocol) be revised, and should other participants be informed of this deviation or violation?

○ Yes

● No

D7. *Please upload details of the protocol deviation/violation in the "Documents" tab*

Protocol deviation/violation

Date: 17 June 2020

Ethics ref: 17/CEN/122

Study title: Can a 'take charge' intervention reduce incidence of repeat acute exacerbation of chronic obstructive pulmonary disease? A feasibility study

Details of the protocol deviation/violation

On 1/4/2019 I submitted a request for an amendment to the original study protocol to extend the data collection at 12 months to include the collection of more qualitative data on the participants' beliefs and experiences regarding what has helped or hindered them to stay out of hospital since their index admission (17/CEN/122/AM02). The Central Health and Disability Ethics Committee (HDEC) provided provisional approval for this amendment on 17/4/2019. This provisional approval included a request to check that the original Participant Information Sheet (PIS) covered this extra data collection, and if it did not allow for the possibility of the additional interview data that a new PIS be created. The provisional approval also required me to provide the HDEC with a copy of the original PIS or the revised PIS.

At the time I receive this provisional approval, I reviewed the original PIS and thought that it already covered the option of more qualitative data collection because the original PIS include:

1. Specific reference to collection of interview data (albeit at 3 months), and
2. Generic reference to collection of data based on asking the participants “some questions about their health at well being” at 12 months.

The mistake I made was not realising that I had to resubmit the original PIS to HDEC again because it was already included in the documentation submitted to HDEC as part of the original ethics application. I missed seeing the request to “upload either the original or additional Participant Information Sheet and consent form” simply because I was too hasty reading this, and assumed that if I checked the original PIS was suitable, that this would be sufficient for meeting the provision approval. I thought that I only need to submit a second PIS if I revised it. Unfortunately, I also missed seeing the reminder from HDEC sent on 12/6/2019.

Subsequently, we progressed with collection of this additional participant data as part of our usual 12 month data collection for the original study. These additional data were collected between May and December 2019. We are no longer collecting any additional data and are working on write up of reports from the study as a whole.

It was not until Monday this week that I realised that the provision approval for the amendment had been withdrawn because I had not resent the original or revised PIS.

Potential for harm

The potential for harm associated with this protocol violation/deviation is very low because:

1. All the participants had already provided informed consent to participate in the original study.
2. The researcher gathering all the data checked with all participants at all stages whether they were willing to contribute further to the study. The participants' involvement in this additional stage of data collection was completely the participants' choice.
3. The participants did not have to answer any question they did not wish to – as was outlined in the original PIS.
4. The scope of the additional data collection still fits within the overall objectives of the research described in the original PIS that all participant received before signing informed consent – the scope being what helps people stay out of hospital after an episode of hospitalisation for acute exacerbation of COPD.
5. The additional qualitative data was gathered and analysed using the methods already outlined in the study protocol that HDEC has already approved. The scope of the questioning for this qualitative data was slightly broader, and the timing of the interviews was at 12 months rather than 3 months.

The main risk associated with this protocol deviation/violation is that participant data might be used in a way that the participants had not originally agreed to.

There is another risk that, having collected this data, we do not actually report on it as the participants are expecting we will, due to this protocol deviation/violation.

Additional context

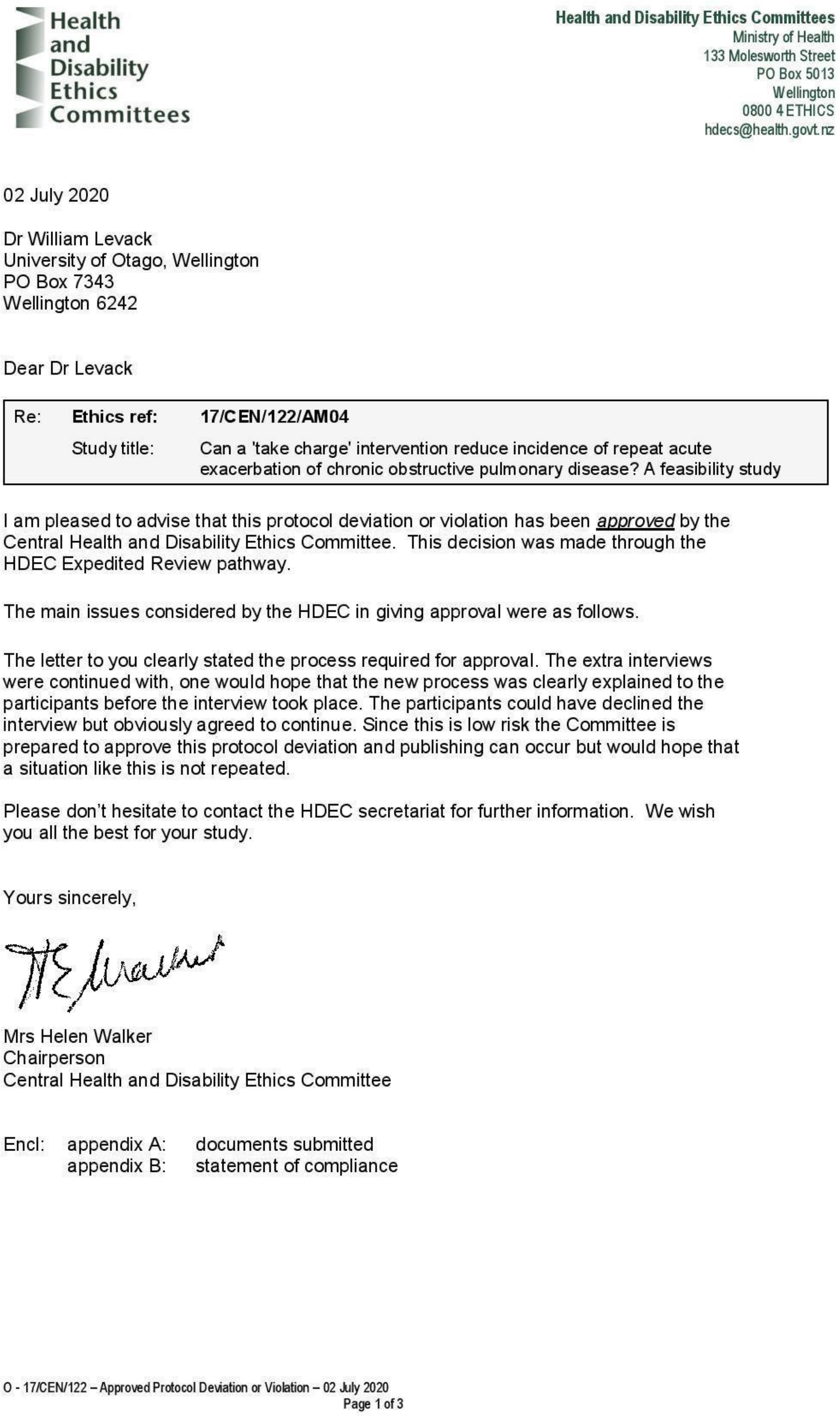
The researcher who collected this data is currently completing a Masters in Health Science endorsed in Rehabilitation, and is due to submit this work. Analysis of these data, anonymised as per our study protocol, is intended as the results of her thesis.

Please advise how we should proceed from here.

Ngā mihi,

Prof William Levack
University of Otago Wellington

Appendix H: Retrospective approval for ethics amendment



Health and Disability Ethics Committees

Health and Disability Ethics Committees
Ministry of Health
133 Molesworth Street
PO Box 5013
Wellington
0800 4 ETHICS
hdecs@health.govt.nz

02 July 2020

Dr William Levack
University of Otago, Wellington
PO Box 7343
Wellington 6242

Dear Dr Levack

Re:	**Ethics ref:**	**17/CEN/122/AM04**
	Study title:	Can a 'take charge' intervention reduce incidence of repeat acute exacerbation of chronic obstructive pulmonary disease? A feasibility study

I am pleased to advise that this protocol deviation or violation has been *approved* by the Central Health and Disability Ethics Committee. This decision was made through the HDEC Expedited Review pathway.

The main issues considered by the HDEC in giving approval were as follows.

The letter to you clearly stated the process required for approval. The extra interviews were continued with, one would hope that the new process was clearly explained to the participants before the interview took place. The participants could have declined the interview but obviously agreed to continue. Since this is low risk the Committee is prepared to approve this protocol deviation and publishing can occur but would hope that a situation like this is not repeated.

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,

Mrs Helen Walker
Chairperson
Central Health and Disability Ethics Committee

Encl: appendix A: documents submitted
appendix B: statement of compliance

Appendix A
Documents submitted

Document	Version	Date
PIS/CF: This is the original PIS/CF that was approved by HDEC and is already uploaded in Online Forms.	1	29 June 2017
Protocol deviation/violation: Details of the protocol deviation/violation.	1	17 June 2020
Post Approval Form	AM04	17 June 2020

Appendix B
Statement of compliance and list of members

Statement of compliance

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- is registered (number 00008712) with the US Department of Health and Human Services' Office for Human Research Protection (OHRP).

List of members

Name	*Category*	*Appointed*	*Term Expires*
Mrs Helen Walker	Lay (consumer/community perspectives)	01/07/2018	01/07/2021
Ms Helen Davidson	Lay (ethical/moral reasoning)	06/12/2018	06/12/2021
Dr Peter Gallagher	Non-lay (health/disability service provision)	30/07/2015	30/07/2018
Mrs Sandy Gill	Lay (consumer/community perspectives)	30/07/2015	30/07/2018
Dr Patries Herst	Non-lay (intervention studies)	27/10/2015	27/10/2018
Dr Cordelia Thomas	Lay (the law)	20/05/2017	20/05/2020

Unless members resign, vacate or are removed from their office, every member of HDEC shall continue in office until their successor comes into office (HDEC Terms of Reference)

http://www.ethics.health.govt.nz

Appendix I: Interview schedule

Patients' beliefs and experiences regarding causes and prevention of rehospitalisation for exacerbations of COPD – A New Zealand Study

Interview Schedule

Key Question 1. What keeps you out of hospital?

Q1. How has your health been in the last year?

What do you think contributed to this?

Prompts: What's been going on for you? What's happening at home? Work? Who do you live with?

Q2: What do you think has kept you out of hospital?

Prompts: Thinking back to when you've been sick, what things do you think contributed to, or made you sick?

-what was happening at the time?

Were there any times you thought you were going to get sick but you managed to pull through and avoid it? What helped?

Normally what steps do you take when you think you're going to get sick? eg sleep, good food, medications, stay home?

What do you think contributes to you getting sick?

What steps do you take to avoid these things?

Do you think animals/ pets/ air quality have any influence?

What do you think keeps you well?

How do you ensure you can do these things?

Tell me about when you were first diagnosed – were you told how serious it is or how to keep well?

Who tells you how to look after yourself?

- Do you have any friends with COPD?
- Can you see any things that you do that you think helps them? Or makes them worse?

What things would you recommend to someone with COPD to help look after themselves/ keep themselves well?

Did you learn any useful tips or tricks from the hospital, rehab, physio?

Do you feel like you're in control of your health?

What things make you feel like you're in control of your health?

Are there any things that make it harder or easier to look after yourself or do the things you think you should do?

What are the things you do daily to look after yourself?

What would you recommend to someone else?

How do you know when to go to the doctor/ hospital?

In what way do you think that your mood affects your activities or health?

- how do you maintain a positive attitude?

Key Question 2: What was your experience of the Taking Charge of COPD study?

Q1. Tell me what you remember about the study?

Q2. What were the bits you liked and what didn’t you like?

How did you make use of that session? What happened as a result of the session? What changes did you make?

In what ways did you think it was useful?

If none: Were there any ways that you thought it was useful?

What else do you think you need in order to stay healthy?

Where do you like to get your help from? GP? Physio? Hospital? Other?

Appendix J: Memo 1. Assumptions and questions

Patients' beliefs and experiences regarding causes and prevention of rehospitalisation for exacerbations of COPD

Assumptions & Questions

Current assumptions

Not enough people know that taking antibiotics early keeps them out of hospital

Taking antibiotics early keeps people out of hospital

Some people with COPD don't believe they have any control over their health. These people are the ones who end up in hospital more often – why? They may not do all the things they should/could to look after their health because they don't believe it makes a difference (e. g. healthy eating, exercise, - things that may not necessarily be comfortable/enjoyable).

Most people with COPD are depressed.

People are reasonably aware of what makes them sick and how to avoid it – but this would come years after getting the disease.

People learn they have COPD by having an exacerbation and ending up in hospital

People are not 'selfish' enough (would feel too guilty) to tell people not to visit when sick/ ask for help.

Thoughts

Hospitalisation

Do people know – really understand how bad it is to go to hospital? No-one wants to go - but do they realise how bad the effects on their health are? If they did – would they take more care of their health? Would they pressure the GP for the back-pocket prescription? Change GPs? Go to the doctor sooner? Do I really understand how much it sucks having to go the GP every second week? I hate it enough going as much as I do – is the cost a big barrier, is it the GP's themselves? What if there was a COPD drop in clinic? Where they could get advice and anti-biotics? What sort of advice would they want? What do they not know?

Living alone vs with another

Would living alone make it better or worse? Stress/ distraction– vs – overthinking and loneliness / neurosis …. i.e. Do those that live alone experience overthinking, over noticing symptoms = panic = exacerbation while those living with a partner/family member are distracted and don't have that reason for exacerbation?

Do those living with partner have more support to go to the doctor/ get antibiotic prescription/seek help when necessary/ take medication regularly/ exercise/eat healthy?
Does living alone make people more prone to depression? Does this make them more prone to not looking after themselves? Not feeling confident to go to the doctor. Not taking meds, eating healthily? Being scared to exercise?

21/06/2019
Just interviewed Sheryl. Her answers were basically that having a positive attitude was what kept her well – she has no stress in her life I wonder if having a positive outlook makes someone look after themself more? I wonder if the lack of stress hormones keeps inflammation away and that why low stress people don't get so sick? Is it true that people with less stress get sick less often? She didn't admit it but when she got sick did she have stress from her upcoming journey? It is stressful travelling, even when it's just a little one, it may not have been the kind of stress that she's used to but it is still a stressor – does the perception of positive or negative have anything to do with chemical reactions in the body?

- She also said she felt down, that's why she bought cigarettes – why was she feeling down? I forgot to ask.

She said she's always looked after others but now she has time to look after herself- her version of looking after herself is looking after her mental health and doing the things she wants to do. Not particularly healthy physical habits – she is only 76 but looks a lot older. Her FEV1 is 0.67L. 30% of expected and she is considered 'very severe obstructive defect' She should be really unwell…. But she well enough to smoke!!

A lot of these people (in the study) blankly refuse to acknowledge negative emotions like stress or sadness

BIASES: Confirmation bias: Interpreting data to support my beliefs – Be aware.