The Impact of Chronic Breathlessness on Psychological Concerns and Quality of Life in an Older, Frail Population in Primary Care

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ABSTRACT

Background Chronic breathlessness is a debilitating symptom with major detrimental impact on individuals, carers, across health care settings. Little is known about prevalence, impact, or experience of breathlessness in the older, frail population.

Aims For older adults at risk of frailty: to explore the impact of chronic breathlessness on patients' and carers' psychological wellbeing and quality of life (QoL), and to explore how chronic breathlessness is identified and assessed in primary care, considering patient, carer, and health care practitioner (HCP) experiences.

Methods A multiple-methods thesis incorporating a systematic review and mixed-methods study. My quantitative narrative systematic review of published literature aimed to determine how clinicians identified and assessed breathlessness across health care settings. My mixed-methods study included: a quantitative cross-sectional survey to determine prevalence and psychological impact of chronic breathlessness, and clinical factors associated with breathlessness, in the primary care setting; qualitative in-depth interviews further explored psychological impact and experiences of management in primary care for patients, carers, and HCPs. Mixed-methods findings were synthesised using modified critical interpretative synthesis, then integrated with the systematic review results.

Findings Chronic breathlessness is prevalent (40%) in older, frail adults and associated with worse psychological outcomes and poorer QoL. People with chronic breathlessness give up activities *because* of their breathlessness which is conflated with the underlying disease and not recognised as therapeutic target by patient or HCPs. Chronic breathlessness is often 'one of many' symptoms and in the primary care context of 'one appointment, one problem', remains invisible and unmanaged. HCPs can feel helpless and do not routinely ask about impact of breathlessness on QoL.

Conclusions Lack of routine assessment in primary care means older, frail adults with chronic breathlessness may not access evidence-based symptom-targeted interventions. Systematic identification, assessment, and management in primary care may help improve psychological health, QoL, and overall wellbeing.

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AUTHOR'S DECLARATION

'I confirm that this work is original and that if any passage(s) or diagram(s) have been copied from academic papers, books, the internet or any other sources these are clearly identified by the use of quotation marks and the reference(s) is fully cited. I certify that, other than where indicated, this is my own work and does not breach the regulations of HYMS, the University of Hull or the University of York regarding plagiarism or academic conduct in examinations. I have read the HYMS Code of Practice on Academic Misconduct, and state that this piece of work is my own and does not contain any unacknowledged work from any other sources. I confirm that any patient information obtained to produce this piece of work has been appropriately anonymised'.

PUBLICATIONS AND PRESENTATIONS

Publications

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Presentations

Oral Presentations

1. Prevalence of chronic breathlessness, and clinical factors associated with chronic breathlessness, in an older, frail population within primary care – Proactive Anticipatory Care Evaluation (PACE) Research Group Meeting – University of Hull – 27th April 2021.
2. The Impact of Chronic Breathlessness on Psychological Concerns and Quality of Life in an Older, Frail Population in Primary Care – Breathlessness Research Group Seminar, Wolfson Palliative Care Research Centre, University of Hull – 29th June 2022.

Poster Presentations

1. A systematic review to look at how chronic breathlessness is identified and assessed for adults with chronic conditions in different health care settings. Hull York Medical School Postgraduate Research Conference at Hull University, 3rd July 2018.
2. Identification and assessment of breathlessness in clinical practice: a systematic review and narrative synthesis. Palliative Care Congress (Online), 25th-26th March 2021.
3. The prevalence of chronic breathlessness and associated psychological symptoms in a frail, elderly population within primary care: a cross-sectional survey within the Proactive Anticipatory Service Evaluation (PACE). European Association for Palliative Care Congress (Online), 6th – 8th October 2021.

CHAPTER 1 - INTRODUCTION TO CHRONIC BREATHLESSNESS: BACKGROUND AND RELEVANT LITERATURE

1.1 INTRODUCTION

1.1.1 Chapter Rationale

Breathlessness is a debilitating symptom with significant and detrimental impact on individuals and carers lives (1), and is also associated with increased utilisation of health care (2, 3). This thesis aims to explore the impact of chronic breathlessness on the older, frail adult and carers' psychological wellbeing and quality of life (QoL). It also aims to explore how chronic breathlessness is identified and assessed in primary care, considering patient, carer, and health care practitioner (HCP) experiences.

In order to understand and contextualise this topic, definitions of breathlessness and chronic breathlessness will be presented in this chapter. This will be followed by an overview of relevant literature relating to the widespread impact of breathlessness (including psychological impact, quality of life, impact on others, and health service utilisation), prevalence of breathlessness (in different populations, health conditions, and by clinical setting), and identification and assessment of breathlessness (including challenges of identification and assessment, and outcome measures). The chapter will then present a summary of the chronic breathlessness literature, followed by an overview of the Proactive Anticipatory Care Evaluation (PACE) project within which this PhD is embedded. I will then close the chapter by presenting the research questions, aims, and objectives for the: overarching thesis; quantitative narrative systematic review; quantitative cross-sectional survey; and qualitative in-depth interviews along with a brief overview of methods and methodology used.

1.1.2 Definitions

Breathlessness is defined by the American Thoracic Society as 'a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity' (p. 436) (4). This symptom is often referred to by other terms, such as 'dyspnoea' or 'shortness of breath', but 'breathlessness' will be used in this thesis. In this thesis, breathlessness which persists over time is called chronic breathlessness and

is defined as 'breathlessness for most days in the last month'. This working-definition was adopted from a study investigating prevalence of acute-on-chronic breathlessness in attendees at the Emergency Department (ED) (2) which used the same definition. Acute-on-chronic breathlessness refers to an acute worsening of chronic breathlessness (5). The first study to estimate the prevalence of chronic breathlessness in the general adult population (in South Australia) defined chronic breathlessness as occurring for most days for more than three of the last six months (6). When breathlessness persists and leads to disability, despite optimal treatment of the causative medical condition, the term chronic breathlessness *syndrome* has been proposed (7). The main focus of this thesis is 'chronic breathlessness', referring to breathlessness that persists over time where optimal, or not, management is not assessed. Where literature is discussed but definitions of breathlessness are not clear, the term 'breathlessness' is applied.

1.2 IMPACT OF BREATHLESSNESS

Chronic breathlessness is important because it has a major detrimental impact on patients and carers, particularly with regard to psychological health, quality of life (QoL), functional, social, and financial impact, and health service use. Each domain will now be discussed.

1.2.1 Psychological Impact on the Individual – Anxiety and Depression

Psychological concerns, particularly anxiety and depression, are common for people with chronic breathlessness (8), indicating the widespread impact this symptom can have on the individual. Chronic breathlessness and anxiety are commonly interlinked (8) where anxiety is often an emotional response to the distressing nature of breathlessness, but can also increase the *perception* of breathlessness (9). The interplay of the two symptoms create a cycle whereby breathlessness may be the cause, or result of, anxiety (1, 9) – a breathlessness-anxiety-breathlessness cycle (10).

A qualitative study investigating patient perspectives on how Idiopathic Pulmonary Fibrosis (IPF) impacts their QoL, found a number of domains which affected the individual (11). These included symptoms (e.g. breathlessness and impact of symptom on physical function), and mental and spiritual wellbeing (e.g. anxiety, worry, and fear).

The condition had become the main aspect of their lives and breathlessness was particularly bothersome (11). A study investigating breathlessness and palliative care needs over time in Chronic Obstructive Pulmonary Disease (COPD) and lung cancer patients (12) found that whilst both groups of patients suffer with breathlessness and distress, COPD patients have higher levels of severe breathlessness and distress over time (12). This signifies the persistent impact that breathlessness has on the individual, across conditions.

A study investigating breathlessness and QoL in older people at home (13) identified 250 breathless and 250 non-breathless participants from a sample of 1,404 individuals obtained from general practice lists. Of those with breathlessness, 62.4% suffered with anxiety and depression, compared to 36.4% of those without breathlessness, as evidenced by anxiety and depression scores on the Hospital Anxiety and Depression (HAD) measure. Those with breathlessness also had lower scores on the mental component of the SF-36 (a generic health status measure relating to physical and mental health components) compared to those without breathlessness (13).

Depression is also common in medical conditions where chronic breathlessness is a symptom, such as COPD, and is related to increased disability and morbidity (14, 15). A recent review stated that individuals with severe COPD were twice as likely to develop depression as individuals with mild COPD (15). COPD patients are also 85% more likely to develop anxiety disorders in comparison to healthy matched controls (15).

A cross-sectional study recruited older adults with chronic breathing disorders from a Veterans Affairs centre in the United States of America (USA), and screened for anxiety and depression (16). Of the 1,334 individuals who reported a breathing problem and were screened using the Primary Care Evaluation of Mental Disorders (PRIME-MD) tool, 862 (65%) were depressed or anxious, 133 (10%) were anxious only, and 72 (5%) were depressed only. Of these 1,067 patients, 557 completed further screening using the Beck Depression Inventory (BDI) or Beck Anxiety Inventory (BAI). Of this sample, 444 (80%) screened positive for depression and/or anxiety. Overall, there was a high prevalence of anxiety and depression in individuals with chronic breathing problems (16).

A cross-sectional study of 154 COPD outpatients of a medium-large hospital in Norway explored the relationship between breathlessness and other symptoms (17). Lung function tests (spirometry) and questionnaires measuring a range of outcomes were

used, and results showed that breathlessness was statistically significantly associated with depression, anxiety, sleeping difficulties, fatigue, and pain (after controlling for demographic and clinical variables) (17). Similarly, a study using a community sample of older adults (65+), taken from the Duke Established Populations for Epidemiological Studies of the Elderly (EPESE) cohort in the USA, aimed to explore links between breathlessness and other symptoms (18). Questionnaires gathered information on psychological, physical, social, and cognitive functioning. It was found that chronic breathlessness (determined by self-report breathlessness) correlated with symptoms of depression at baseline and was associated with mortality at three year follow up. Chronic breathlessness was also a significant predictor of depression three years after assessment, even when controlling for baseline depressive symptoms (18).

Further, a recent cross-sectional online survey of the adult population (19) evaluated associations between chronic breathlessness and anxiety, depression, and functional status. Of the 2,977 participants, anxiety was present in 6% (n=179), depression in 2.7% (n=80), and coexisting anxiety/depression in 6.1% (n=181) of the population. It was also found that age, experience and duration of breathlessness, and function were significantly associated with psychological morbidity (19). Similar results have been found in a study of community-dwelling older adults (≥70) in the last year of life which showed a relationship between restricting breathlessness and anxiety and depression (20).

Chronic breathlessness has a detrimental impact on the individual, with a particular emphasis on psychological factors such as anxiety and depression (8). There is a wealth of evidence about this topic in the literature, but relatively little data regarding the older, *frail* population. Therefore, we need to understand the impact of chronic breathlessness on the older, frail adult and carer's psychological wellbeing and quality of life. This would help identify appropriate breathlessness related interventions and management in this group.

1.2.1.1 Other Psychological Aspects of Breathlessness

Other psychological factors are also evident in chronic breathlessness, such as fear. A qualitative metasynthesis of experiences of advanced COPD (21) found that, when

individuals experience breathlessness at night, this was often coupled with a fear of not seeing the next day, and being frightened that this symptom may lead to death – particularly an unpleasant death of suffocation (21). A further qualitative study of the unmet healthcare needs in COPD (22) found that individuals often feared for the future, regarding losing their independence or missing important family events (22). Other research interviewing patients and their families during acute episodes of COPD (10) found that breathlessness was described as an experience that was intricately associated with anxiety and emotion, reporting that anticipating and experiencing breathlessness was difficult emotionally and "very scary" (p. 765) (10).

Fear may also *increase* breathlessness (4). Whilst the physical feeling of breathlessness originates from sources such as the lungs, muscles or heart, there is a conscious awareness of this symptom which arises in the brain. Repeated association between environmental reminders (e.g. anticipation of climbing stairs) and breathlessness can increase the awareness of this symptom (23). In a study using patients with COPD and healthy participants (23), functional Magnetic Resonance Imaging (fMRI) was used to detect brain activity in response to breathlessness related word cues. It was found that the emotional centres of the brain were activated in response to these words, suggesting that heightened responses to these cues may increase the sensation, experience, or fear of this symptom (23). Further to this, a Bayesian brain model has also recently been applied to the situation of chronic breathlessness (24) which describes how the brain produces sensations based on expectations learnt from previous experiences (priors), which then modify incoming signals. For example, a signal might be amplified if there was a previous bad experience and an expectation that it will be awful. Within this model, psychological factors may be influential (acting as moderators) and could lead to a different interpretation of the symptom (24). In this supplementary analysis of previously published data, findings suggest that sensitivity to anxiety can reduce the robustness of the Bayesian sensory perception system, leading to changes in perception of breathlessness. This study was conducted in healthy individuals but explains how psychological factors may influence experience of physical symptoms (24).

A pilot project investigating the provision of psychological interventions in respiratory settings has shown that this form of support can be effective for chronic respiratory disease (25). In this service evaluation, psychological intervention was implemented as

appropriate within a multidisciplinary team (MDT). Seventy-nine inpatients and eight outpatients with a chronic respiratory condition received psychological intervention with a clinical psychologist. Depending on need, inpatients received on average two to three sessions and outpatients received between six and ten sessions. Interventions included a focus on breathlessness-related anxiety, mood management, and chronic condition adjustment. It was found that psychological provision reduced emotional distress, increased patient experience of healthcare, increased staff awareness/willingness to address patient needs, showed a decline in hospital admissions, and was also cost effective (costs of psychology provision were offset by savings in reduced admissions). These results highlight the psychological need within this patient group, and show the potential benefits of including psychological support in respiratory services (25).

1.2.2 Health Related Quality of Life (HRQoL)

Chronic breathlessness has a widespread impact on the individual and their families, severely influencing their everyday functioning and emotional wellbeing. The worse chronic breathlessness gets, the more individuals limit their daily functions in order to avoid the symptom and its negative effects (1). In the general population, as the severity of chronic breathlessness increases, there is a deterioration of HRQoL by disease, age, and prognosis (26).

A systematic review (27) has highlighted the massive impact of breathlessness of the individual (and carer/family). This review describes the concept of 'Breathing Space', a conceptual framework which illustrates the experiences of living with breathlessness, as well as patient coping, help-seeking and clinician response to this symptom (for more detail see section 2.3: Conceptual Frameworks). The interaction of these components influences whether the individual achieves optimum breathing space or whether they are restricted by breathlessness (27).

A population study collected data via the South Australian Health Omnibus Survey, measuring HRQoL using the Short-Form 12 (SF-12) (26). This is a 12 item questionnaire assessing physical and mental health. Of the 3,005 respondents, 260 (8.7%) had mMRC (modified Medical Research Council breathlessness scale) 1 and 88 (2.9%) had mMRC 2-

4. When comparing those with and without chronic breathlessness, it was found that those with mMRC 1 or ≥2 had reduced predicted mean physical and mental component scores on the SF-12. Results showed that mental and physical HRQoL worsened with severity of chronic breathlessness. Older age also indicated greater impact of chronic breathlessness on both physical and mental HRQoL components (26).

A study investigating breathlessness and QoL in older people at home, also found that there was a significant relationship between breathlessness and functional status (13). There were 1,404 participants randomly selected from general practice lists of 5,002 individuals living at home in a South Wales town. Postal questionnaires and interviews were conducted to measure breathlessness using the mMRC scale along with a number of other measures of function and QoL. Among these were the Nottingham Extended Activities of Daily Living (NEADL), which measures participation of 21 activities in four categories (mobility, kitchen, domestic, and leisure); the Hospital Anxiety and Depression (HAD) scale which contains 14 items relating to the amount of distress experienced during the previous week; and the SF-36, a generic health status measure relating to physical and mental health components. Results showed a significant relationship between breathlessness and functional status, determined by comparing the NEADL scores of breathless and non-breathless participants. Breathless participants also scored less on the physical component of the SF-36 compared to the non-breathless participants, showing poorer HRQoL (13).

A cross-sectional population based study assessed QoL and duration of breathlessness in adults, using data from the South Australian Health Omnibus Survey (28). Quality of life was assessed using the EuroQol-5D (EQ-5D-5L which measures mobility, self-care, usual activities, pain, and anxiety/depression) and the SF-12, and breathlessness was assessed with the mMRC. Results showed that chronic breathlessness was related to reductions in QoL with particular impact on mobility, activities of daily living, and pain. However, anxiety/depression and self-care were more impaired in those individuals with more severe breathlessness (mMRC 4). Quality of life was most impaired for those experiencing chronic breathlessness for between two to six years (28).

Other issues are also impacted when considering chronic breathlessness and HRQoL, such as sleep. A cross-sectional survey also using data from the South Australian Health Omnibus Survey explored the relationship between chronic breathlessness and sleep

problems, independent of diagnosis and health service contact (29). Of the 2,977 interviewees, there were 2,900 participants who answered questions on breathlessness and sleep. The prevalence for breathlessness (mMRC 1-4), sleep problems-past, and sleep problems-current, were 8.8% (n=254), 2.7% (n=78), 6.8% (n=198), respectively. Those participants with sleep problems-past were more likely to have breathlessness, be older, and have a higher Body Mass Index (BMI); those with sleep problems-current were also more likely to be female. This study found a strong association between chronic breathlessness and presence of sleep problems (past and current). Specifically, those with chronic breathlessness were 1.9 times more likely to suffer with sleep problems-past than those without chronic breathlessness; the odds of sleep problems-current were similar (29). Sleeping problems are prevalent in the community, but are more common in older adults (30), as is chronic breathlessness (26).

Evidence shows that chronic breathlessness impacts day-to-day function (26), impairment of domestic and leisure tasks (13), sleep (29), and physical and mental health (26), with substantial impact on HRQoL.

Chronic breathlessness has a major impact on an individual's QoL; the current literature is poorly representative of the views of those older, frail adults in regard to this. It is therefore important to address this gap in order for this population to benefit from effective interventions and management.

1.2.3 Functional, Social, and Financial Impact on the Individual

To reduce their breathlessness, individuals may decrease their physical activity, becoming sedentary. This leads to poor fitness, deconditioning, increased anxiety, depression and a poor quality of life (1). The impact of breathlessness on the individual has also been linked to a loss of the will to live near death, an increased probability of admission to hospital, and earlier death (1).

Chronic breathlessness has an impact on the individual's daily life. As sufferers attempt to deal with everyday activities such as domestic chores, task-related (activity/exercise induced) breathlessness occurs (9). In order to prevent this, triggers of breathlessness are usually avoided, commonly averting any exertion (9, 11). Ultimately, physical activity becomes diminished or impaired due to breathlessness (11) and this can lead to a cycle

of impaired functional status and deconditioning (1, 9). A previous study looking at patients' perspectives on how IPF affects quality of life showed that individuals had to limit and plan their daily activities, whilst also considering how to conduct these activities in a way that avoids exertion. This often resulted in pausing during the performance of normal daily activities such as brushing teeth (11). A population based cross-sectional cohort study using an online survey reported on the activities forgone due to chronic breathlessness in Australia (31). There were 3000 participants of which 583 were defined as having chronic breathlessness (mMRC ≥1 for more than three months). Participants were asked to report three activities they had given up because of their chronic breathlessness. For those individuals with mMRC 1 (n=533) only 35% reported that they did not give up any activities, for mMRC 2 (n=38) this was 9%, and for mMRC 3-4 (n=12) it was 3%. Across all mMRC scores, breathlessness worsens, with more intense and strenuous activity being affected first. As chronic breathlessness worsens, regular daily activities become increasingly difficult (31).

Individuals living with chronic breathlessness may therefore restrict their previous activities – feeding a cycle of reduced physical activity, reduced muscle mass, and increased breathlessness - which could lead to an inactive lifestyle (21), potentially becoming housebound (26). Restrictions of these social abilities/activities could result in a change in their social role (9), and may result in social isolation, potentially feeding into a vicious cycle of isolation, depression, and anxiety. In a study looking at unmet healthcare needs in COPD, it was found that individuals often report being restricted to their home because of their lung condition and consequently feel socially isolated (22). Individuals with advanced respiratory disease are often socially isolated as a consequence of their long-term illness (32). An exploratory qualitative study in Portugal, exploring the perspectives of patients and family members about the impact of COPD on their family life (33) found that patients felt deprived from family and social activities as a result of worsening COPD related symptoms, such as fatigue, sleep disturbances, mobility issues and breathlessness. This led to social isolation, a lack of sharing with family and friends, and feelings of sadness and loneliness. This loneliness extended to family carers who had to give up social roles or activities as caring responsibilities and dependency of the ill person increased (33). Older adults in particular are at greater risk

of social isolation or loneliness (34) and social isolation is also associated with an increased risk of hospital admission in older adults with respiratory disease (35).

Financial consequences also exist for the individual experiencing chronic breathlessness. It may be difficult to continue economic productivity (21) and financial problems may occur if an individual is no longer able to earn an income due to disability (36). A cross-sectional study using the South Australian Health Omnibus, explored associations between paid workforce participation and breathlessness intensity, and economic impact on working age adults (37). Workforce participation was self-reported as either full or part time work, and breathlessness was determined using the mMRC scale. Results showed that those individuals with the most severe chronic breathlessness were much less likely to be in full or part time employment. Additionally, older adults were also more likely to have chronic breathlessness and therefore less likely to be in paid employment. Overall, more severe chronic breathlessness was associated with lower paid workforce participation and this had direct financial impact (37).

1.2.4 Impact on Survival

Presence of breathlessness is an important predictor of mortality (38-43), and a more accurate predictor than spirometry (39). A multicentre prospective study using case reports and five-year follow up in Japan, demonstrated that level of breathlessness in patients with COPD was more strongly correlated with survival than by disease severity as measured by spirometry (39). A population based, prospective cohort study in Norway conducted a respiratory postal survey and found a positive association between symptom score, as well as respiratory symptom groups, and 30-year mortality (40). A similar general population-based cohort in the Netherlands measuring breathlessness severity, changes, and mortality found that moderate or severe breathlessness were significantly associated with all-cause, cardiovascular, and COPD-related mortality. Those with persistent, and newly developed breathlessness also had increased risk of mortality (41).

As breathlessness is an important predictor of mortality, it is essential that it is identified and assessed routinely across clinical settings; this could help improve prognosis as well as management of the symptom.

1.2.5 Impact on Others

Chronic breathlessness has an impact on other individuals, such as carers and social networks (1). Friends and family of people with advanced disease are frequently involved in providing informal care and as a result, undertake a number of extra responsibilities. These tasks vary widely from physical care, emotional support, and overseeing treatment (44). As a result, carers may suffer as they provide physical, emotional, social, and financial care, often disregarding their own needs in the process (44). The impact and responsibility of caring for another in such ways can lead to poor physical and mental health, such as depression, anxiety, exhaustion, and medical illness (45). This suggests that carers require specific support.

In a qualitative study investigating the experience of burden in informal carers of individuals with COPD (46), it was found that as the disease worsened, greater physical and emotional burden was found for both individuals and their carers. Burden on the carer may create stressful changes in relationships that impact their ability to cope, notably for female spousal carers. A downward spiral of physical, social and emotional effects impact the carer, their relationships or partnerships, and leave them with feelings of anxiety about the future (46). This is highlighted further in a study investigating the experience of QoL in women caring for their husbands with COPD. The women's QoL was determined by the role they held as their husbands' carer. They believed that caring for their husband was their duty, and as a result, found it difficult to focus on their own quality of life (47).

Informal carers of individuals in cancer and palliative care have high needs and psychological morbidity (48). In a study of the needs of informal carers of patients with heart failure or lung cancer (49), results found that higher burden was associated with worse carer psychological health; there was an equal level of unmet need and burden between carers of these two patient groups. Those individuals caring for patients with more severe breathlessness reported fewer positive or rewarding caring experiences. This study concluded that services for breathlessness patients should also provide interventions for carers which could include symptom management guidance and such interventions should be based on breathlessness severity and carer need, rather than cause of breathlessness (49).

A systematic review to determine the key elements of educational interventions for carers of patients with advanced disease (50) suggests that symptom management may help address both patient and carer needs, especially in relation to distressing symptoms such as chronic breathlessness. This review recommends that providing education about symptoms, and incorporating information about evidence-based nonpharmacological interventions, may be effective in addressing the needs of both patient and carer. However, it also highlighted that educational interventions focussing on symptoms alone are rare, and none were identified in this review that provided education for breathlessness (50). Further to this, an online survey was conducted to determine clinicians' views of educational interventions for carers of patients with breathlessness due to advanced disease (51). Findings show that most carer education is done via clinical contact with, and when educating, the patient. Education of the carer alone was rarely conducted. Clinicians suggested that joint education about breathlessness, with patient and carer, in a simple and practical manner would be beneficial. Clinicians also thought that breathlessness education interventions should enhance patient experience and the ability of the carer to look after the patient, rather than addressing the caring experience or impact of their role (51). A further study investigating the interaction between carer and health care professionals showed that carers were disappointed with support received, relating to involvement of the carer in the patient's treatment/care, attention to carer wellbeing, or informational needs (44).

Chronic breathlessness has widespread impact on all aspects of the individual and carers lives (27, 52), and experiences of this symptom are shared (52). However, the carer seems vulnerable to increasing emotional distress and therefore chronic breathlessness interventions for both patient and carer, and carer alone, are needed in order to address shared and individual needs (52). Further, a narrative review outlining carer needs in those supporting patients with COPD (53), stated that an assessment of carers which considers their support needs, caring capacity, and their own clinical requirements, would help to address unmet needs of the carer (53).

1.2.6 Impact on Health Service Use

Chronic breathlessness is a common symptom causing individuals to seek health care, and has a large impact on health care services (3, 54) (see section 1.3.4: Breathlessness

by Clinical Setting). A cross sectional analysis using the South Australian Health Omnibus Survey 2017 – a systematic sample survey administered to participants (≥15) in their own homes – explored health service utilisation and chronic breathlessness (due to any cause) in a sample drawn directly from the community (3). Chronic breathlessness (mMRC breathlessness scale ≥1) was reported by 8.8% of participants. Results showed that those who had contact with health services (outpatient, inpatient, any medical consultation, frequent medical consultations, and any ED visits) were older, and experienced more severe chronic breathlessness. There was a significant association between worse chronic breathlessness and increased health service utilisation (3).

A multicentre observational study in Spain identified factors associated with high utilisation of health care resources in people with COPD (over 40 years old) (55). Of the 115 patients included, 64 (55.6%) were high users of healthcare resources (defined as, in the previous year to study involvement, had either one hospital visit for a COPD exacerbation, two or more visits to the ED due to an exacerbation, or two or more non-scheduled COPD-related visits to an outpatient department) and had higher MRC (Medical Research Council breathlessness scale) scores than those with lower healthcare utilisation (55). Similarly, a study investigating resource use and risk factors in high-cost exacerbations of COPD in the Netherlands and Belgium (56) found that increased breathlessness (determined by a low BDI [Baseline Dyspnea Index] score at baseline assessment) was significantly associated with increased risk of hospitalisation (56). Further, a cross-sectional secondary analysis investigated variations in cost of formal and informal health care for patients with advanced chronic disease and refractory breathlessness (on exertion or rest, MRC breathlessness scale ≥2) (57). Results found that higher health care costs were associated with increasing disability associated with breathlessness, breathlessness on exertion, and an underlying condition of COPD. The presence of an informal carer was also significantly associated with high total, and informal, care costs (57).

Appropriate management of breathlessness has been shown to reduce health service costs. One randomised controlled trial (RCT) showed that specialised care – in this case a Breathlessness Support Service (BSS) in London - can have significant improvements on an individual's capacity to manage their breathlessness (58). In this study patients with breathlessness and advanced disease were assigned to either usual care or the BSS.

Patients entering the BSS displayed greater improvement in mastery (control) over their breathlessness than the usual care group at six week follow up. Interestingly, the mean costs of the BSS and usual care were similar; £1,422 and £1,408, respectively, although costs varied between individuals (58). This shows that individuals receiving care through a BSS have more effective management of their breathlessness without increased financial burden on health services.

1.2.7 Impact of Breathlessness Summary

There is an association between chronic breathlessness and a number of psychological factors, such as anxiety and depression (8). Anxiety and breathlessness are interlinked whereby one may be the cause or result of the other – the breathlessness-anxiety-breathlessness cycle (10). Depression is also prevalent in those conditions where chronic breathlessness is a symptom and has a marked impact on the individuals QoL (14, 15). Anxiety and depression are also highly prevalent in older populations experiencing chronic breathlessness (13, 18). Other psychological factors such as fear (21, 22) impact heavily on the individual. There is a considerable amount of evidence regarding the psychological impact of chronic breathlessness on the adult and older adult populations, and psychological intervention for chronic breathlessness in respiratory services has been shown to be effective (25). However, better understanding is needed regarding the impact of chronic breathlessness on the older, *frail* adult and carer's psychological wellbeing and quality of life.

Chronic breathlessness is a distressing symptom with widespread impact on the patient and carer (27), consequently leading to reduced HRQoL (26). It is a common symptom leading to social limitations/reduced personal roles (9), indicates poor prognosis, is an important predictor of survival (39), and is also associated with increased health care utilisation (3). Identifying the impact of chronic breathlessness on patients and carers is paramount so symptom targeted interventions and appropriate management can be applied.

1.3 PREVALENCE

Chronic breathlessness is also important because it is common in many different populations, health conditions, and healthcare settings.

1.3.1 Breathlessness in the General Adult Population

Prevalence estimates of breathlessness within the general population vary depending on the population sampled and the method of breathlessness assessment used (59).

A population-based study across 15 countries (the Burden of Obstructive Lung Disease [BOLD] Study) showed a breathlessness prevalence (any breathlessness as measured by the mMRC breathlessness scale) of 27% (60), but only included people over the age of 40. The Health Survey for England (HSE) 2011, a household population survey, found a prevalence (MRC breathlessness scale ≥2) of 15% for males and 26% for females (59, 61). A recent web-based population survey conducted across the adult population in Australia found that 9.5% (961 of 10,072) of respondents reported clinically important breathlessness (mMRC breathlessness scale ≥2) (62). This symptom was associated with ill health and included individuals without respiratory or heart conditions (62).

The Health Omnibus Survey, which included all adults in a community population study conducted in South Australia, estimated the prevalence of *chronic* breathlessness (defined as breathlessness most days for more than three of the last six months) for the general adult population (6). This research identified nine percent of individuals reporting chronic breathlessness, representing significant burden across the general population. This estimate most closely reflects the prevalence of *chronic breathlessness* across adults in the *general population*.

1.3.2 Breathlessness in Different Health Conditions

Older adults with frailty are likely to have multiple long-term conditions (63). As the focus of this thesis is chronic breathlessness in the older, frail population, it is highly likely that the study population will experience chronic breathlessness as a result of chronic disease – primarily cardiorespiratory disease - or multiple long-term conditions. Therefore, the prevalence of breathlessness across conditions will be outlined followed

by a description of other breathlessness aetiology. This will provide an understanding for the wider context of breathlessness across the general population.

1.3.2.1 Cardiorespiratory Conditions

There is a high prevalence of breathlessness in respiratory and cardiovascular conditions, many of which – such as Chronic Obstructive Pulmonary Disease (COPD) and cardiovascular disease – often occur together with worse combined outcomes (64). In a systematic review of advanced disease, the prevalence of breathlessness was high in cancer (16-77%), chronic heart failure (CHF) (18-88%), end-stage renal disease (ESRD) (11-82%) and particularly high in COPD (56-98%) where nearly all patients experienced breathlessness (65). An earlier systematic review also identified high prevalence of breathlessness in heart disease (60-88%) (66).

A systematic review investigating symptom prevalence in patients with progressive idiopathic fibrotic interstitial lung diseases (PIF-ILD) determined that breathlessness was prevalent in 68-98% of patients (67). A study investigating psycho-physiological factors of interstitial lung diseases (ILD) in hospitalised patients in China – not included in the review – also reported a high prevalence (73%) of breathlessness (MRC breathlessness scale ≥2) across all subtypes of ILD (68).

Breathlessness is common in other conditions, including asthma, pneumonia, and pulmonary embolism (PE), amongst others. Respiratory and cardiovascular diseases often coexist, and comorbidity is common across these conditions (69). A recent cross-sectional study using data from the Swedish Cardiopulmonary bioImage Study (SCAPIS) (38) aimed to identify the underlying contributing conditions to breathlessness amongst middle-aged individuals (50-65 years old). Respiratory disease and heart disease were two of the main contributing conditions and overlap was common with 66% of participants having two or more conditions (38).

1.3.2.2 Other Causes of Breathlessness

There are other, non-cardiorespiratory conditions that also cause breathlessness. These conditions include anaemia, neuromuscular disorders, and psychological disorders.

Anaemia occurs when the oxygen transporting capacity in the blood is diminished. Subsequent exertional breathlessness can occur, and this can be worse if individuals have other underlying cardiopulmonary conditions (4).

Neuromuscular diseases - disorders affecting the nervous system - include conditions such as motor neurone disease (MND) (70). This is characterised by degeneration of motor neurons, consequently causing muscle weakness including respiratory muscles of ventilation (71). As a result, most, if not all, MND patients will develop respiratory complications at some stage (72). Other neuromuscular diseases such Duchenne muscular dystrophy (DMD) (73) – a severe neuromuscular disease - are distinguished by advancing muscle weakness causing loss of movement, including respiratory muscles. As the disease progresses, respiratory and cardiac complications develop (73).

Other muscle weakness relates to disorders such as cancer cachexia which is characterised by loss of skeletal muscle mass (sarcopenia) and diminished physical functioning (74). Respiratory muscle fatigue is common and a cause of breathlessness in the cachectic cancer patient (75).

Psychological, mental health disorders, and disorders with medically unexplained symptoms may also cause breathlessness. These include: anxiety, hyperventilation syndrome, and panic disorders (4) which often increase distress and worsen perceptions of breathlessness (69). Disorders of the ear, nose and throat can also cause obstruction to airflow, resulting in breathlessness. This can occur through infections or trauma (69) or when the larynx acquires a functional role (76). In the latter case, dysfunctional breathing such as vocal cord dysfunction, chronic cough and voice or swallowing disturbances may occur due to increased physiological or environmental stressors, resulting in breathlessness (76).

1.3.3 Breathlessness in Older Adults

The prevalence of breathlessness increases with age (77). The Health Omnibus Survey, outlined above (section 1.3.1), identified that 16.9% of adults aged 65 years and over have chronic breathlessness (6). Additionally, the Health and Retirement Study, a nationally representative sample of community dwelling older adults in the United States, found 25% of those over 70 years old experienced breathlessness (clinically

significant breathlessness defined as often or sometimes experiencing breathlessness while awake), with prevalence higher in those with chronic lung disease (63%), multimorbidity (≥2 chronic conditions) (45%), and heart disease (36%) (78). In one community based study, Ho et al (13) identified their cohort (individuals over 70 years old living at home) through general practitioner (GP) lists, and found a breathlessness prevalence (MRC breathlessness scale 3-5) of 32%. However, this estimate could reflect the prevalence of breathlessness within this particular population, and not the community as a whole (6). In a Norwegian study recruiting elderly patients (aged 60-79 years) from general practice, the prevalence of breathlessness (World Health Organisation [WHO] classification ≥1) was 31.3% (79). Other evidence supports this and suggests that one third of older adults suffer with daily breathlessness (80). This is not surprising as many medical conditions, which are more common in older people, cause breathlessness, especially in those with advanced disease (78).

In older individuals where multiple long-term conditions are common, there can be several causes for chronic breathlessness (69). A study investigating breathlessness in elderly adults (≥70 years) in the last year of life found a number of factors associated with this symptom. In particular, breathlessness sufficient to restrict activity was associated with multiple long-term conditions and included causes such as: heart and lung disease, mobility problems, anxiety and depression, smoking status and cancer leading to death (20).

1.3.3.1 Older Adults and Frailty

Worldwide, the older population is increasing; in the UK alone 18% of the total population are 65 or over with this figure estimated to continue rising over time (81). As seen above, chronic breathlessness is prevalent in older adults (80). Older adults with breathlessness are likely to suffer with multiple long-term conditions (78), and evidence shows that comorbidity, disability, and frailty often occur simultaneously (82).

Frailty is defined by Conroy and Elliott (81) as a 'dynamic state of increased vulnerability and loss of resistance to external stressors, resulting in an increased risk or adverse outcomes' (p. 15) (81). It is characterised by the presence of three or more of the following symptoms: unintentional weight loss (sarcopenia), weakness, exhaustion

(poor endurance/energy), slowness and low physical activity (63, 81). Frailty is prevalent in older age, with a prevalence of 10% in those over 65, increasing with age (81), and has a higher risk of associated health issues and conditions (63). There is an increased risk of adverse outcomes in the older, frail population, such as falls, disability, hospitalisation, mortality (83, 84), and higher health care utilisation (63). As breathlessness is also related to sarcopenia, as well as multiple long-term conditions (85), it could be expected that there will be a higher prevalence of breathlessness in older, frail adults, but this has been poorly explored to date.

1.3.3.1.1 Older Age, Frailty, and Breathlessness

A study which examined the prevalence of frailty in fibrotic interstitial lung disease (ILD) patients (adults ≥40) who were recruited from a specialised clinic, found that frailty was highly prevalent (50%), and strongly and independently associated with breathlessness severity (86). A study investigating symptom-burden in adults with chronic kidney disease (CKD) and frailty found similar results in that those with frailty were more likely to experience breathlessness than the non-frail adults (87). Research using data from a UK biobank for the general population (493,737 participants, aged 37-73) found multiple long-term conditions to be common in frail participants, and that the prevalence of frailty (and pre-frailty) increased with higher number of comorbidities (88). Additionally, a study investigating frailty and QoL in elderly primary care users (89) found associations between frailty and poorer QoL, where functional capacity, impact of physical problems, and general health were the most affected (89).

The connection between chronic breathlessness, frailty, and older adults is important as an ageing – and frail – population creates additional concerns and challenges for the health care system (81). A cross-sectional study investigating frailty, depression, and anxiety in community dwelling adults ≥60 (90) showed that higher depression and anxiety scores were evident for both pre-frail and frail groups compared to those without frailty (90). Likewise, a recent study conducted in Poland studying frailty and the occurrence of anxiety and depression in elderly adults with Atrial Fibrillation (91) found that frailty was common in this population; an association between anxiety and depression and the incidence of frailty was also found.

However, despite the apparent relationship between older age and breathlessness, and older age and frailty, the link between the three conditions is poorly explored within the current literature.

1.3.4 Breathlessness by Clinical Setting

The primary care, secondary care, and specialist palliative care settings will now be discussed.

1.3.4.1 Primary Care

Chronic breathlessness accounts for a high proportion of attendances at general practice. Breathlessness is mainly a result of respiratory and cardiac diseases within this setting (79, 92-94). A study conducted within Australian general practice, using data from an annual survey of 1000 general practices, showed that individuals (over 18 years old) presented to their practitioner with breathlessness as one reason for encounter in 7,255/755,729 (1%) consultations (92), although this is likely to be an underestimate. Of those presenting with breathlessness as a reason for encounter, those aged 75 years or older accounted for 36.8% of these consultations. Patients 65 years and over made up more than half (57.7%) of the consultations for breathlessness. In this study (92), breathlessness was three times more likely to be the reason for encounter in a community consultation rather than a clinic consultation and referrals to hospital were three times as likely from community rather than clinic encounters (92).

A similar study investigated reasons for consultation in a primary care setting in Germany (using secondary data from two studies - SESAM and Transition Project) (93). Results showed that between 1% (SESAM) and 4% (Transition Project) of consultations were for individuals presenting for breathlessness and that the consultation prevalence increased with age (1.44% for 65-74 year olds, and 1.74% for those >75) (93). However, this study involved all ages, not just the adult population as in the above study. Breathlessness was also found to be related to other reasons for encounter in approximately two thirds of cases, including cough, chest pain, fatigue, medication request, cardiovascular screening, wheezing, and oedema (93, 95). The same research team confirmed in a following study with an elderly population (≥ 65 years) (96) that

breathlessness was the fifth most common nonprocedural reason for visiting a GP, accounting for 1% of all reasons for visit (96). A recent cross-sectional study using the South Australian Health Omnibus Survey 2017, showed that there is a significant association between worse chronic breathlessness and increased health service utilisation; older adults and those with more severe chronic breathlessness had more contact with health services (3).

A study investigating breathlessness and presentation to the emergency department (ED), (2) found that two-thirds of presentations to the hospital occurred when their regular health care professional (e.g. family doctor) was not available. Seventy three percent of individuals presenting to the ED reported their GP as the practitioner they had previously consulted about their breathlessness, recognising them as a significant component of their support. The role of the family practitioner highlights how important primary care is to the patient with breathlessness (2). This is important as primary care could be considered the first port of call for symptom management and treatment, where appropriate primary or community care intervention for chronic breathlessness may prevent unnecessary hospital admission, particularly in the older populations where breathlessness is increasingly prevalent.

1.3.4.2 Secondary Care/Emergency Department (ED)

Breathlessness is a common symptom associated with presentation to the ED (2). It is within the top 10 reasons for attendance reported by the National Hospital Ambulatory Medical Care Survey 2007 (97). A study investigating breathlessness and presentation to the ED in England (2) found that 424/1,212 (35% CI 32.2-37.7%) presentations made to the 'majors' department (major emergencies) of the ED were by people *living with* chronic breathlessness (self-report of breathlessness most days in the last month). One in five presentations (245/1212 [20%]) presented *because* of acute-on-chronic breathlessness. People with chronic breathlessness made up 5% of all presentations to the ED. Therefore, at least one in five presentations brought by ambulance to the ED were due to acute-on-chronic breathlessness (2). Despite this, case note review found that breathing difficulties were documented by triage nurses as the main presenting complaint in only one third of those presenting with self-reported breathlessness. Difficulties with breathing were also documented by doctors (as the primary or

secondary presenting complaint) in approximately two thirds of case notes (2). Breathlessness severity decreased between the decision to present and whilst waiting in the ED (2), showing that breathlessness evidently settles over time or at rest. This is relevant to the findings that approximately one third were able to go home without the need for hospital admission (122/177; 69% were admitted) (2). Therefore, improvements in community care may be able to keep individuals at home using breathlessness interventions (helping to calm and reassure them), without the need for hospitalisation.

The prevalence of 5% of all ED presentations found in Hutchinson et al (2) is mirrored in a prospective observational study of breathlessness in emergency departments which collected data at three time points over 72 hours in EDs in the Asia-Pacific region (98). Of 60,059 ED attendances, breathlessness was a reason for presentation in 3,105 patients, showing a prevalence of 5.2% (95% CI 5.0-5.4%). The same dataset was used in a similar study investigating the epidemiology and outcome of older patients presenting with breathlessness to the ED (99). This study found that older patients (> 75) with breathlessness accounted for 1.8% (1,097/60,059; 95% CI 1.7%-1.9%) of ED attendances, showing a high ED case load for this population (99).

Breathlessness prevalence has also been determined in hospitalised patients. A prospective cohort study set in Boston, USA, examined the prevalence of breathlessness in adult patients (n=46,481) at the time of hospital admission (67,362) (100). Routinely collected data were taken from patient assessments conducted within 12 hours of admission. Using a numerical rating scale (NRS) from 0-10 where 10 was 'unbearable', it was found that 11% of all patients reported current breathlessness (>0), with 4% reporting breathlessness of score 4 or higher (moderate to severe). Breathlessness over the previous 24 hours was found in 16% of all patients, with 10% reporting breathlessness of score 4 or higher (100). This study was the first large scale prevalence study of breathlessness in hospitalised patients showing that breathlessness is common in patients within this setting, and that it is feasible to measure this symptom upon admission (100). In a previous pilot study, nurses routinely documented patient-reported breathlessness at time of initial patient assessment (study 1, n=581) or once each nursing shift (study 2, n=367) (101). In study 1 prevalence of burdensome breathlessness (≥4 on 4 on a 10-point rating scale) upon admission was 13% (77/581;

95% CI 11-16%). In study 2 prevalence of burdensome breathlessness at some point during the hospital stay was 16% (57/367; 95% CI 12-20%). These studies identified significant symptom burden of breathlessness within hospitalised patients and also concluded that routine collection of breathlessness data could aid symptom management (101).

The prevalence of breathlessness is again common in secondary care settings, showing that this symptom is a major problem across clinical practice. As identified in section 1.2.6: Impact on Health Service Use, worsening chronic breathlessness is significantly associated with increasing health care utilisation (3). Hence, appropriate management at an earlier stage (primary/community care) may prevent unnecessary health care usage.

1.3.4.3 Specialist Palliative Care

Palliative care aims to provide care for patients during serious illness and up to the end of life, and support for their families (102). It is highly likely that those experiencing palliative/end of life care could be categorised as older, frail, or both. As the older, frail adult is the focus of my thesis, prevalence in this setting is important to understand the impact of this debilitating symptom. A retrospective analysis conducted in a post-acute care facility in Brazil reviewed electronic charts to determine ESAS (Edmonton Symptom Assessment System) scores in 54 patients who died with cancer and 57 patients who died with dementia (102). The prevalence of breathlessness in cancer was 72% (39/54) and in dementia was 60% (34/57). Other symptoms assessed in this study included pain and agitation, however, breathlessness was the most prevalent in both patient groups (102). This supports a previous, consecutive cohort study set in Western Australia which determined the prevalence and intensity of breathlessness (using an NRS) towards the end of life in the general population (103). Participants were categorised according to health condition (lung cancer, secondary cancer to lung, heart failure, end-stage pulmonary disease, and no identifiable cardiorespiratory cause), with data collected across three time points (60-53 [T3], 30-23 [T2], and 7-0 [T1] days before death). Across the time points, the prevalence of severe breathlessness (≥7/10 on an NRS) increased closer to death, from less than 10% to 26% at time of death. In the last three months of life, patients with non-cancer diagnoses had higher levels of breathlessness, whilst those

with cancer had lower breathlessness levels initially which increased in the last 10 days of life (103).

Additionally, a retrospective case note assessment to assess palliative care needs of those with PIF-ILD was conducted using patient records from two London hospitals (104). Palliative care needs, palliative treatments, palliative care involvement, and end of life planning were all collected. Of the 45 patients identified in the study, 42 experienced breathlessness at the end of life (104), showing high prevalence in this population.

Within this setting, the prevalence of breathlessness is again high. This is particularly important when considered alongside the prevalence in primary and secondary care, as it is yet unclear how this symptom is identified, assessed, or managed, in different clinical settings.

1.3.5 Prevalence Summary

Chronic breathlessness is a common symptom across the general population (6), older adults (77), and chronic conditions (65). Prevalence is high in primary (92), secondary/emergency (2), and palliative care settings (particularly towards the end of life) (103). The high prevalence across populations and clinical settings highlights the need for appropriate care in different settings.

Given the prevalence of chronic breathlessness across clinical settings, we can see that this symptom is associated with higher health care utilisation in primary care, secondary care (emergency care/admissions), and palliative/end of life care (see section 1.2.6 for more information on health care use). A previous study in the ED identified one third of presentations due to breathlessness which did not require admission, along with 73% of individuals who identified their GP as the practitioner they previously consulted about breathlessness (2). This shows us that primary care could be the most effective setting to attend to this symptom; practitioners in this setting are ideally placed to identify and arrange effective support in order to deliver better management of this symptom (80). If chronic breathlessness were identified and managed more effectively within a primary care setting, it may lead to a decrease in rates of attendance at the ED/hospital admissions, providing cost savings for the National Health Service (NHS) and improving

overall patient care and symptom management for those with chronic breathlessness, ultimately improving quality of life.

Overall, older, frail adults with chronic breathlessness appear to be under-researched. There are gaps in the literature relating to those individuals living in the community regarding the prevalence of chronic breathlessness and their experiences of this symptom in primary care. Therefore, we need to understand the experiences of patients and carers in relation to the identification and assessment of chronic breathlessness in the primary care setting. Further, we need to understand the impact of these experiences on the patient, carer, and health care practitioner (HCP). An understanding of these experiences is of utmost importance as it could help provide opportunities for effective symptom targeted intervention and improved management for this population.

1.4 IDENTIFICATION AND ASSESSMENT

1.4.1 Challenges of Identification and Assessment

Chronic breathlessness is well recognised as an 'invisible' symptom (105, 106); hidden from everyone but the patient. It is often not understood by family and friends, the general public or even health care practitioners. This is because patients are usually comfortable at rest when breathlessness and its effects are not obvious (106).

Practitioners seldom ask about breathlessness and, perhaps due to this, patients may not feel comfortable reporting it – or see the relevance of doing so, especially if not asked or given any indication that there are possible therapeutic options (107). Practitioners may simply avoid the topic of breathlessness if there is no visible sign of this symptom, particularly if they believe there is little to be done to improve it (107). Despite the importance of the GP or primary care for the patient with breathlessness (section 1.3.4.1), this symptom may not be well identified or managed, remaining invisible.

One factor involved in the practitioner's potential unawareness of breathlessness may be a lack of structured identification of this symptom in the clinical environment. History taking may ask the question 'are you breathless?', which may elicit a negative response unless the patient is breathless in the moment. However, the question of 'what have

you had to give up because of breathlessness?' would give rise to issues such as not being able to walk the dog, hang out the washing, or other daily activities. Unless the practitioner actively enquires further, the patient may feel these are trivial or unexplainable issues which reduce their legitimacy, preventing discussion in the clinical environment (106, 107). A prospective study compared number of symptoms volunteered and those chosen by systematic assessment in adults referred to a palliative medicine programme in the USA (108). The median number of symptoms volunteered was one, compared to the median number identified by systematic assessment, which was 10; only a small proportion of those symptoms with increasing severity were volunteered (108). This shows the importance of systematic questioning in the clinical environment.

If practitioners treat the underlying conditions with disease-targeted treatments, but do not also focus on the symptom, chronic breathlessness will remain invisible and therefore not treated, or, if noticed, may be considered as an inevitable part of the clinical picture (107). The symptom becomes de-prioritised once there is a diagnosis in favour of the treatment of the causative condition (105). The patient may feel raising their concerns over their breathlessness is inappropriate, or futile, given that nothing has been offered to help them deal with this symptom. Ultimately, both practitioner and patient may not raise the subject and as such breathlessness goes unmentioned (107). A sense of powerlessness over this symptom is evident in both patients and practitioners (105). This is apparent in a recent study which conducted a secondary analysis of qualitative interviews with physicians in South India (109) on the recognition, assessment, and management of people with chronic breathlessness syndrome (breathlessness that persists despite optimum treatment of the underlying condition) (7). Practitioner's experienced discomfort and helplessness as a result of this symptom and at witnessing the patient's suffering; often due to feelings of distress, lack of awareness of assessment tools and therapeutic interventions, often avoided the topic. This contributes to the invisibility of breathlessness by only focussing on the underlying condition (109).

Other studies have also focussed on the invisibility of breathlessness. In a previous study on breathlessness in the ED (2), participants who presented with breathlessness which they rated as 'severe', later reported that it settled to 'mild' once in a "place of safety".

By the time assessment takes place, there may not be any noticeable signs that breathlessness was an issue (2). Also, a double-blind, web based trial using hypothetical scenarios was used to compare the recognition and treatment by practitioners of either chronic breathlessness or chronic pain (110). Fewer physicians recognised the need for further treatment (only 10% of respondents vs 31%), fewer offered symptomatic treatment (4% vs 24%), and fewer offered treatment with opioids (3% vs 23%) in the chronic breathlessness group compared to the chronic pain group. Ultimately chronic breathlessness was less well recognised as needing further treatment. This evidence demonstrates that breathlessness is often unidentified and as a result can go unmanaged.

Further, two previous studies have shown that a significant proportion of individuals with COPD have chronic breathlessness despite optimal treatment of the underlying pathophysiology (chronic breathlessness syndrome) (111, 112), identifying the need to bring breathlessness into view. In a longitudinal analysis of data from the Swedish National Register of COPD (n=1,689 adults, >35 years) (111), the prevalence of chronic breathlessness was 54% at baseline (mMRC breathlessness scale ≥2 at baseline), and persistent disabling breathlessness (defined as disabling breathlessness at baseline and follow up) was present in 43% of patients despite treatment, and 74% of patients despite combined inhaled triple therapy and physiotherapy (111). Similarly, a prospective study (n=120) of COPD patients in a tertiary care centre (112) found that 53% of patients had severe breathlessness (mMRC breathlessness scale ≥3) despite 94% having received optimal inhaled medications, and 40% having received pulmonary rehabilitation in the previous two years (112). Also in this study, 52% of pulmonologists who responded to a questionnaire about breathlessness management were willing to prescribe opioids for chronic breathlessness, however none of the patients in this study received these treatments (112). The results from these studies raise awareness of the significant problem of chronic breathlessness, the need for systematic assessment, and effective treatment approaches.

In view of the 'invisibility' of breathlessness, its widespread impact, and the fact that it is common, it is clear that practitioners have a responsibility to identify and assess this symptom and the impact it has on the individual and their carers. Appropriate identification can form the basis for assessment and appropriate management.

Identification in routine clinical care can be completed by a general and simple enquiry, of which there are tools available to help the practitioner make an assessment. These will now be discussed.

1.4.2 Measurement Tools/Outcome Measures

Identification and assessment of chronic breathlessness is rarely done in a systematic manner (59). There are a number of tools which measure different elements of breathlessness - these are usually unidimensional or multidimensional, and either breathlessness or disease specific measures (113, 114) - but there is no 'gold standard' (114). This is particularly important within routine clinical practice where it is crucial to use something which can be incorporated into routine care (100).

1.4.2.1 Unidimensional Tools

Unidimensional tools measure one aspect of breathlessness and this is usually intensity, unpleasantness or breathlessness-related distress (59). There are a number of commonly used instruments such as: the Visual Analogue Scale (VAS) which is a horizontal or vertical line measuring 100mm, with verbal anchors at each end ('not breathless at all' to 'extremely breathless') where an individual can mark the line to state how breathless they are (114); the Numerical Rating Scale (NRS) which is similar to the VAS with comparable verbal anchors, but marked from 0 – 10 (115); and the modified BORG scale which is a 0 to 10 semi-ratio numerical scale similar to the NRS but with descriptive terminology for several numerical values in addition to the verbal anchors (114). The VAS, NRS and modified BORG scale can all be self-administered (114).

Other tools are breathlessness specific and this includes the mMRC (modified Medical Research Council) scale (113). This is a categorical scale classifying the limitations on physical exertion due to breathlessness, ranging from breathlessness on strenuous exercise only, to being too breathless to leave the house (116), and is graded 0 – 4 (117) (see Table 1.1). The original MRC scale has the same descriptors but is graded 0-5 (116). The MRC/mMRC can be self or interviewer-administered and is widely used as an initial assessment within UK clinical settings (114). However, we do not know if or how this is currently being applied across settings.

Table 1.1 modified Medical Research Council Breathlessness Scale and Descriptors (117)

mMRC level	Descriptor
0	Not troubled with breathlessness except with strenuous exercise
1	Troubled by shortness of breath when hurrying on the level or walking up a slight hill
2	Walks slower than people of the same age on the level because of breathlessness or has to stop for breath when walking at own pace on the level
3	Stops for breath after walking about 100 yards or after a few minutes on the level
4	Too breathless to leave the house or breathless when dressing or undressing

1.4.2.2 Multidimensional Tools

Multidimensional tools are those that assess the impact of breathlessness on several domains of an individual's life, such as activities of daily living (ADL's), emotional or mental functioning, sense of control, or other person related outcomes (114). Some of these tools may be disease specific and include the Chronic Respiratory Disease Questionnaire (CRQ) (113). The CRQ is a 20-item questionnaire comprising four sections relating to breathlessness, fatigue, emotional function and mastery or feeling of control (114). It is a widely used tool for assessing QoL in chronic respiratory diseases and can also be self or interviewer-administered (113).

The reviews completed by Bausewein, (113), Bausewein (114) and Dorman (115) provide comprehensive reviews of assessment tools that could be used in people with advanced disease. Results showed that there is no single comprehensive scale that encompasses the wide ranging effects of breathlessness on the patient and their family (113, 114) and none can be recommended as 'gold standard' (114, 115). Combinations of unidimensional (e.g. VAS) and disease specific or multidimensional scales may be

most appropriate for assessment in a clinical setting, although this must be seen in context of the individuals history and examination/test results (114). Some assessments such as the NRS, BORG Scale, CRQ, or CDS (Cancer Dyspnoea Scale) may be most suitable to the palliative care setting but further evaluation is required prior to adopting any scale as a standard measure (115).

Subsequent to these reviews taking place, there have been further developments in assessment tools which include the Dyspnoea-12 (D-12) (118), the Multidimensional Dyspnea Profile (MDP) (119), and the Dyspnea Management Questionnaire (120).

The D-12 (118) is a 12-item questionnaire with questions related to breathlessness and how it troubles the individual and is scored as 'none', 'mild', 'moderate' and 'severe'. This measure incorporates both the physical and affective (emotional) aspects of breathlessness across disease groups and gives subscale and summary scores (118).

The MDP (119) includes 12 items that encompass immediate sensory intensity, immediate unpleasantness, sensory qualities (tightness, muscles work), and emotional responses (frustration, anxiety). All items are measured on a 0 to 10 rating scale and give a profile rather than a score. This is an assessment tool to understand the patient experience, rather than an outcome measure (119). The MDP can be used at rest and is not disease specific (59). Both assessment tools are quick and easy to use in clinical settings; the D-12 has been validated across conditions and translated into several languages (59) and the MDP has been validated across clinical settings (121) and translated into Swedish (122).

The Dyspnea Management Questionnaire (DMQ) (120) measures psychosocial and behavioural responses to breathlessness and was developed and validated for adults with COPD. The DMQ has five dimensions: breathlessness intensity (when performing ADL's and leisure activities), breathlessness anxiety (anxiety associated with breathlessness), activity avoidance (extent to which anxiety associated with breathlessness impacts activities), activity self-efficacy (an individual's confidence in breathlessness management whilst partaking in activity), and satisfaction with strategy use (individual's evaluation of their mastery of breathlessness management strategies) (120). The DMQ can be used as a measure of breathlessness in both clinical and research settings for adults with COPD (120).

In the clinical setting, practitioners may have limited time in order to identify, assess, and manage a patient's breathlessness, compared to time allowed in the research setting where a number of outcome measures could be applied. Therefore, a tool which is simply, quick, and easy could be beneficial to the identification and assessment of chronic breathlessness as it could be effectively incorporated into routine clinical practice.

1.4.3 Evidence-Based Interventions for Breathlessness

The lack of identification and assessment of chronic breathlessness is problematic because there *are* evidence-based interventions available for effective management, such as pharmacological (e.g. opioids) (123) and non-pharmacological (e.g. relaxation or handheld fan) (124) treatments, or breathlessness support services (BSS)/breathlessness intervention services (BIS). Breathlessness support services offer multi-disciplinary support that provide a combination of respiratory, physiotherapy, occupational therapy, and palliative care assessment and management. They evaluate and treat physical, emotional, psychological, and spiritual issues through one integrated service (58).

A systematic review has identified a number of breathlessness intervention services (BIS) that have demonstrated improvement in outcomes for breathless patients over usual care (125). The studies included showed: improvements in breathlessness, and in physical and emotional states in patients with lung cancer (126); reduction of distress caused by breathlessness for patients with advanced cancer (127); a qualitatively positive impact of BIS on patients with advanced non-malignant conditions and their carers (128); greater mastery over breathlessness in those with advanced disease (58); and the positive impact of breathing training for adults with malignant lung disease (129). Costs associated with these intervention services show that in one study (127), while costs were higher at baseline, total costs were £354 lower in the intervention, compared to the usual care group.

Breathlessness intervention services focus on the integration of symptom management with early access to palliative care (both general and specialist as indicated) and deliver multidisciplinary treatment focusing on holistic approaches (125). They improve

breathlessness management in patients and their carers, and do so cost-effectively (130). As breathlessness is a reason for unplanned medical care leading to significant costs to the NHS annually (130) and related to significant patient and family burden, the addition of intervention services (through community or primary care settings) to aid in the management of breathlessness should be considered.

1.4.4 Identification and Assessment Summary

Chronic breathlessness severity and experience are subjective. Whilst tools such as self-report scales (e.g. VAS) are vital in any clinical setting (131) and are indeed helpful, other methods of enquiry could be more beneficial. This could include asking about breathlessness and what has been given up because of this symptom, initiating a dialogue between patient and practitioner. Tools are helpful but general enquiry could be the first form of identification. The systematic identification and assessment of chronic breathlessness and its contributing factors in clinical practice is important but is rarely conducted routinely (59); adequate identification could allow potential interventions to be implemented (132).

The current literature has identified a number of different outcome measures that can be used to assess breathlessness (in practice and research), but little is known about how these are applied across clinical settings. Therefore, a greater understanding is needed of 1) how clinicians identify and assess breathlessness across clinical settings, and 2) the experiences of patients, carers, and clinicians in the identification and assessment of chronic breathlessness in primary care, along with the impact these experiences have on this population.

1.5 CHRONIC BREATHLESSNESS SUMMARY

Chronic breathlessness is a distressing symptom and has a major detrimental impact (including psychological health) on both patients and carers (1). To avoid breathlessness, individuals may decrease their physical activity thus setting up a cycle of deconditioning. This leads to poor fitness, restrictions in social interaction with subsequent anxiety, depression, and poor quality of life (QoL) (1, 9, 20, 26), with potentially detrimental effects on both workforce participation (37) and social activities/roles (31). There is also

a significant care burden for carers of those with chronic breathlessness. Spouses report anxiety and helplessness (133), ongoing physical and emotional burden (46) and a downward spiral of physical, social, and emotional effects as the disease progresses (46).

Chronic breathlessness is associated with an increase in health care utilisation (3); one percent of presentations to primary care (92, 93) and at least 5.2% of presentations to the emergency department (ED) (2) are due to breathlessness; one of the most common reasons for attendance (97). Despite evidence that states one third of ED attendances with chronic breathlessness may be prevented if there was better management in primary care, and that of those attending, most individuals reported their GP as the practitioner they discussed their breathlessness with (2), there is still little evidence of proactive primary care for this patient group.

Chronic breathlessness is prevalent across the general population (59) with studies estimating prevalence between 9 and 59% (6, 134) depending on population studied and measure of breathlessness used. It is particularly concerning in older adults, where approximately one third suffer with this symptom on a daily basis (80). Further, breathlessness is prevalent across common cardiorespiratory diseases, cancer, lung diseases and heart diseases (65, 69), as well as those with multiple long-term conditions (85).

There are effective evidence-based interventions available, such as breathlessness intervention services (125), or pharmacological (such as opioids) (123) and non-pharmacological (such as relaxation or handheld fan) (124) treatments, which can be used alongside management of underlying conditions. These treatments support self-management strategies, such as the use of self-help websites. In order for self-management to be effective, an important balance of healthcare resources, behaviours, and treatments (pharmacological and non-pharmacological) must be adopted (135, 136).

However, interventions are poorly implemented, influenced by the invisibility of breathlessness. Once optimal treatment of the underlying condition has been provided, breathlessness may continue and is not often considered as a symptom for therapeutic target. Patients are usually comfortable at rest and breathlessness is not always evident (106). It is therefore often ‘invisible’ (105, 106), not seen or understood by family members, the general public or even health care professionals. Chronic breathlessness

can be identified and assessed using a variety of tools or outcome measures, many of which measure different elements of breathlessness (113, 114), but there is no 'gold standard' (114). Clinicians rarely ask systematically about breathlessness, across settings, and patients feel uncomfortable reporting it, especially if not asked (107). This means that chronic breathlessness is often unidentified and untreated, limiting the management options for this debilitating symptom.

This 'invisibility' seems to be experienced by all adults with chronic breathlessness, however, we must consider that older adults seem to be particularly disadvantaged. They are more likely to have frailty (81) with its characteristic sarcopenia (63) which is recognised as being associated with breathlessness (85). The link between chronic breathlessness, older age, and frailty is under-researched. Older adults with frailty may be more likely to have multiple long-term conditions which could intensify the invisibility of breathlessness due to other symptoms/conditions taking priority. Consequently, chronic breathlessness in the older, frail adult has immediate need for better identification, assessment, and management. The optimum way to identify and manage this population - by including community support to prevent avoidable hospital admission - is unknown. Therefore, primary care may be ideally placed to provide proactive management, although there is little work exploring this.

1.6 PROACTIVE ANTICIPATORY CARE EVALUATION (PACE) OVERVIEW AND SETTING

1.6.1 Context of my Thesis

Due to the importance of the problem of chronic breathlessness, and to address issues with frail, older adults, my PhD project was embedded within and administered as part of the Proactive Anticipatory Care Evaluation (PACE). This was a non-randomised, controlled study with an embedded qualitative component to assess the effectiveness of a proactive, anticipatory, multidisciplinary care intervention for older, frail people, within the Hull area of the East Riding of Yorkshire. The PACE project was designed to evaluate this new service, and to address the broader issues relating to older, frail adults and as such presented an opportunity for myself and two other PhD students to further investigate under researched areas affecting this population, such as chronic

breathlessness (my project), adverse effects from pain medications (Sophie Pask [SP]) and unintentional weight loss (Ugochinyere Nwulu [UN]) in the older, frail population.

1.6.2 New Frailty Care Pathway

The NHS Hull Clinical Commissioning Group (Hull CCG) redesigned the care pathway for older, frail people, in order to provide high quality healthcare which can positively impact the health and wellbeing of older, frail individuals. Recognising the need to support those with frailty, and to reduce high health care usage and unexpected admissions, as well as to improve health outcomes, the frailty care pathways in Hull were redesigned across a newly built Integrated Care Centre (ICC) and care homes, to offer a comprehensive integrated approach.

This pathway included a standardised comprehensive, anticipatory assessment and follow up, for all older, frail people in the Hull CCG. It was provided by a multidisciplinary team of Geriatricians, General Practitioners with Extended Roles (GPwER), Physiotherapists, Occupational Therapists, Social Workers, Pharmacists, and members of other voluntary sector organisations.

The new frailty service identified older, frail people (either in the community or in a care home) at risk of severe frailty using the electronic Frailty Index (eFI) (83) alongside clinical judgement made by the General Practitioner (GP). The eFI is a tool used routinely within primary care to classify an individual's frailty level (none, mild, moderate, and severe) (83). Identified individuals received an invitation to attend a multidisciplinary, integrated assessment at either the ICC or their care home (if residing in one). If they agreed, they received a pre-assessment visit by a clinical support worker or nurse at their home (where PACE study information sheets were also given so patients were aware they may be invited to participate in the service evaluation). Patients were then booked onto a date for their integrated assessment which was held at the ICC. After their assessment at the ICC, the multidisciplinary team would meet and develop a personalised care plan for, and agreed by, the patient.

1.6.3 Quantitative Cross-sectional Survey as part of PACE Data Collection

Once at the ICC for their multidisciplinary assessment, patients were approached and invited to participate in the PACE service evaluation (see section 4.2.3 for Patient Journey Flowchart and 4.2.6 for Recruitment and Consent procedures).

Surveys were developed as part of the service evaluation and measured health status and quality of life (QoL) (see section 4.2.5 for information on Data Collection Tools/Outcome Measures). These were conducted at a break during the patient's multidisciplinary assessment. The same surveys were repeated at 2-4 weeks and 10-14 weeks after initial intake into the study (the latter collected by Mabel Okoeki [MO], the project manager). The survey included the following outcome measures: Integrated Palliative care Outcome Scale (IPOS) and the EuroQol-5D (EQ-5D-5L). In addition, three symptom surveys about chronic breathlessness (HE), adverse effects from pain medications (SP), and unintentional weight loss (UN) were collected once, during baseline data collection at the ICC if these issues were self-reported on screening questions. In addition, demographic and medical data were also collected from patient records. The IPOS, EQ-5D-5L, and demographic/medical data were all collected as part of the service evaluation.

Data collected from patients residing in care homes was not used in my analysis as this would not reflect experiences in the primary care clinical setting. Follow up data were not used as I was not looking at longitudinal data and only required a cross-sectional snapshot of information from the population. Data were collected at the ICC, care homes, or patients' homes, in Hull, as appropriate.

1.6.4 Qualitative In-depth Interviews

A subset of patients who completed the chronic breathlessness survey, and a convenience sample of carers and health care practitioners (HCPs) (recruited from the ICC or patients referring medical practice) were recruited for interview about their experiences of the identification and assessment of chronic breathlessness in the primary care setting (See section 5.2.5 for more information on Sampling, Recruitment and Consent).

1.7 RESEARCH QUESTIONS, AIMS, OBJECTIVES, AND METHODS

Research questions, aims, and objectives are presented in Table 1.2. Section 1.7.1 outlines the methods used to address these questions within my thesis, comprising a quantitative narrative systematic review, a mixed-methods study incorporating a quantitative cross-sectional survey and qualitative in-depth interviews, and critical interpretive synthesis.

Table 1.2 Thesis and Chapter Research Questions, Aims, and Objectives

Thesis Component	Research Questions	Aims	Objectives
Thesis	For older adults at risk of frailty: 1. What impact does chronic breathlessness have on patients and carer's psychological wellbeing and quality of life? 2. What experiences do patient and carers have in relation to the identification and assessment of chronic breathlessness in primary care, and what impact do these experiences of care have on patients, carers, and health care practitioners?	For older adults at risk of frailty: 1. To explore the impact of chronic breathlessness on patients and carer's psychological wellbeing and quality of life. 2. To explore how chronic breathlessness is identified and assessed in primary care, considering the patient, carer, and health care practitioner experiences.	For older adults at risk of frailty: 1. To understand the impact that chronic breathlessness has on patients and carer's psychological wellbeing and quality of life. 2. To understand the experiences of patients, carers, and health care practitioners in relation to the identification and assessment of chronic breathlessness in primary care.

Quantitative Narrative Systematic Review	How do clinicians identify or assess breathlessness in different healthcare settings?	To identify how clinicians identify or assess breathlessness in different healthcare settings.	For adults with breathlessness due to chronic conditions: • To identify and describe how breathlessness is identified • To identify and describe how breathlessness is assessed • To observe any differences between different healthcare settings • To synthesise the findings in order to identify gaps in knowledge and practice in the primary care setting.
Mixed-methods Study: Quantitative Cross-Sectional Survey	1. How common is chronic breathlessness in the older, frail population? 2. How do clinical and demographic characteristics compare for older adults with frailty who report chronic	To determine the prevalence of older, frail adults with chronic breathlessness, and to explore experiences of identification, assessment, and access to breathlessness interventions in a primary	1. To determine the prevalence of self-reported chronic breathlessness in older adults with frailty. 2. To explore the clinical and demographic characteristics associated

	breathlessness, and those who do not? 3. Does quality of life differ between those with chronic breathlessness and those without? 4. Is chronic breathlessness associated with psychological problems and reduced quality of life? 5. What is the impact of chronic breathlessness on activities of daily life? 6. What is the experience of older adults with frailty and chronic breathlessness regarding care received in the primary care setting?	care setting, with a focus on psychological factors and quality of life.	with self-reported chronic breathlessness. 3. To describe quality of life of older adults with frailty in those with and without self-reported chronic breathlessness. 4. To explore the relationship between chronic breathlessness and psychological problems and quality of life. 5. To describe changes in activities in those with chronic breathlessness. 6. To explore experiences of identification, assessment, and access to breathlessness interventions in a primary care setting.

Mixed-methods Study: Qualitative In-depth Semi-structured Interviews	1. How does chronic breathlessness affect psychological wellbeing of older adults with frailty? 2. How do older adults with frailty, their carers', and practitioners experience identification and assessment of chronic breathlessness in the primary care setting?	1. To explore the psychological impact of living with chronic breathlessness in frail older adults and their carers. 2. To explore and understand how older adults with frailty, their carers, and practitioners experience identification and assessment of chronic breathlessness in the primary care setting.	To explore, in the context of the primary care setting, with older adults with frailty, their carers and practitioners: 1. The psychological impact of chronic breathlessness on the older adults with frailty and their carer, in the context of: a. Their history of breathlessness, broader impact of breathlessness 2. The effect of chronic breathlessness on overall quality of life of the older adults with frailty and their carer, considering: a. Adaptations of activities and other self-management strategies for breathlessness 3. The lived experience in the identification and assessment of chronic

			breathlessness in the primary care setting, considering: a. Patient and carer interaction with primary health care practitioners and services regarding the symptom of breathlessness; views regarding the legitimacy of breathlessness as a reason to consult and how best to address this; and views about chronic breathlessness definitions.

1.7.1 Methods and Methodology

My multiple-methods thesis incorporated a quantitative narrative systematic review, and a mixed-methods study with a sequential (explanatory) design which included a quantitative cross-sectional survey, and qualitative in-depth interviews. Findings were synthesised using a modified Critical Interpretive Synthesis. The methodological approach and justification for the study methods are discussed in Chapter 2: Methodology.

Chapter 3 presents the methods, findings, and discussion of the quantitative systematic literature review and descriptive narrative synthesis. Chapter 4 presents the methods, findings and discussion of the quantitative cross-sectional survey, embedded as part of the PACE project; a service evaluation of a new Integrated Care Centre (ICC) (see section 1.6 above for more information). Chapter 5 presents the methods, findings, and discussion of the qualitative study incorporating semi-structured in depth-interview, again embedded as part of the PACE project. Chapter 6 presents the overall synthesised findings for the thesis, bringing together the synthesis of the mixed-methods study and findings from the systematic review.

1.8 INTRODUCTORY CHAPTER OVERVIEW

In this introductory chapter, I have demonstrated how chronic breathlessness is common and has a major detrimental impact on the individual, carers, society, and across all settings of the health sector. There are effective interventions for the improved management of breathlessness, however they are not often recognised or managed systematically. Older adults with frailty appear to be a high risk for breathlessness, but little is known about the prevalence, impact, or experience of breathlessness (or its identification and assessment) across health care settings, or in particular how management in primary care may support them better in the community.

I have then described the inclusion of my PhD project within the PACE service evaluation. This was followed by presentation of my research questions, aims, and objectives to be addressed for: the overarching thesis, the quantitative narrative systematic review, and the mixed-methods study (quantitative cross-sectional survey, and the qualitative in-depth interviews).

The next chapter will describe and provide a rationale for the methodological approaches and study designs used throughout my thesis. After this, the first empirical component of my PhD will present a quantitative narrative systematic review to determine how clinicians identify or assess breathlessness in different healthcare settings. This will give an overview and general understanding of the tools/outcome measures used, to identify or assess breathlessness, in relation to their main purpose of care. The following chapters will then focus on chronic breathlessness in primary care, presenting my mixed-methods primary research. Justification and reasons for the focus on primary care are provided throughout the methodology chapter (see Chapter 2: Methodology) and the systematic review chapter (see Chapter 3, section 3.7: Conclusions, and 3.8: Chapter Summary and Focus on Chronic Breathlessness in the Primary Care Setting).

CHAPTER 2 - METHODOLOGY

2.1 INTRODUCTION

2.1.1 Chapter Rationale

In this chapter, I will discuss my methodological approach and provide the rationale for the study designs used throughout my thesis. My thesis adopts a multiple-methods approach, incorporating a quantitative narrative systematic review, and a mixed-methods empirical study (using a quantitative cross-sectional survey and qualitative in-depth semi-structured interviews). The mixed-methods study is embedded within the Proactive Anticipatory Service Evaluation (PACE) (see section 1.6 for an overview).

A description of the overall research paradigm – a pragmatic approach – which draws on aspects of positivism and interpretivism and is about selecting the right methods to answer my research questions, will be presented. This is followed by a discussion of how this paradigm has been applied to my thesis. The conceptual frameworks that underpin the study are then presented; they are Total Dyspnoea (137) and Breathing Space (27). Then, I provide a justification of my choice of methods used for each discrete component of the thesis and how they were used to answer the overarching research questions (the methods themselves are presented in the relevant study chapters). Finally, consideration is given to the ethical issues presented by different aspects of the study, along with discussion of how I exercised reflexivity during my role as the researcher, before concluding the chapter.

2.2 METHODOLOGY

All research takes place within a selected paradigm; different paradigms allow different research questions to be asked and use different research methods as they have separate assumptions about the nature of reality and knowledge (138). Positivism, for example, (objective knowledge) is associated with quantitative approaches and interpretivism (subjective knowledge) is associated with qualitative approaches (139). Each paradigm encompasses both ontology (the study of the nature of being and what is real) and epistemology (the nature of knowledge and how it is created or discovered)

(138). See section 2.2.4 for an understanding of how my thesis draws on selected paradigms.

2.2.1 Positivism

Positivism considers that knowledge and facts are objective and can be proven, with the use of observation and measurement (140). A positivist approach commonly uses quantitative methods (138, 141). It is underpinned by a position of realism, with a view that objects exist independent of the knower (138, 142). For example, an individual may experience breathlessness (whether identified or not) as a result of a medical condition, diagnosed based on objective scientific measures, and could therefore be an objective 'truth'. Positivistic statements are considered to be factual, with a knowledge that is absolute (138). Therefore, the objective nature of positivism considers that knowledge should be free from bias related to the researcher, their values or beliefs (140). The positivist approach allows objective data to be collected and used to make scientific observations (e.g. prevalence of reduced lung function in a given population). However, positivism cannot help us answer research questions about the experiences or depth of understanding an individual may have as a result of their medical condition.

2.2.2 Interpretivism

In contrast, interpretivism posits that knowledge is subjective and can be constructed based on experience and understanding (140), and is largely associated with qualitative research (141). For example, the aforementioned individual, diagnosed with a medical condition causing reduced lung function, will have their own interpretation and understanding of their lived experience. Hence, interpretivism considers that reality is subjective and constructed by the individual (138). By collecting these observations we are able to make justifiable claims, or social facts. The subjective nature of interpretivism acknowledges that the researcher can never really be free from their own values or beliefs, and consequently acknowledges that this may inform their findings (140).

2.2.3 Pragmatism and the Pragmatic Approach

2.2.3.1 Pragmatism

The philosophical movement of pragmatism began as a rejection of the single scientific method of inquiry as a way to understand the nature of knowledge and reality (143). This has allowed researchers to apply this to research and consider plurality of methods (143). Pragmatism is therefore a way for researchers to address the potential dualism between different approaches to research (141), for instance, positivism and interpretivism. Pragmatism brings forward the notion that the research question(s) is of utmost importance, more so than the method or underlying philosophical worldview (139) and is seen as the most appropriate philosophical position for multiple, and mixed-methods research (144).

2.2.3.2 Adopting a Pragmatic Approach

Multiple, and mixed-methods research, aim to use methods and theory that bring together the explanations offered by both quantitative and qualitative designs into a practical solution (141). A pragmatic approach is characterised by a moderating, common-sense approach to philosophical debate (positivism *versus* interpretivism, objective *versus* subjective) where knowledge is considered to be 'constructed *and* based on the reality of the world we experience and live in' (141) (p. 18). A pragmatic approach can help inform how different research approaches can be mixed productively, giving the best possible opportunity to answer any and all research question(s) (145).

Adopting a pragmatic approach to multiple, and mixed-methods research, means appreciating the differences in epistemology between the quantitative and the qualitative lines of enquiry; acknowledging that these approaches may be different but that they have a shared aim – 'to produce positive change in the world' (146) (p. 7).

Additional to the use of pragmatism, pragmatic *decisions* can be made for reasons relating to convenience, opportunity, and suitability of circumstances (for example data collection as part of the PACE service evaluation).

2.2.4 How my Thesis Draws on Positivism, Interpretivism and a Pragmatic Approach

My thesis uses multiple-methods (see section 2.4: Multiple and Mixed-methods Research) and a pragmatic approach. A pragmatic approach values a practical 'what works' approach, drawing on both objective (positivism) and subjective (interpretivism) knowledge (139), and is the paradigm best suited to my research which seeks to explore 1) the impact of chronic breathlessness on (older, frail) patients and carer's psychological wellbeing and quality of life, and 2) how chronic breathlessness is identified and assessed in primary care, considering the patient, carer, and health care practitioner experiences.

Initially, I conducted a quantitative narrative systematic review in order to determine the current knowledge of how breathlessness and chronic breathlessness are assessed for adults in different health care settings. This was a quantitative exercise which allowed me to map tools/measurements used in different clinical settings. The systematic review included already published literature; in reviewing the literature I extracted data relevant to my systematic review research questions which were numerate/quantifiable in nature. The data obtained as part of a systematic review were subject to duplicate screening by another researcher and should therefore be unbiased, comprehensive, replicable, and robust. Therefore, the results obtained as part of this systematic review should be considered objective and reflect a positivist position.

Then a mixed-methods study incorporating a quantitative cross-sectional survey and in-depth qualitative interviews was conducted.

My quantitative cross-sectional survey also adopted a positivist position. A self-report survey was used to determine the prevalence of self-reported breathlessness and factors which related to breathlessness and the older, frail adult. The first question determined whether individuals have experienced breathlessness most days in the last month and enabled a prevalence rate of chronic breathlessness to be determined for the older, frail population. The remaining survey questions gathered information from close-ended questions (some required free-text responses which were then quantified) related to breathlessness, identification, assessment, and access to interventions in primary care, with a focus on psychological factors and quality of life (QoL). The nature of knowledge within this section of the thesis sought to objectively measure a phenomenon (establish given statistics such as prevalence along with other clinical

factors related to breathlessness) for the older, frail population. However, this was a self-report survey, and was not measuring biological or objective measures, but perceived experiences of this population, therefore there may be some subjectivity in participant answers.

My qualitative in-depth semi-structured interviews provided richer, and more in-depth data. Using a semi-structured approach to interviews allowed me as the researcher flexibility to address topics of interest in depth but also to diverge from the key areas for discussion, following up on prompts or pursuing further information deemed important to the participant (147). This element adopted an interpretivist standpoint and gathered subjective data regarding psychological impact of living with chronic breathlessness in older, frail adults and their carers; and older, frail adults, their carers, and health care practitioners (HCPs) experiences of identification and assessment of chronic breathlessness in the primary care setting. The primary aim of qualitative data is not to generalise, but to "provide a rich, contextualised understanding of human experience through the intensive study of particular cases" (148) (p. 1452). The nature of the knowledge found within this section of the thesis brings together the views, thoughts, and experiences of this selected population. Although the results of this section may not be reproducible within an alternate study population, the findings may still have wider implications and could be applicable to other populations of older adults.

Consideration has therefore been given to the fact that my thesis uses data and evidence from both quantitative (positivist) and qualitative (interpretivist) positions. Bringing together these approaches, using practical and 'what works' methods for data collection, was deemed most appropriate to answer my overarching research questions. Therefore, a pragmatic approach was necessary as different methods were employed across the components of my PhD.

In summary, the quantitative narrative systematic review was able to map the tools/measurements used to identify breathlessness and chronic breathlessness across clinical settings, giving a high-level overview of the amount and types of tools used. Then, having identified a gap in the primary care setting, this contextualised my mixed-methods study (quantitative cross-sectional survey and qualitative in-depth interviews) (see section 2.4.1 for more information on Mixed-methods Study Design) in community dwelling older, frail adults, as a group at high risk of breathlessness. The quantitative

component (cross-sectional survey) was able to determine prevalence of chronic breathlessness, descriptive information relating to the identification and assessment of chronic breathlessness, and associations between breathlessness and other clinical factors, in primary care. The qualitative component (in-depth semi-structured interviews) was then needed to build on and expand this data, by gathering views from older, frail adults, their carers, and practitioners', about the impact of chronic breathlessness, and further, their experiences of identification and assessment of chronic breathlessness in the primary care environment. As shown, a combination of methods was employed which were most appropriate to study the phenomenon at hand (149, 150). A pragmatic approach applies most appropriately to multiple, and mixed-methods research, in that researchers can draw liberally from both quantitative and qualitative data to best understand the research problem (151).

The use of different methods throughout this thesis allows me to answer discrete research questions (and this has been highlighted throughout this section). I then used a modified Critical Interpretive Synthesis to draw together the findings of all aspects where they inform my overarching research questions (see section 2.4.2 for more information). Now, consideration is given to the conceptual frameworks employed in this thesis.

2.3 CONCEPTUAL FRAMEWORKS

My thesis draws upon two conceptual frameworks for study design and interpretation of findings: Total Dyspnoea (137) and Breathing Space (27).

The Total Dyspnoea framework was developed in order to understand the physical, psychological, social, and existential (spiritual) experiences of breathlessness (137). It was developed similarly to the concept of Total Pain, originally established by Dame Cicely Saunders in 1964 (152). Total Pain incorporates the various aspects of an individual's distress and includes four domains (all understood from the patient's perspective) which are physical, psychological, interpersonal (social, financial, family), and existential. Total Dyspnoea reinterprets the Total Pain model in the form of the breathless individual, encompassing the holistic nature of patient suffering (137), using the same domains. Total Dyspnoea was developed as a management strategy applicable

to the widely distressing experience of breathlessness, with suitable interventions for each of the four domains; each intervention customised to the individual (137). See Figure 2.1 for Total Dyspnoea conceptual framework diagram (153).

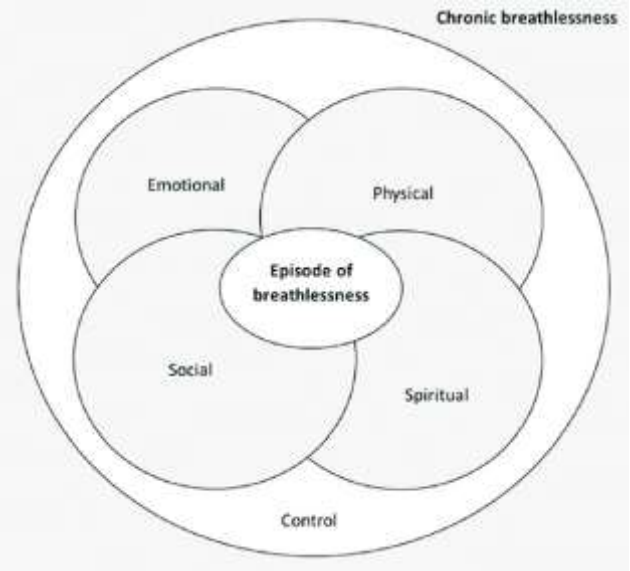

Figure 2.1 Total Dyspnoea Conceptual Framework Diagram (153)

The concept of Total Dyspnoea has been used in a previous systematic review which looked at the experiences of people living with breathlessness and their carers (27). Total Dyspnoea was originally developed as a theoretical framework to understand the widespread effects of breathlessness and was expanded on in this recent review (27) to describe additional concepts of patients' coping, help-seeking, and clinician responsiveness. This provided the theoretical underpinning of a qualitative synthesis from which the Breathing Space conceptual framework (27) was developed, which was also used in this thesis.

The Breathing Space framework is complimentary to Total Dyspnoea. It describes the widespread effects of breathlessness but goes beyond to consider the impact of patients' coping (engaged or disengaged), help-seeking behaviours (for persisting breathlessness or in crisis only), and clinicians' responsiveness to breathlessness (clinician responsive to breathlessness and underlying disease *or* clinician responsiveness to underlying disease only) on quality of life (27). Patients' coping refers to how well an individual manages the stress of breathlessness, and whether they are

engaged in seeking solutions (such as problem solving or seeking social support) or disengaged (such as problem avoidance, or social withdrawal) in their coping strategies. Help-seeking behaviours relate to the ability to recognise the problem and take action, seeking help, and disclosing the problem. Finally, clinicians' responsiveness relates to how receptive, open, and approachable the clinician is to the patient's breathlessness as a therapeutic target in its own right (27) (see Figure 2.2 for Breathing Space conceptual framework diagram) (27).

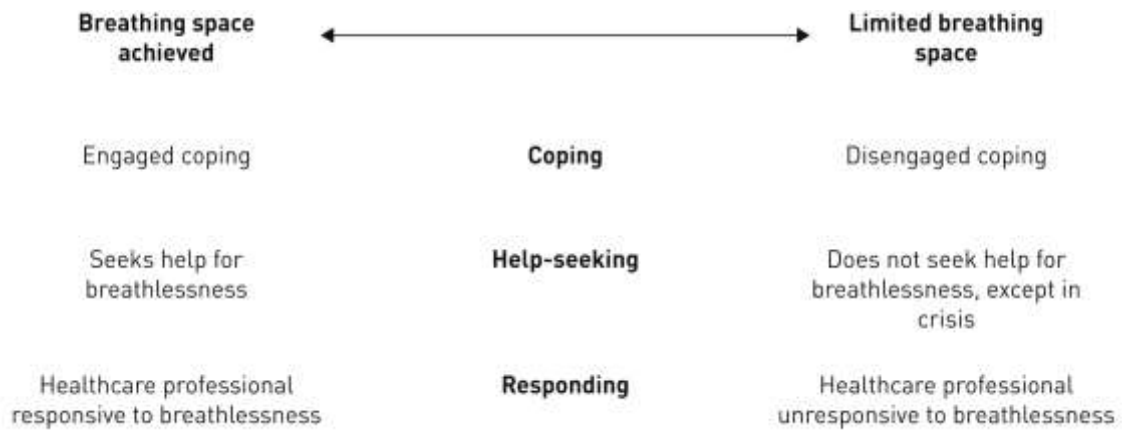

Figure 2.2 Breathing Space Conceptual Framework Diagram (27)

The Total Dyspnoea and Breathing Space frameworks informed a number of aspects of my thesis. First, research questions (see section 1.7) were influenced by - and developed with consideration for - both frameworks. Total Dyspnoea is most applicable to research question one which considers the widespread (physical, psychological, social, and existential) impact of chronic breathlessness, and Breathing Space is most applicable to research question two which considers the role of primary care in the identification and assessment of older, frail adults with chronic breathlessness (and considers coping, help-seeking, and clinician response).

Second, the components of Total Dyspnoea (137) informed the development of the quantitative survey (See Appendix A for questions). For example, the psychological component of breathlessness was considered by the following question, 'Do you ever feel anxious or depressed **because of your breathlessness**?'. Furthermore, the clinician responsiveness component of Breathing Space (27) was considered by asking, 'Does

your GP, nurse, or other health professional from your GP surgery ask you about how breathlessness **affects your daily life**?'.

Third, the topic guides used when interviewing patients, carers, and practitioners were also influenced by the conceptual frameworks. For example, aspects of Breathing Space (27) were drawn upon (See Appendix B for patient/carer topic guide) where experiences of the widespread effects of breathlessness were invited by the question 'Can you tell me a bit about your breathlessness?'; prompts such as 'how long', 'what impact does it have on your daily life' and 'how do you manage it' were all used to enquire further during patient/carer interviews. The clinician responsiveness domain was considered with the question 'Can you tell me about your experiences when presented with someone suffering with chronic breathlessness'?; prompts such as 'what happens', 'how do you respond to their breathlessness' and 'how do you proceed' were used to enquire further during practitioner interviews (See Appendix C for HCP topic guide).

Fourth, the two conceptual frameworks were used during coding and theme development in the qualitative analysis section. Here, a deductive approach was used where codes were mapped onto the pre-existing frameworks (Total Dyspnoea - physical, psychological, social, and existential; and Breathing Space - patients' coping [engaged, disengaged], help-seeking behaviours [for breathlessness, in crisis only], and clinician responsiveness [to breathlessness and underlying condition, to underlying condition only]). This was done so by having a copy of each framework at hand as coding/theme development took place, so it could be decided whether any results fit within these domains. Alongside this, an inductive approach was used, where codes and themes were determined by results rooted in the data (154).

2.4 MULTIPLE AND MIXED-METHODS RESEARCH

The combination of quantitative and qualitative approaches is common, especially within health research (155). Multiple-methods research "involves qualitative and quantitative projects that are relatively complete on their own, and then used together to form essential components of one research program" (156) (p. 2). This description applies to my PhD thesis in that there were two main components - a quantitative narrative systematic review, and a mixed-methods study including a quantitative cross-

sectional survey and qualitative in-depth interviews – each of which could be independent but form 'essential components' of my overall project. Mixed-methods research can be defined as a "type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g. use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration" (157) (p. 123). This refers to the mixed-methods study of my PhD which presents two components (survey and interviews) contributing to their own discrete research questions, findings of which were synthesised to answer the overarching thesis research questions.

The data from both components of the mixed-methods study were analysed in order to describe and interpret the results considering whether they challenge or support each other. This synthesis provides new insight and understanding and is further integrated with (where relevant) the systematic review findings. See section 2.4.2 for details of the analysis (critical interpretive synthesis).

2.4.1 Mixed-methods Study Design

A sequential (explanatory) design was used for the mixed-methods data collection component (quantitative cross-sectional survey and qualitative in-depth interviews) of this thesis. This is a sequential design as the quantitative data were collected first, providing a basis for subsequent collection of the qualitative data (158, 159) (observations made during quantitative data collection helped inform qualitative interviews), and analysed first, allowing these findings to influence the interpretation of qualitative findings. Explanatory refers to how the qualitative data attempts to explain or build on understanding from emerging quantitative findings (158). Both types of data (quantitative and qualitative) have equal importance in my analysis.

2.4.1.1 Integration and Synthesis of Methods

Integration of quantitative and qualitative methods can occur across three different levels (160). Firstly, the design level relates to whether research uses exploratory sequential, explanatory sequential, or convergent designs. Secondly, the methods level

relates to whether each set of data leads to the other by connecting, building, merging, or embedding. Finally, the interpretation and reporting of these data are achieved through narrative, data transformation, or joint display. The methods used within this thesis have been synthesised in order to answer the overall research questions and have been integrated at each of the three levels outlined.

At the design level, an explanatory sequential method allowed the qualitative data to build on and explore the quantitative results further (160). Here, the survey (quantitative) was developed first around areas of interest, and the topic guide (qualitative) was designed to explore these concepts further. For example, in my research, responses in the quantitative survey (see Appendix A) to questions such as 'Do you feel anxious or depressed **because of your breathlessness**?' and 'Have you had to give up or change any of the following **because of your breathlessness**? were followed up at interview by probing the impact of chronic breathlessness on the individual and their daily life. Further, the quantitative survey question 'Roughly, how often do you see a GP, nurse, or other health professional from your GP surgery **about your breathlessness**?' informed further discussion at interview about help-seeking behaviour in the primary care setting.

At a methods level, a connecting approach was adopted. This occurs when one type of data links with the other through the sampling frame (160). In my research, I identified participants for interview from the population of participants who had completed the survey, using a purposive approach.

Finally, at the interpretation and reporting level, I have used a narrative, contiguous approach, where findings of the quantitative narrative systematic review, quantitative cross-sectional survey, and qualitative in-depth interview sections are presented separately in their own chapters (160). This is supplemented by an overall synthesis conducted in two stages: 1) synthesis and discussion of the mixed-methods quantitative and qualitative results (161), drawing overarching inferences in light of, and between, the data (162), then 2) further integrated with (where relevant) the systematic review findings (see next section for more detail).

2.4.2 Critical Interpretive Synthesis

I used a modified Critical Interpretive Synthesis (CIS) (163) approach, drawing on the principles and concepts of this method, to synthesise my quantitative and qualitative findings, before further incorporating findings from my systematic review. Critical interpretive synthesis is a method which allows synthesis of quantitative and qualitative data, through an interpretive lens (163, 164). Here, recognition is given to the interpretive process required to produce a synthesis based on separate forms of evidence (165). This method has been used in a recent systematic review which aimed to improve the understanding of psychological symptoms among Indian women with breast cancer (166), synthesising the findings produced from both quantitative, and qualitative studies.

I adapted the method to synthesise, firstly, the mixed-methods study findings, and then further integrate with the systematic review findings, where relevant, using an integrative grid (see Table 6.1 in Chapter 6: Synthesis). An alternative option would be to have a separate chapter synthesising and discussing the mixed-methods study findings, and then a final discussion chapter incorporating the systematic review findings. However, this would have meant significant repetition in my thesis, so to limit duplication, I have brought all findings together as a final synthesis and discussion chapter.

In Table 6.1, components of the thesis were identified across the top line, with the overarching research questions listed down the left hand side. Columns were used and populated with key findings from each component in relation to the overarching research questions, with one column for mixed-methods synthesised findings, and one with integrated insights from the systematic review, involving an interpretation grounded in the findings of the separate components (163). I (HE) initially synthesised the data and then discussed this with my supervisors (Joseph Clark [JC] and Miriam Johnson [MJ]) who offered viewpoints and suggestions about the analysis. The synthesis was refined based on reflexive group discussion.

2.5 OVERVIEW OF, AND RATIONALE FOR METHODS

In order to answer the overarching research questions, my project was conducted in two sections: a quantitative narrative systematic review, and a mixed-methods study (including a quantitative cross-sectional survey, and qualitative in-depth interviews), each with their own research questions, aims and objectives (see section 1.7 for an overview of these, and Chapters 3-5 for individual component research questions).

A multiple-methods approach was used for this thesis as there were a number of related research questions that could only be answered in different ways using different methods. This section presents an overview of the different methods used to answer the discrete research questions throughout my PhD. Detailed methods and techniques used during each component of the project (e.g. data collection and analysis) are presented separately within their own chapters.

The key substantive aspects of the project are presented below. A detailed description of why these methods were selected, in the presence of alternatives, will follow.

1. A quantitative narrative systematic review of measures used in routine clinical practice to identify and assess breathlessness and chronic breathlessness in different healthcare settings.
2. Mixed-methods Study:
    a. Quantitative cross-sectional survey of experiences of chronic breathlessness and associated clinical factors in the primary care setting, administered as part of the Proactive Anticipatory Care Evaluation (PACE) project (see sections 1.6 and 4.2 for information on PACE).
    b. Qualitative in-depth, semi-structured interviews with patients, carers, and practitioners about experiences of chronic breathlessness in the primary care setting, embedded as part of the PACE project.

2.5.1 Quantitative Systematic Review – Descriptive Narrative Synthesis

A systematic review of the literature was conducted, to explore how breathlessness, *and* chronic breathlessness is identified and assessed for adults in different health care settings through the lens of the published primary research. A descriptive narrative synthesis approach was used as a natural first step to answer my research questions, as

it provided a high level overview of the tools/measurements used in different clinical settings.

Systematic reviews are a robust, replicable way of identifying and synthesising multiple research studies to present and summarise key findings to widespread audiences, such as researchers, clinicians, and decision makers (167), in order to answer a focused research question. Systematic reviews use predefined scientific and transparent methods which allow for reproducible work by the researcher, attempting to identify all relevant studies and extract data systematically, thereby minimising bias. Bias in reviews could include reporting bias; this occurs when choice of studies or review outcomes may be changed in favour of more significant findings (168), and selection bias; this can occur when inclusion or exclusion criteria are not clearly defined before conducting the review, potentially restricting inclusion of some relevant studies (169). Risk of these biases can be reduced by using a predefined and published protocol to increase replicability (168) (the protocol for my systematic review was registered on PROSPERO [CRD42018089782]), and using two reviewers to independently conduct the assessment and inclusion of studies (169). Findings from systematic reviews can also show potential gaps in the literature and can guide further research (167). Ultimately, systematic reviews tend to have more focused research questions, more explicit methods, and less bias than other types of reviews (170) due to their robust, scientific, and transparent methods (167).

Other types of literature review, for example, literature/narrative reviews, do not gather relevant information in a replicable way. This is because they commonly provide a broad overview of a particular topic, without predefined and rigorous inclusion/exclusion criteria, and present general description of studies rather than synthesis of evidence (171, 172). A literature/narrative review may, somewhat unintentionally, omit sections of the literature or may not be critical enough of included literature (171). This type of review would therefore not be able to give an unbiased, comprehensive account of the relevant published literature and therefore would not have been an appropriate approach for my review.

For my systematic review, literature relating to breathlessness and the question of 'How do clinicians identify or assess breathlessness in different healthcare settings?' was anticipated to be extensive. A sensitive (to retrieve as many results as possible) search

was chosen over a specific (more precise) search in order to make the search as comprehensive as possible. A consequence of my sensitive search meant a high number of identified studies which included a significant number of studies which did not meet my inclusion criteria. Despite being labour intensive, this approach was preferable to the specific search where some relevant studies may be missed entirely (167). Therefore, due to the anticipated large volume of results, some initial scoping of the literature took place to ensure that the search strategy was appropriate to find relevant literature. This included looking through the first one hundred results of the preliminary searches to determine whether the literature was relevant to the research question.

Therefore, a systematic review was chosen as an appropriate method to contribute to the overarching research question by mapping the tools and techniques used to identify and assess breathlessness, across health care settings. It was appropriate to take a broad approach and consider the context of all clinical practice when conducting this review, in order to understand the approaches used in each setting. Emergent findings from my review (showing little evidence for identification and assessment of breathlessness in primary care) partly justified the need for the quantitative cross-sectional survey and qualitative in-depth interview components of my thesis, which go on to further investigate chronic breathlessness in the primary health care setting.

2.5.2 Mixed-methods Study

2.5.2.1 Justification for the Population and Study Setting

My research included older, frail people, and was conducted within the primary care setting. An opportunity was presented to collect data within the context of the PACE service evaluation (see sections 1.6 and 4.2 for more information). The PACE service evaluation was designed to address the broader issues relating to older, frail adults. This presented the opportunity to include further investigation of chronic breathlessness in this population, which we know is a serious and debilitating symptom experienced by many older adults (80). Additionally, findings from my systematic review identified few papers (9/97) reporting routine use of breathlessness identification or assessment tools within the primary care setting, indicating a gap in clinical practice (or lack of published research). Further, the review did not identify any research focussing on the older, frail

population. However, as seen from the literature (See Chapter 1) it is likely that older, frail individuals are those most likely to have troublesome breathlessness.

A number of pragmatic decisions were made throughout this thesis, providing further opportunity for the population and study setting. Firstly, data collection occurred as part of a larger service evaluation and therefore we had easily available and ready access to individuals who would be available to answer questions about chronic breathlessness. The patient population was therefore already identified and available as part of the PACE project. Secondly, the survey developed for the purposes of the service evaluation included a number of outcome measures relevant to my research interest and therefore presented the opportunity to use the data, whilst also being able to add my own smaller survey on chronic breathlessness. Thirdly, the participants who agreed to take part in the breathlessness survey were the same ones who were later approached for interview. They were therefore aware of the study and had already been in contact with one of the researchers on the larger PACE project. It was a practical decision to recruit participants through already developed means (the PACE service evaluation), allowing the quantitative and qualitative data to be linked through the participant sample. Qualitative in-depth interviews then occurred, which were required to gather views and experiences of a select sample of participants (148).

2.5.2.2 Cross-sectional Survey

A survey screening for chronic breathlessness and investigating the identification and assessment of breathlessness, was developed and administered as part of a larger survey looking at overall health and wellbeing, which was conducted within the Proactive Anticipatory Care Evaluation (PACE) project.

My breathlessness survey was developed specifically for my PhD and began with a single, brief screening question for chronic breathlessness: 'Have you suffered with breathlessness for most days in the last month?'. This screening question allowed self-report of breathlessness which was then used to determine the prevalence of chronic breathlessness in older, frail adults attending the ICC for a comprehensive multidisciplinary frailty assessment. If patients answered this question with 'yes', then

they completed the other items in the survey relating to the identification and assessment of chronic breathlessness in primary care (see section 4.2.5 for detail).

I included my survey about chronic breathlessness within the PACE project baseline data collection. Two further surveys were included from two additional PhD students: adverse effects from pain medications (SP), and unintentional weight loss (UN). Symptom survey data were collected on the patient's visit to the ICC if these issues were self-reported on screening questions. The opportunity to collect and use the health status and QoL (IPOS and EQ-5D-5L) data from the PACE project - in addition to my breathlessness data - allowed me to compare clinical characteristics between groups (breathlessness and non-breathlessness). Collection of breathlessness data only occurred for those self-reporting chronic breathlessness.

A bespoke survey was needed as there was no validated survey relating to my area of interest (chronic breathlessness in the primary care setting). Also, the development of a screening question was necessary to identify those with chronic breathlessness (defined as having breathlessness for most days in the last month). This was useful to minimise participant burden, as patients did not have to complete the rest of the survey if they did not suffer with chronic breathlessness. The survey was developed using peer and supervisor input and review. It was piloted on fellow PhD students, supervisors, and a post-doctoral researcher, with further input from patient and public involvement (PPI) (see section 2.6.2.2 for more information on PPI).

To determine the prevalence of chronic breathlessness in the older, frail population, and explore other clinical factors associated with breathlessness, a cross-sectional survey was deemed the most appropriate method. A cross-sectional survey captures information about a particular population (older adults with frailty) at a single time point (the initial assessment visit to the ICC). These data can then be used to investigate any relationships between variables (173). Cross-sectional studies are most suitable for determining the prevalence of particular behaviours or diseases in a given population (174). Further, my survey (completed only by people who self-reported breathlessness when answering my screening questions) used mostly closed questions (some were free text responses which were then quantified) which allowed data to be collected from a large number of people, providing generalisable information for that population (175). However, there are also limitations to using cross-sectional surveys. We must consider

that results may be different if data had been gathered a different time, and because of this snapshot of information, only associations, not causations, can be determined between exposures and outcomes (176). Questions were also self-reported, and we must be aware of issues inherent in such designs, such as social desirability or potential under-reporting of symptoms (possibly due to an individual's lack of awareness/adaptation to the limitations of their own breathlessness or its impact (92)).

Alternative approaches such as experimental designs (e.g. randomised controlled trials [RCT]), would not have been appropriate for my quantitative study as I did not wish to compare effectiveness of an intervention between groups of individuals (177), but to gather observational data relating to health, behaviours or attitudes of a selection of participants at a given time (174). Other observational methods such as retrospective case note review or use of existing datasets/secondary data would also not have been appropriate as we know from previous literature (Chapter 1) that breathlessness is not routinely identified or documented on patient medical records. Therefore, use of retrospective data would not have given confidence that we knew who was experiencing breathlessness, and the other breathlessness survey questions would not have been collected. In this way, survey data collection was the most appropriate method to allow for a cross-sectional snapshot of information to be gathered.

The breathlessness survey captured information at a population level, however it would only be able to partially explain the experiences of the identification and assessment of chronic breathlessness, when visiting a primary care practitioner. Therefore, richer data were sought in the use of qualitative in-depth interviews, to gain greater insight into the individual experience (see section 2.5.2.3 for more information).

This method – an observational, cross-sectional survey – answered my overarching research questions by providing quantitative information relating to how breathless the older, frail individual is, the impact breathlessness has on them, whether health care practitioners discuss breathlessness with them, and whether they have been offered any treatments for their breathlessness. This method also provided information about associations between chronic breathlessness and other clinical characteristics within the overall older, frail population.

2.5.2.3 Qualitative In-depth Interviews

In-depth semi-structured interviews were conducted with individuals who had self-reported chronic breathlessness, completed my breathlessness survey, and who had expressed interest in participating in an interview. For participants who had a nominated carer, and who wished to be interviewed together, a dyad interview was conducted. In addition, health care practitioner (HCP) interviews were conducted with practitioners working in primary care, either from the ICC or from the patients referring GP practice, in order to elicit experiences of both groups.

In a dyad interview, two participants are interviewed at the same time (178), and may interact in response to the interview questions (179). For example, comments from one participant may prompt responses from the other (179). This allowed interesting data to emerge regarding worry and concern about their family member/partners breathlessness. The decision to conduct dyad interviews was a practical one, given that participants in my study were older, frail adults, and consideration was given to make sure there was minimal impact and time taken from their day.

Topic guides were developed to direct questions during patient/carer and HCP interviews. Questions were open-ended and flexible. One topic guide was developed for patients/carers (Appendix B), and one for HCPs (Appendix C). Topic guides were reviewed by two patient and public involvement (PPI) groups and amended based on any suggestions given. Refinement of topic guides occurred with supervisor input. See section 5.2.6 for more information on PPI and topic guide development/review.

In-depth semi-structured interviews were chosen to explore issues identified by the quantitative survey in more depth. Conducting interviews with a small selection of participants allowed for deeper understanding and greater appreciation of the experiences of the identification and assessment of chronic breathlessness in the primary care setting by older, frail adults and their carers, along with new insights about these experiences from practitioners.

Interviews are one of the most common methods of qualitative data collection, particularly within healthcare research (147). I chose to conduct interviews instead of using other qualitative methods, such as ethnography or participant observation, which require the researcher to be involved with and observe individuals or groups over a

prolonged time period (180). Participant observation would not have been appropriate as it could have required observing a patient-clinician encounter and this would not have gathered individual views and thoughts about this situation (this may have raised ethical issues regarding patient information). Therefore, in-depth interviews were more suitable.

Thematic analysis (154) was used to analyse the data (see section 5.3 for more detail). A reflexive thematic analysis approach was chosen which refers to "the researcher's reflective and thoughtful engagement with their data and their reflexive and thoughtful engagement with the analytic process" (181) (p. 594). This means that codes and themes are 'developed', 'constructed', or 'generated' (and can be added, removed, or changed) throughout the analytic process (181). This method was chosen as it is flexible, can be applied across many different theoretical approaches, and could provide a rich and detailed account of the data (154). Thematic analysis is also an appropriate method to use when researchers seek to understand shared experiences or meanings across a given population (182), particularly when little is known about the topic area – chronic breathlessness in the older, frail population - and detailed insight is required from study participants (147).

I used an inductive and deductive approach to coding in order to develop themes. An inductive approach means that the codes and themes generated were determined by results firmly rooted in the data (154). This suggests that some results found may not fall within the categories of the research question, but provide additional insight into the participants' experience (154, 183). It may not always be possible for the researcher to free themselves completely from their theoretical interests and therefore, to incorporate a theoretical basis for this study and thesis, a deductive approach was also used to analyse the data using two conceptual frameworks: Total Dyspnoea (137) and Breathing Space (27) (described in section 2.3). The conceptual frameworks were not expected to explain all of these results but functioned as a guide in which to organise and categorise the data. Both approaches were used (inductive and deductive) in order to develop new insights from participants (ensuring that views and concerns were reflected), and to build on existing knowledge (183).

I aimed to include a purposive sample of 20 patients (based on mMRC [modified Medical Research Council breathlessness scale] grade and gender) and a convenience sample of

five carers, and 10 HCPs, to include a broad range of views. The issue of data saturation – when no new themes or codes emerge from data – was not considered as a useful concept in relation to my data collection (as recently discussed by Braun and Clarke) (184). Instead, the specific focus of my topic area meant that the number of interviews conducted provided sufficient information power (185), and was also practical within the constraints of a PhD project.

This method – in-depth semi-structured interviews - informed the answer to the overarching research question giving further insight into experiences of identification and assessment of chronic breathlessness for individuals, carers, and practitioners, in the primary care environment, such as the impact of breathlessness, interactions with the health care practitioner, and views around 'chronic breathlessness syndrome' terminology.

2.6 ETHICAL CONSIDERATIONS

2.6.1 Ethical Approvals

My project was conducted consistent with principles of Good Clinical Practice (GCP), an internationally recognised set of standards upholding ethical, scientific, and practical quality which must be followed when conducting and reporting research (186). The project received full ethical approval from the University of Hull, Hull York Medical School (Ref 1825; 3rd October 2018), and NHS Ethics (IRAS Project ID 250981; 22nd March 2019. (See Appendix D for a copy of ethical approvals).

2.6.2 Ethical Issues Arising Throughout the Study

This study included older, frail people, and as such, consideration was given to a number of ethical issues throughout quantitative and qualitative components. These primarily related to ensuring that study methods were not too onerous on participants and offering assistance in terms of helping with the completion of surveys, having a suitable location for interviews, and consideration of emotional impact/impact of breathlessness during interviews. Given that the focus of this research was the older, frail population, participant burden was minimised wherever possible. Further information on these

issues can be found in individual chapters (Chapter 4: Quantitative Component and Chapter 5: Qualitative Component).

2.6.2.1 Reflexivity and Bias

It is understood that the researchers background and position will have an impact on their choice and angle of investigation, the methods chosen and the conclusions observed (187). Reflexivity can be described as "attending systematically to the context of knowledge construction, especially to the effect of the researcher, at every step of the research process" (187) (p. 484). Therefore, being able to look back and shed a critical eye on one's own actions during the conduct of research is important. Here it is also beneficial for a researcher to consider their own background and possible unconscious biases or preconceptions they may bring. I have a background in psychology and health psychology and have worked on a number of different research projects, conducting interviews with many different individuals with various health conditions. To minimise the effects of bias in this research, I exercised my own reflexivity throughout the research process. I have received training in good clinical practice, quantitative and qualitative data collection, and counselling skills training, where I was able to learn about and understand active listening skills. My own experiences as a young, white, healthy, female may be different to those individuals from a number of patient groups. However, my ability to listen objectively and appreciate and understand another's experience through their narrative, helps takes steps to address unconscious biases, creating an environment where patience and respect is given to research participants.

Further, consideration was given to the risk of researcher bias throughout all stages of this research project. Bias refers to "any trend or deviation from the truth in data collection, data analysis, interpretation and publication which can cause false conclusion" (p. 12) and can be both intentional or unintentional (188). It must be recognised that bias exists in all studies, but the acknowledgement of these biases helps develop a critical appreciation of the research findings (189). Therefore, bias is not eliminated, but transparently accounted for (187). Decisions are made on an ongoing basis and interpretative data (especially rich, in-depth interview data) involves the researcher considerably. Additionally, some measures are by their very nature

subjective, for example self-reported breathlessness which is the focus of the screening question in the quantitative survey.

I considered my own actions and reflexivity in a number of ways throughout my project. During the systematic review, a second reviewer was used to assess inclusion/exclusion criteria for the inclusion of a percentage of papers. This allowed a second, independent opinion to help determine that appropriate decisions were being made and helped to account for reporting bias (which occurs when studies/outcomes are reported based on significant findings) (168), and selection bias (which occurs when criteria have not been clearly outlined, restricting inclusion of some relevant studies) (169). See section 2.5.1 for more information on these types of bias.

During the quantitative section of this project, surveys were only conducted with patients if voluntary informed consent was obtained. Patients were able to complete the survey themselves if they wished, however some completed it with a family member/friend, but most completed it with a researcher. Further, three researchers were involved in data collection and entry of data into a predetermined database; the project manager also assisted with data collection. After each step had been started, meetings and discussions were held between the researchers in order to determine consistency of collection and data entry, making sure that unnecessary bias was avoided.

During the qualitative section, I utilised active listening and empathy to ensure that participants were given the fullest opportunity to share their views and experiences. Whilst I may not be able to identify specifically with the patient population in my research (I am not an older, frail adult with chronic breathlessness), I was still able to understand and appreciate their experience by listening intently to their story; as an interviewer I believe it is important for participants to express themselves fully whilst at ease. I also used a field diary after each interview to record thoughts and opinions about the interview which was referred back to before analysis began. I also discussed interviews with my supervisor after I had conducted three patient interviews, and then again after conducting ten patient and one HCP interview. This allowed me to reflect on my work so far, utilising feedback about interview technique.

Although my project was deemed low risk of any harm to participants, there are unavoidable risks present for the researcher when conducting research/interviews in

patients' homes about sensitive topics. Personal safeguarding and emotional wellbeing were considered throughout the interview process. I reported to a colleague when attending and leaving someone's house, so they knew where I was when lone working. And if any issues arose from interviews with the potential to impact my emotional wellbeing, I discussed these with my supervisor or peers. Further, during analysis, double coding occurred with two transcripts (one patient and one HCP), minimising bias and enriching interpretation. I also discussed initial thoughts and potential themes with the second coder (Ann Hutchinson [AH]). More detailed discussion took place within the supervisory team about codes, themes and meaning of overall results (JC, MJ, and David Currow [DC]).

2.6.2.2 Patient and Public Involvement (PPI)

Finally, patient and public involvement (PPI) has become a necessary and expected part of research (190). When designing and conducting patient-related research it is important to include the views and opinions of patients and the public to make sure the focus of the research is relevant to the lived experience of the patient group (190). Ultimately, PPI makes an important contribution to the overall research project (190), and may improve quality, importance, and participation in research (191). I conducted patient and public involvement for both the quantitative survey and qualitative topic guides. My quantitative survey was reviewed as part of PPI for the PACE service evaluation which reviewed study documents and all questionnaires. I, along with the other two PhD students (SP and UN), sourced PPI guidance for our qualitative interview topic guides. Two separate community groups were attended to gather views about the topic guides regarding how understandable they were, my line of enquiry, whether appropriate language was used, and whether any changes were necessary (see section 5.2.6.2 for more information).

2.7 CONCLUSION

This chapter has described the overall methodological approach of my thesis, along with the justification for a multiple-methods approach. My approach has drawn on the conceptual frameworks of Total Dyspnoea and Breathing Space in order to answer the

overarching research questions. Methods employed for each component of the thesis have also been presented, followed by discussion of ethical considerations and reflexivity.

The next chapter presents the first discrete component of my thesis: a systematic review of the measures used to identify and assess breathlessness across health care settings.

CHAPTER 3 - IDENTIFICATION AND ASSESSMENT OF BREATHLESSNESS IN CLINICAL PRACTICE: A SYSTEMATIC REVIEW AND NARRATIVE SYNTHESIS

3.1 AUTHOR CONTRIBUTIONS AND ACKNOWLEDGEMENT OF PUBLICATION

I acknowledge that text from this chapter was used in the publication of this systematic review as an article (192). It was published online on 23rd October 2019 in the Journal of Pain and Symptom Management (192). The writing of this article was a collaborative process, and all authors are acknowledged for their involvement. This chapter has expanded on the original published article (particularly the introduction, methods, and discussion), but for the most part is identical (see Appendix E).

I (HE) was responsible for the design of the study, collection, and analysis of the data, and drafting and revision of the manuscript. MJ and JC supervised the project and contributed to study design, analysis and re-drafting of the paper. The descriptive narrative synthesis was discussed thoroughly with my supervisors as the analysis approach had to be refined in order to interpret findings in the context of the purpose of different health care settings. UN acted as second reviewer, screening records, and extracting data along with revisions to the manuscript. All authors approved the final draft.

3.2 INTRODUCTION

3.2.1 Rationale for the Review

My Introduction chapter (Chapter 1) highlighted the problems associated with breathlessness across the population and clinical practice, with particular reference to widespread impact (psychological factors and quality of life [QoL]) and challenges of identification and assessment. It also identified chronic breathlessness as being prevalent within the general population with older adults an at-risk group. Recognition that breathlessness may be persistent and disabling despite optimal treatment of the causative medical condition, led to the naming and defining of chronic breathlessness

syndrome (7). The recognition that breathlessness is disabling is highlighted in the context of poor identification, assessment, and treatment. This in turn creates further challenges for health care, raising questions about the nature of chronic breathlessness, as well as the clinical assessment of new or daily persistent breathlessness. It is therefore important to understand how breathlessness is identified and assessed across different healthcare settings.

Evidence-based interventions and clinical frameworks to aid assessment of breathlessness (54) and assessment and management of chronic breathlessness are available (193). Access to, and use of, these may improve patient and family experience, support clinicians to be more effective, and reduce pressure on the health system and resources. The identification and assessment of breathlessness in all clinical settings is therefore important, but it is not conducted systematically in clinical practice (59), and breathlessness tends not to be reported by patients routinely (106). As patients usually appear comfortable at rest, practitioners may not identify this symptom (107) without specific enquiry (105). Therefore, breathlessness is all too often 'invisible' (105, 106), and unidentified or managed in clinical practice in spite of its negative impact.

A number of tools or tests can be used in clinical practice to identify the presence or measure breathlessness severity and the impact on the individual's physical and mental quality of life or functional status, as well as the cause of the breathlessness (113-115). However, little is known about how these are used in clinical practice across healthcare settings and how they vary according to the main purpose of care; 1) primary care for initial presentation, referral and ongoing management of disease and symptom management of chronic breathlessness; 2) secondary care for diagnosis and ongoing management of disease and symptom management of chronic breathlessness; and 3) palliative care for symptom management of chronic breathlessness, maintenance of function and support for other symptoms or concerns in advanced disease.

Routine outcome measurement of problems like breathlessness can help to drive service improvement (194), and could provide consistency of care for all people with breathlessness. Clinical audits and research can help to demonstrate service effectiveness or identify areas for improvement. As management of long-term conditions is an increasing necessity across nations, outcome measurement can help provide evidence to clinical commissioners of the need for resources (194).

The extent to which clinicians use routine outcome measurement tools in the identification and assessment of breathlessness in routine clinical practice is unknown. I therefore reviewed the published literature presenting data on the identification and assessment of breathlessness in clinical practice, across health care settings.

3.2.2 Aim

To identify how clinicians identify or assess breathlessness in different healthcare settings.

3.2.3 Research Question

How do clinicians identify or assess breathlessness in different healthcare settings?

3.2.4 Objectives

For adults with breathlessness due to chronic conditions:

- To identify and describe how breathlessness is identified
- To identify and describe how breathlessness is assessed
- To observe any differences between different healthcare settings
- To synthesise the findings in order to identify gaps in knowledge and practice in the primary care setting.

3.3 METHODS

3.3.1 Systematic Review

My systematic literature review and descriptive narrative synthesis is reported in accordance with Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) guidelines (195). The protocol is registered on PROSPERO (CRD42018089782).

3.3.2 Search Strategy Approach

Systematic review search strategies intend to be as comprehensive as possible to ensure that as many relevant studies are retrieved and subsequently included in the review (196). The sensitivity and specificity of a search strategy must be considered. A sensitive search is designed to retrieve as many results as possible, however, commonly the number of returned results is high and may include studies which do not meet the inclusion criteria. Alternately, specific searches increase the precision of the search, thereby lowering the number of irrelevant studies. However, in doing so, relevant studies may be missed entirely (167).

In order to retrieve as many relevant results as possible, the overall approach of this search strategy was conducted with a sensitive, rather than specific approach. The consequences of using this approach are that the search results were high and included a number of irrelevant studies. The search therefore allowed for high level information (tools/techniques/measures used to identify/assess breathlessness) to be extracted. Whilst smaller number of results would have allowed more detailed extraction and analysis, this was not the focus of my review, which was to 'identify' or map the tools used across settings.

The search strategy was formulated using several search terms (MeSH terms and keywords – see section 3.3.3.1) to account for various synonyms of breathlessness and for identification and assessment. As the literature was anticipated to be extensive, initial scoping of the first 100 results of each search was conducted to determine relevance to the research question. The search strategy was iteratively developed to account for high numbers which would have been unmanageable (and not feasible within the scope of a PhD project), whilst still preserving sufficient ability to identify relevant studies. This allowed for an iterative process to take place, refining the search strategy further each time to achieve a balance of sensitivity and practicality.

3.3.3 Final Search Strategy for Identification of Studies

A final search strategy was devised through discussion and guidance from my supervisors (JC and MJ) and information specialists. This strategy included a number of synonyms for breathlessness as this symptom is often referred to by many different

terms (e.g. dyspnoea, dyspnea, short of breath). The strategy also included simple terms which would account for any form of identification or assessment of breathlessness. The phrase “patient reported outcome measures” was thought to be useful to account for any self-report of breathlessness which may identify or give need for the assessment of breathlessness.

Limits were also applied to help reduce high results. This included a restriction on timeframe (2000 – current) which helped keep results reflective of current clinical practice; a restriction on Human only studies; and a restriction on Language (English Language only as no resources were available for translation at the time). An international evidence base was still identified (and allowed for grouping of studies by country – see section 3.4.1.1 for General Characteristics of Studies).

3.3.3.1 Final Search Strategy and Information Sources

Dyspnea exp **OR** dyspnea **OR** dyspnoea **OR** breathlessness **OR** “shortness of breath” **OR** “difficult* breathing” **OR** “breathing difficult*”

AND

“symptom assessment” exp **OR** assess* **OR** “patient reported outcome measures” exp **OR** “patient reported outcome”

Five databases, MEDLINE(Ovid), PsycINFO (Ovid), Cochrane Library, Embase (Ovid) and CINAHL (EBSCO), were searched between 2000 and 19 February 2018 and reference lists of relevant articles hand searched. The electronic databases used here are widely used within the health sciences. Keyword searches and MeSH terms (title and abstract only) were matched to the above simple search strategy for each database (see Appendix F for a search strategy example). MeSH terms included “dyspnea”, “symptom assessment”, and “patient reported outcome measures” and the other terms were included as keyword searches.

3.3.4 Inclusion and Exclusion Criteria

I developed an inclusion and exclusion criteria to identify the range of measures used to identify and assess breathlessness across health care settings, as reflected by primary research studies conducted in routine clinical practice (see Table 3.1). Where needed, justifications for exclusion criteria are detailed in the table.

Table 3.1 Inclusion and Exclusion Criteria

Inclusion
• All observational quantitative and qualitative study designs (that use routinely collected data within the context of routine clinical practice [primary, secondary, emergency], for example service evaluations, clinical audits, chart reviews, or similar) • Primary research • Any health setting (e.g. primary care, secondary care, community care) • Studies published since 2000 • Adults (18+) with breathlessness (studies including adults and children were included if the adult population data can be adequately extracted) • Adults with breathlessness due to any chronic illness or disease (apart from those listed in the exclusion criteria; studies that have any of these excluded conditions along with any 'chronic illness or disease' only included if the 'chronic illness or disease' data can be adequately extracted)
Exclusion
• Case histories, commentaries, opinion pieces, conferences presentations, and other grey literature • Systematic reviews • Experimental studies (Randomised Controlled Trials [RCT], quasi-experimental) for example, interventions of breathlessness assessments/measures or of breathlessness treatments were excluded • Anything not applied in routine clinical practice • Studies including children and/or animals • Studies not in the English Language • Healthy adults with induced-breathlessness (e.g. recreational exercise, sports, exercise laboratory) • Adults with asthma (specific pathophysiology, treatment pathways and its own literature), hyperventilation syndrome (not due to chronic pathology), obesity (not necessarily considered as disease), sleep apnoea or other sleep related disorders (usually consequence of disease rather than a disease itself) which may present with breathlessness • Adults with breathlessness as a side effect or adverse reaction to a drug or medication, or as a result of a medical procedure • Unexplained breathlessness

3.3.5 Study Selection

Papers identified through the electronic search were imported into Endnote software. Microsoft Excel was used for the application of inclusion/exclusion criteria (see Table 3.1).

I reviewed titles and abstracts against the inclusion criteria, with a percentage being subject to independent second reviewing by a second researcher (10% by UN) with recourse to JC and MJ in the case of disagreement. Where decisions could not be made from the titles and abstracts, full texts were retrieved, and the same process followed.

The random 10% of papers selected for second review by UN was subject to the following method: An online random number generator was used (www.randomizer.org) to generate a set of unique random numbers between 1 and 12,501; the list of random numbers was generated in Microsoft Excel and copied into the Excel file of titles and abstracts under a new column (Random Number Column); the titles and abstracts were then randomised by sorting the file in ascending order by the Random Number Column. The first 10% (1250 papers) were then saved into a new file where the second reviewer could screen them blind to the first reviewer's decision. Independent screening then took place. A consensus check of the 10% of titles and abstracts determined there was an initial agreement of 98.88% between the two reviewers. After discussion about disagreements, final agreement increased to 100%.

Full texts were then sourced via online search methods, requests from authors/colleagues or from inter-library loan services. I successfully retrieved and reviewed papers in full text format. Independent second reviewing included a consensus check of 10% of full texts (by UN), with arbitration from JC and MJ if disagreement occurred. There was 80% agreement between reviewers (HE and UN). After discussion about disagreements, final agreement increased to 100%.

As effectiveness outcomes of studies were not being considered, no formal quality assessment was conducted. However, it was noted whether or not any measures found had been psychometrically validated.

3.3.6 Decisions Made Throughout Full Text Reviewing

Papers which did not define the age range of the population, but where a mean and standard deviation was given (>18 years), were included in the review as it could be inferred they referred to an adult population. Papers stating an age range below 18 years, or which included both children and adults, were excluded, unless the adult data were easily identifiable/adequately extractable.

Papers that comprised both included and excluded health conditions were excluded, unless the relevant health condition data were easily identifiable/adequately extractable.

Initial exclusion criteria stated that papers where 'breathlessness as a side effect or adverse reaction to a drug or medication' would be excluded, was adapted to add papers where breathlessness was also 'as a result of a medical procedure'.

3.3.7 Data Extraction

Ninety-four papers were included for data extraction. The references of these papers were searched, and three additional papers were identified. Ninety-seven papers were finally included within the review and data extracted.

Data were extracted using a piloted form to collect the following: author, title, year, setting, geographic location, study design, sample size, age, health conditions, and measures of identifying and assessing breathlessness. Individual study outcomes were not collected, as this did not address our research question. The first 10% of data extraction (consecutive papers) were checked for accuracy and consistency by UN. There were no disagreements and so no further double data extraction was performed.

3.3.8 Study Settings

Health care settings have different but complementary aims relevant to breathlessness management. Included studies were grouped by health care setting, reflective of their purpose:

i) Primary care: this included general practice and long-term care facilities assuming most received their medical care from community services. This setting is commonly associated with initial presentation, referral, and ongoing care.

ii) Secondary care: this included all studies set in hospital-based services, whether secondary or tertiary care, such as outpatients, inpatients, emergency departments and rehabilitation services. This is associated with diagnosis and ongoing management.

iii) Specialist palliative care (SPC): this included specialist palliative care services whether provided in community, hospital, or hospice settings. Commonly associated with symptom management, maintenance of function and holistic support in advanced disease.

3.3.9 Categorisation of Measures Identifying and Assessing Breathlessness

Measures were categorised and described as those able to identify: the presence or absence of breathlessness; those that assessed the symptom severity; those that assessed the impact of the symptom; and tests to help assess the underlying cause of the symptom. Some were able to both identify presence/absence and measure aspects of the symptom. For example, the Visual Analogue Scale tests both presence/absence and the amount of breathlessness, and the modified Medical Research Council [mMRC] scale could identify presence/absence and gave a measure of the impact on physical exertion. Where a measure/test could be counted in more than one category, they were counted in both.

3.3.10 Analysis

I used a descriptive approach to present the included studies and a narrative synthesis was used to analyse the findings. Included studies were grouped by study setting, noting the primary diagnosis of study participants. Measures of identification and assessment of breathlessness were grouped by their purpose (symptom severity, impact of symptom, cause of symptom) and by study setting. It was not possible to distinguish between measures identifying breathlessness and chronic breathlessness specifically. Therefore, throughout the manuscript, I refer to breathlessness. However, in

circumstances where breathlessness is *likely* to be chronic, for example in COPD pulmonary rehabilitation or palliative care, where treatment of underlying cause is likely to have been optimised, I infer chronic breathlessness as appropriate.

3.4 RESULTS

3.4.1 Included Studies

My search strategy returned 19,062 articles. Three additional articles were identified through reference searching (n=19,065). Duplicates (n=6,561) were removed, and two independent authors (HE and UN) screened the remaining 12,504 articles by title and abstract, of which 12,356 were excluded. There were 148 articles to be included at full text review. Following full text review and discussion, 97 articles were included (See Figure 3.1 for PRISMA flowchart and Appendix G for reference list of included studies).

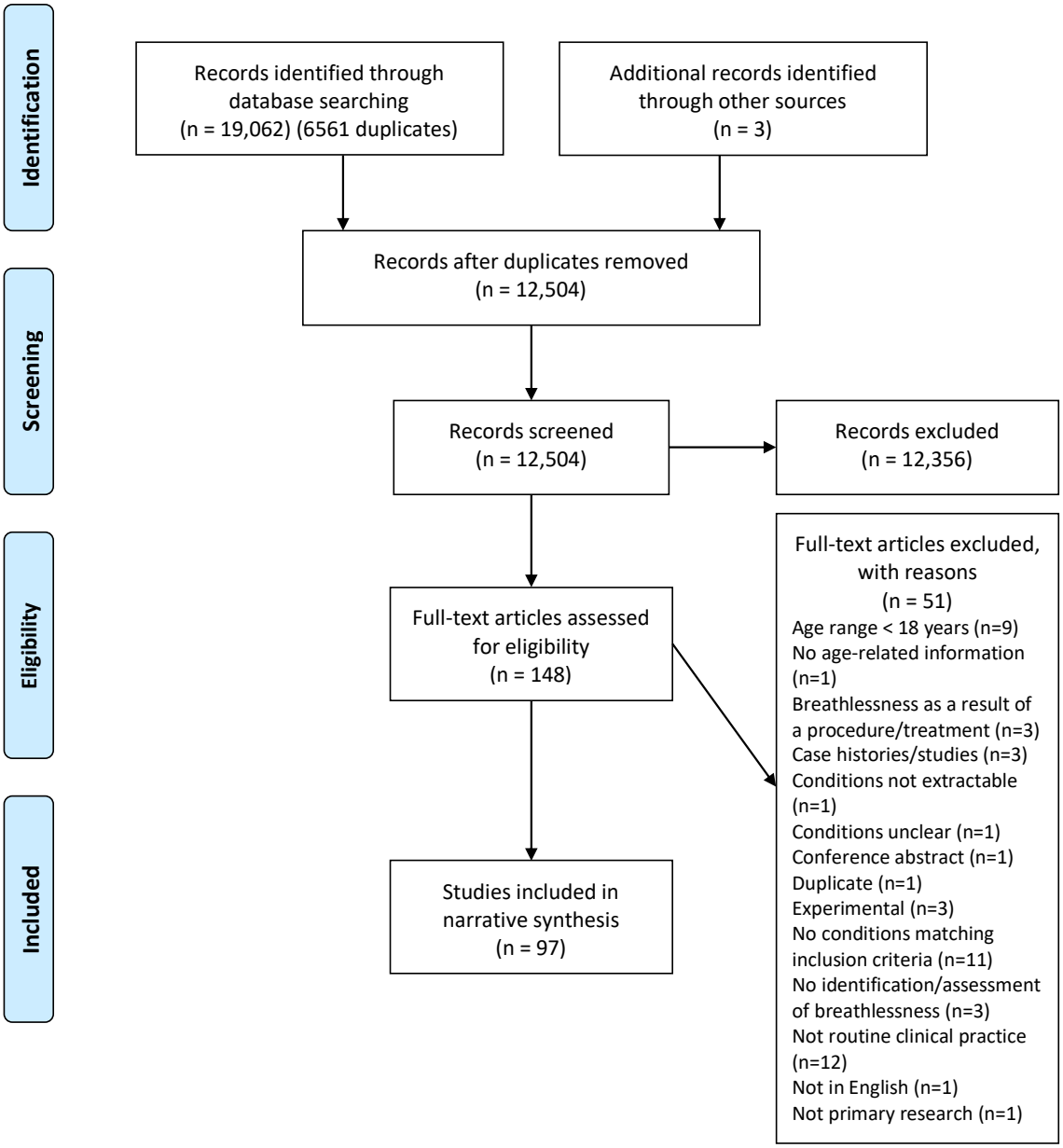

Figure 3.1 PRISMA Flowchart

3.4.1.1 General Characteristics of Studies

Included studies were published between 2000 – 2018, the numbers per year increasing over time. Included studies were conducted in North America (n=49 [50.5%]); Europe (n=38 [39.2%]; 15 from the UK [15.5%]), Asia (n=9 [9.3%]) and one from Australia [1%]. All studies were observational and included case note assessment/chart reviews/medical records review (n=36 [37%]), retrospective cohort/studies (n=30 [31%]), longitudinal/prospective cohort studies (n=11 [11.3%]), audits/clinical audits (n=6 [6.2%]), evaluations/service evaluations (n=5 [5.2%]), cross-sectional studies (n=3 [3.1%]), database review (n=3 [3.1%]), descriptive analysis (n=2 [2.1%]) and case-series

study (n=1 [1%]) (See Appendices H, I, and J for General Characteristics of Studies tables). Studies varied widely in their sample size, ranging from seven to 67,362 participants.

3.4.1.2 Health Care Setting

Most studies reporting approaches to the identification and assessment of breathlessness were in the secondary care (n=53 [54.6%]) setting, followed by SPC (n=35 [36.1%]). Very few studies were in the primary care setting (n=9 [9.3%]) (see Figure 3.2).

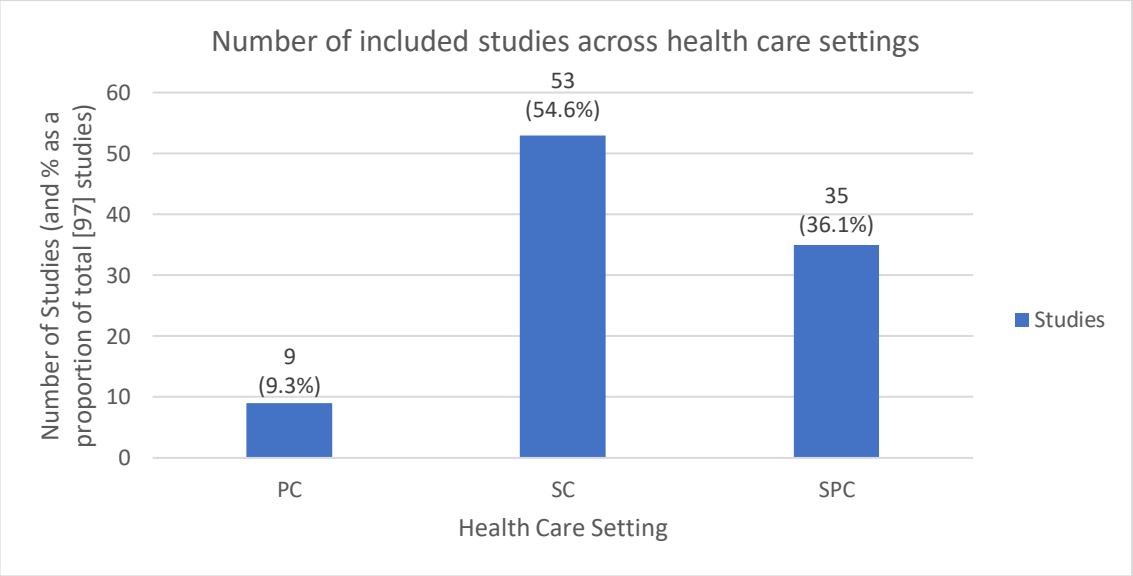

Figure 3.2 Number of Studies by Health Care Setting
PC – Primary care
SC - Secondary care
SPC – Specialist palliative care

3.4.1.3 Primary Health Conditions

Most included studies reported the identification and assessment in the context of a diagnosis of COPD (Chronic obstructive pulmonary disease; n=31 [32%]) or cancer (n=30 [31%]). Of the others, the most common were studies reporting a range of primary medical conditions (n=17 [17.5%]), interstitial lung diseases (n=7 [7.2%]) or heart failure (n = 4 [4.1%]).

3.4.2 Measures of Identification of Presence or Absence of Breathlessness

Of the 97 included studies, 93 (95.9%) reported at least one breathlessness measure or other method of enquiry of identifying breathlessness in clinical use. There were 25 distinct measures of identifying breathlessness reported by included studies (Appendix K). The top three most frequently used measures were the MRC or mMRC (Medical Research Council breathlessness scale, or modified version) [used in 27 studies (27.8%)], ESAS (Edmonton Symptom Assessment Scale, or variant) [n=22 (22.7%)], and BORG (or variant) [n=13 (13.4%)]. Only two measures were used across all three health care settings; CAT (COPD Assessment Test) [primary care n=2 (2.1%), secondary care n=4 (4.1%), SPC n=1 (1%)], and where breathlessness was identified but the method was not described [primary care n=1 (1%), secondary care n=7 (7.2%), SPC n=3 (3.1%)].

In addition, some studies only used clinician assessment (history/examination/observation) (n=9; 9.3%), patient volunteered symptom (n=4; 4.1%) or where breathlessness was identified but the method was not described (n=11; 11.3%).

3.4.3 Measures of Assessment of Breathlessness (symptom severity, impact of symptom, cause of symptom)

Of the 97 included studies, 85 (87.6%) reported at least one measure of assessing breathlessness (symptom severity, impact, or cause). There were 41 distinct measures in clinical use across settings (Appendix L). The most common measures reported overall were LFM (Lung Function Measurements) used in 41 studies (42.3%), MRC [n=27 (27.8%)] and ESAS [n=22 (22.7%)]. Only two measures were used across all health care settings: LFM [primary care n=8 (8.2%), secondary care n=30 (30.9%), SPC n=3 (3.1%)] and CAT [primary care n=2 (2.1%), secondary care n=4 (4.1%), SPC n=1 (1%)].

Measures of symptom severity were most common (studies n=70; 72.2%); followed by measures of the impact of breathlessness such as quality of life, patient concerns or functional status (n=55; 56.7%); and lastly, measures of the underlying cause/diagnosis of breathlessness (n=47; 48.5%). A summary of symptom severity, impact, and cause measures of assessment by health care settings can be found in Table 3.2 (see Appendices K and L for detailed lists).

Table 3.2 Different Types of Breathlessness Identification and Assessment across Health Care Settings Summary

Number of studies	**Primary care n = 9**	**Secondary care n = 53**	**SPC n = 35**	**Total n = 97 (100%)**
Identification	**n (%)**	**n (%)**	**n (%)**	**n = 93**
Studies using measure to identify presence/absence of breathlessness	9 (100)	51 (96.2)	33 (94.3)	93 (95.9)
Assessment of symptom severity				**n = 70**
Studies using measures of breathlessness symptom	6 (66.7)	38 (71.7)	26 (74.3)	70 (72.2)
Assessment of impact of symptom				**n = 55**
Studies using impact measures of breathlessness	6 (66.7)	33 (62.3)	16 (45.7)	55 (56.7)
Measures of the cause/diagnosis of breathlessness				**n = 47**
Studies using cause/diagnosis measures of breathlessness	8 (88.9)	36 (68)	3 (8.6)	47 (48.5)

3.4.4 Validation of Measures

Of the measures used for both identification and assessment of breathlessness, the majority were validated tools (n=25), some were adaptations or simplified versions of scales, and many were medical tests (n=13). Validation was determined by examining academic papers which referred to these tools.

3.5 DISCUSSION

Most published literature since 2000 regarding the identification and measurement of breathlessness in clinical practice is from the secondary care and palliative care setting. Fewer than one in ten studies were from primary care. Nearly all studies used some form of identification of presence or absence of the symptom. However, the pattern of

symptom severity assessment, impact of symptom and diagnostic tests varied by clinical setting, in part reflecting the setting's purpose. Thus, primary care and secondary care studies reported a pattern consistent with diagnosis, disease management/monitoring and ongoing patient care, and in palliative care, of improving quality of life through symptom management in those with diagnosed advanced diseases of many aetiologies and multiple symptoms.

3.5.1 Measures by Setting

3.5.1.1 Primary Care

The few papers in primary care might be explained by its sheer range of clinical concerns, however, given the prevalence of breathlessness this still indicates a gap in clinical practice (or a lack of published research). One to two percent of primary care consultations are reported as due to breathlessness but is likely to be an underestimate (92, 93, 197). This may be due to under-reporting of symptoms where individuals have adapted to the limitations of persistent breathlessness (92), or where medical notes have documented the causative disease with little or no further mention of the symptom. Around one in ten of the general population have limiting breathlessness experienced for at least three months over the past six months (6). In people commonly attending primary care, breathlessness prevalence is much higher: about a third of older adults (80) and most with advanced chronic conditions (e.g. COPD) (65). Primary care is an excellent setting to identify, assess, and manage the disease and the symptom of chronic breathlessness (80) given that most chronic condition management takes place here (198) if primary care is well developed.

The Quality and Outcomes Framework in UK primary care includes payments if a target proportion of people with COPD and mMRC ≥3 are offered pulmonary rehabilitation (199). In this context, breathlessness is likely to be chronic, given the assumption that optimisation of COPD treatment will occur prior to or alongside pulmonary rehabilitation. However, patients with breathlessness due to other causes, e.g. heart failure, are not included in this process (therefore not receiving routine support), and other breathlessness interventions (e.g. handheld fan) are not mandated for those with COPD. Our included primary care studies were mostly in the context of COPD, raising a

concern that many with breathlessness due to other causes are potentially unknown, unassessed, and unmanaged. If breathlessness is not systematically sought and assessed in primary care, then avoidable suffering may go unnoticed. A recent British Lung Foundation general public online survey, "The Breath Test", showed that a third of 365,043 respondents who were worried about their breathing (MRC grade 3 to 5) had not sought medical advice, and of those that had, 58% had not found the advice helpful (200).

Suboptimal identification and management of breathlessness in primary care has consequences for the wider health system, especially for urgent care. Around a third of patients conveyed by ambulance to the emergency department are discharged home without hospital admission (2). A recent systematic review found that breathlessness was the symptom general practitioners found the most difficult to address and were reluctant to prescribe opioids for severe COPD related chronic breathlessness despite its potential benefit, preferring to admit patients to hospital (201).

Improved community-based care, including crisis plans (202) and self-management skills (183, 203), may prevent at least some urgent hospital attendance.

3.5.1.2 Secondary Care

Secondary care had the most included studies with symptom severity, impact, and cause of breathlessness measured. This is expected given that medical conditions causing breathlessness - and that are managed in this setting - are common. A number of studies in this setting were from pulmonary rehabilitation services where walk tests, BORG and MRC scales (204-207), found in our included studies, are part of standard patient monitoring (208, 209).

The pattern of measurements is consistent with the investigative, diagnostic and disease management/monitoring purpose in this setting. Most studies were in respiratory conditions such as COPD, with a few in cancer. However, breathlessness is common in other conditions such as heart disease, which has a similar clinical disease severity classification (New York Heart Association Class) (36). However, only eight studies within this setting included patient groups other than respiratory or cancer, which may indicate that breathlessness is less likely to be addressed as a clinical target in other conditions.

The importance of patient-reported outcome measures (PROMS) is increasingly recognised in oncology practice with recent work showing better patient survival when PROMS are embedded in routine practice and used in patient-clinician decision making (210). In general, high breathlessness NRS scores predict hospital admission from the emergency department (2, 211, 212), longer length of hospital stay, in-hospital adverse events (100, 101), and can be measured routinely (100). However, in secondary care, other than with pulmonary rehabilitation, whilst there is evidence that breathlessness is identified and measured in COPD to inform classification of disease severity, treatment choice and to monitor response to treatment, there does not appear to be a specific clinical concern in the symptom as a *therapeutic target,* i.e. for chronic breathlessness. A recent cohort study of optimally treated people with COPD estimated that just over half had chronic breathlessness syndrome with little evidence that this was being addressed (112). This is despite the availability of evidence-based treatments or full recognition of its widespread impacts.

The revised Global Initiative for Chronic Obstructive Lung Disease (GOLD) criteria requires symptoms (MRC), broader impact (CAT) and exacerbations to be assessed along with spirometry, to classify stage of disease, guide COPD management and monitor progress (213). This approach could be used in other conditions.

3.5.1.3 Specialist Palliative Care

The high number of studies found in the palliative care setting reporting measures of breathlessness identification and assessment is expected in the context of a population with advanced illness receiving disease management and support with a focus on prevention, relief of suffering, and enhancement of quality of life through symptom control (214). Unsurprisingly, diagnostic and pathophysiological tests were rarely reported although optimisation of disease treatment, and diagnosis of new conditions remain important in palliative care. However, the clinical focus of chronic breathlessness syndrome in this setting is highly likely, given that optimal treatment is likely to be optimised prior to a referral to palliative care.

Holistic clinical assessment is a core competency of the palliative care clinical practice curriculum (214) and forms the content of first palliative care consultations. However,

implementation of standardised documentation of such assessment has been slow (194). Notable exceptions, such as the Palliative Care Outcome Collaborative (PCOC) in Australia, are seen. Most Australian palliative care services contribute core outcome sets for national benchmarking, using the feedback as a stimulus for service improvement, showing year on year improvement in patient report outcomes (194). Recent initiatives, such as the Outcome Assessment and Complexity Collaborative (OACC) – a suite of outcome measures used within palliative care to measure and improve care for patients, families and caregivers (215), derived from the PCOC, are beginning to be implemented in areas of the UK and elsewhere.

A number of breathlessness measurement approaches were identified often as part of broader symptom – such as the ESAS (216-237) - or more recently as part of holistic assessments of patient concerns - such as the Patient Outcome Scale Symptom Module (POSs) (238), indicating that holistic measures may be growing (215). Nearly half of the studies had a broad measure of performance/functional status (Appendix K). Although in the context of overall symptom assessments, breathlessness-specific quality of life impacts would not be expected, patient-reported holistic concerns were few.

Effective implementation of routine outcome measurement would be helpful to drive service improvement, provide evidence of clinically effective services for commissioners, and contribute to the delivery of better person-centred care.

3.6 STRENGTHS AND LIMITATIONS

Breathlessness identification and assessment in the included studies from around the world was within the context of routine clinical practice rather than selected trial populations to provide generalisable findings. The literature was broad with robust methods to minimise selection bias. Inclusion of studies where breathlessness was measured both as a primary outcome and also as part of a full symptom assessment enabled patterns of assessment across a range of settings to be seen.

The major limitation with regard to answering our question is the use of published literature only. If health services have implemented routine identification and assessment but have not published findings, then this knowledge is unrepresented. Some healthcare settings have a stronger culture of publication than others e.g.

secondary more than primary care and therefore good practice in primary care may have been missed. Secondly, included papers were limited to English language, and finally, most studies were either retrospective or used routine medical records with recording inaccuracies common with such designs.

3.6.1 Implications for Clinical Practice and Research

In all healthcare settings, measurement of breathlessness is important because it is common, associated with poor clinical outcomes, and there are interventions which benefit patients (239). There are clinically feasible tools available to identify and assess the wider impact of breathlessness (100) both at initial assessment, and on follow-up to assess effectiveness of interventions. The importance of breathlessness as an indicator of disease severity – as for COPD – along with a focus on breathlessness as an ongoing therapeutic target, could be incorporated in the management of other chronic conditions. Routinely documented systematic measurement of holistic patient concerns is important, including in services where holistic assessment is a core component of care. Systematic documentation of outcome measures allows benchmarking of services, illustrates service effectiveness, drives service improvement, informs service funding, and provides representative data to address clinically relevant research questions. Routine assessment of breathlessness is also required to identify chronic breathlessness syndrome, which may not be volunteered by the patient themselves.

Prospective research is needed to determine tailored-to-setting core outcome measurement sets, how best to implement core clinical outcome measures routinely in all healthcare settings, and how to use them to drive improvements in care. Use of routinely collected clinical data provides a rich source to interrogate to identify current practice gaps, e.g. an analysis of England's primary care Clinical Practice Research Database showed that lung cancer, rather than COPD, drove access to palliative care services for people with respiratory conditions highlighting an inequity in care (240). Further trials could test if breathlessness identification and management in primary care - and first responder - based interventions will reduce inappropriate emergency hospital care. A better understanding of patient and clinician experience of identification and assessment of breathlessness particularly in the primary care setting, where it sits as one problem among many, would help inform future work.

3.7 CONCLUSIONS

Patterns of acute and chronic breathlessness identification and assessment vary across healthcare settings in routine clinical practice. Mostly, the patterns reflect the purpose of the health services involved but highlight missed opportunities. Firstly, primary care is well placed to seek and diagnose causes of breathlessness at an early stage and initiate and support ongoing symptom management. Secondly, routine use of simple breathlessness severity scores should be embedded into all clinical practice to identify patients in need of evidence-based interventions. Thirdly, patient-reported measures should be used serially in all settings to monitor management and ensure that breathlessness remains a visible therapeutic target rather than a signpost to diagnosis and prognosis only.

3.8 CHAPTER SUMMARY AND FOCUS ON CHRONIC BREATHLESSNESS IN THE PRIMARY CARE SETTING

This review found very little evidence (nine papers) relating to the identification and assessment of breathlessness within the primary care setting (six of which were in the UK), highlighting missed opportunities and most need for improvement in the ongoing management of this symptom. Further, there were no papers identified that focused on the *older, frail* population. However, it is acknowledged that identification and assessment may occur, but it is not evident from the published literature and is therefore likely to be patchy.

Prevalence of chronic breathlessness (in terms of breathlessness experienced over a number of weeks to months (1, 6) has already been determined in the general population, in different clinical groups, and within certain health conditions. However, there is no evidence reporting the prevalence of chronic breathlessness in the older, frail population. Improved assessment and management within primary care will likely benefit those involved and prevent unnecessary hospital attendance and admission. Additional research in primary care clinical practice is therefore needed to understand procedures within this setting.

The next chapter draws on the results of this systematic review and further investigates chronic breathlessness in the older, frail adult within the primary care setting. To do this, the thesis moves on to develop and pilot a survey to estimate the prevalence, and psychological impact, of chronic breathlessness in the older, frail adult in the primary care setting. The survey will also investigate experiences of identification, assessment, and access to breathlessness interventions in primary care.

CHAPTER 4 - THE PREVALENCE OF CHRONIC BREATHLESSNESS, AND CLINICAL FACTORS ASSOCIATED WITH CHRONIC BREATHLESSNESS, IN AN OLDER, FRAIL POPULATION WITHIN PRIMARY CARE: METHODS AND RESULTS

4.1 INTRODUCTION

4.1.1 Chapter Rationale

In chapter three (Systematic Review), potential missed opportunities for the identification and assessment of breathlessness were identified across clinical settings. Few papers reporting routine use of breathlessness identification/assessment tools were identified in the primary care setting. In addition, my systematic review did not identify any papers that focused on adults with frailty. This is a problem as frailty is increasing in the United Kingdom as a consequence of the growing older population (81) and are likely to be at risk of breathlessness, or conditions which cause breathlessness.

Chronic breathlessness is associated with significant psychological distress (see Chapter 1: Introduction), but there is little research exploring its impact on older adults at risk of severe frailty in whom the prevalence of chronic breathlessness could be considered to be higher than in the general population. Therefore, in this study I determined the prevalence, and psychological impact, of chronic breathlessness in older frail adults, in the primary care setting.

This research is part of the mixed methods component of my PhD thesis (see Chapter 2: Methodology) using a quantitative cross-sectional survey and qualitative in-depth interviews. In this chapter I present the methods and findings of the quantitative (cross-sectional survey) component.

4.1.2 Aim

To determine the prevalence of older, frail adults with chronic breathlessness, and to explore experiences of identification, assessment, and access to breathlessness

interventions in a primary care setting, with a focus on psychological factors and quality of life.

4.1.3 Research Questions

1. How common is chronic breathlessness in the older, frail population?
2. How do clinical and demographic characteristics compare for older adults with frailty who report chronic breathlessness, and those who do not?
3. Does quality of life differ between those with chronic breathlessness and those without?
4. Is chronic breathlessness associated with psychological problems and reduced quality of life?
5. What is the impact of chronic breathlessness on activities of daily life?
6. What is the experience of older adults with frailty and chronic breathlessness regarding care received in the primary care setting?

4.1.4 Objectives of quantitative study

1. To determine the prevalence of self-reported chronic breathlessness in older adults with frailty.
2. To explore the clinical and demographic characteristics associated with self-reported chronic breathlessness.
3. To describe quality of life of older adults with frailty in those with and without self-reported chronic breathlessness.
4. To explore the relationship between chronic breathlessness and psychological problems and quality of life.
5. To describe changes in activities in those with chronic breathlessness.
6. To explore experiences of identification, assessment, and access to breathlessness interventions in a primary care setting.

4.2 METHODS

My study of chronic breathlessness in primary care was embedded within a service evaluation of a newly developed Integrated Care Clinic (ICC) providing holistic assessment and management of older adults with frailty (see below, Figure 4.1 and section 1.6 for more information on the Proactive Anticipatory Care Evaluation [PACE]).

I was a team member, along with one project manager (Mabel Okoeki [MO]) and two other PhD students (SP and UN) conducting informed consent and sharing the data collection for PACE. The PACE evaluation included a number of measures in the form of a survey (see Table 4.1). This allowed me to include my own questionnaire to identify older adults at risk of severe frailty with chronic breathlessness, to gather further information about their experiences in primary care, and to identify potential participants for interview. The two other PhD students included topic-specific questionnaires related to their own areas of interest in the same way (SP – adverse effects from pain medications, and UN - unintentional weight loss). Each PhD student collected survey data on behalf of the other two.

Participants were referred into the ICC by their general practitioner (GP) as being *at risk* of severe frailty using the eFI (electronic Frailty Index) and usually with a score of >36. The eFI is a calculated score based on the presence or absence of 36 deficits (e.g. symptoms, diseases, or disabilities), as a proportion of the total (83). In some cases, risk of severe frailty was determined as a result of clinical judgement by the practitioner and therefore, a few participants were referred with lower eFI scores. Once at the ICC, participants frailty status was re-categorised in their multidisciplinary assessment using the Rockwood Clinical Frailty Scale (CFS). To prevent repetition in this chapter, I therefore refer to all people referred to the ICC (older adults at risk of severe frailty), as 'older adults with frailty', or 'older, frail' adults.

4.2.1 Study Design

A quantitative, observational, cross-sectional survey was conducted, embedded as part of a larger service evaluation of a new Integrated Care Centre.

4.2.2 Study Setting

Primary care/community based: Data were collected at the ICC; participants were community-dwelling older adults being assessed in a community-based integrated care centre as day cases.

4.2.3 Participants

4.2.3.1 Inclusion and Exclusion Criteria

Eligible participants were 65 years old or over; identified as at risk of severe frailty by their GP practice (using the eFI score >0.36 along with clinical judgement); a resident of and registered with a Hull GP practice; and able to speak English (or had the use of an interpreter). Failure to meet these inclusion criteria led to exclusion from the study.

A subset of the overall participants who self-reported chronic breathlessness were recruited for interview about their experiences of chronic breathlessness in the primary care environment (See Chapter 5: Qualitative component of this study).

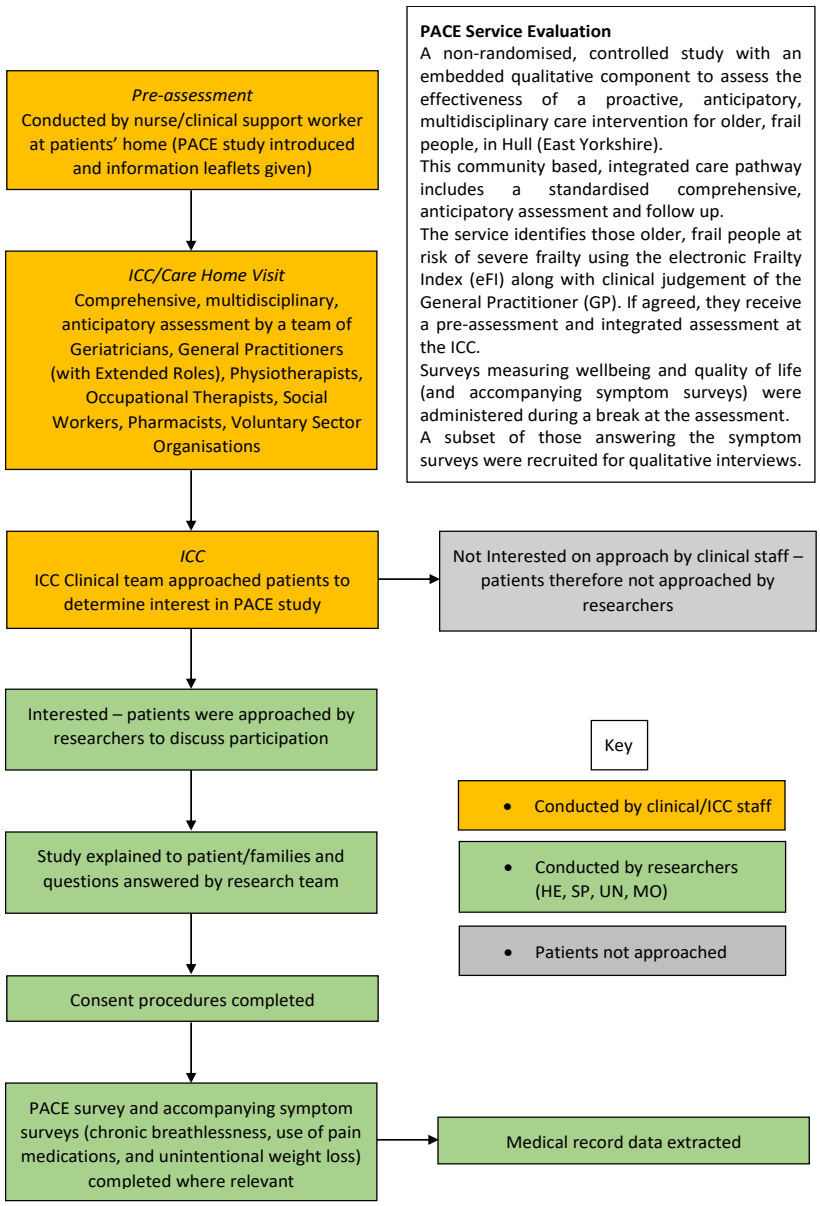

Figure 4.1 PACE Service Evaluation Information and Patient Journey Flowchart

4.2.4 Ethics/HRA Approval

The PACE project was compliant with Good Clinical Practice (GCP) (186). The project received full ethical approval from the University of Hull, Hull York Medical School (Ref 1825; 3rd October 2018), and NHS Ethics (IRAS Project ID 250981; 22nd March 2019).

4.2.5 Data Collection Tools/Outcomes Measures

The overall survey was developed for the PACE study (See Appendix A) and combined two standardised measures: the Integrated Palliative care Outcome Scale (IPOS) and

EuroQoL-5D (EQ-5D-5L). This was administered upon attendance at the ICC, then again at 2-4 weeks, and 10-14 weeks (for follow up data) after initial recruitment. My own survey - a bespoke questionnaire about chronic breathlessness - was developed (see section 4.2.5.3) and added as a separate symptom screening questionnaire at the end of the PACE survey. This was included with two other symptom screening questionnaires (about adverse effects from pain medications [SP], and unintentional weight loss [UN]) which were only collected once, on the patient's visit to the ICC if these issues were self-reported on the screening questions. Demographic data were collected from participants' medical records. Descriptions of each of these measures are given below. All data were collected for analysis in the PACE evaluation and PhD students' research, apart from the symptom screening questionnaires which were used for PhD research only. See Table 4.1 for a list of outcome measures and purpose of collection and section 4.2.8 for information about variable selection.

Table 4.1 Data Collection Outcome Measures

Categories	Outcome Measures/Information to be collected	Collected for PACE service evaluation	Collected for my PhD research
Demographics	Age, Sex, Ethnicity, Relationship Status, Living Situation, Postcode (Socioeconomic Deprivation), Smoking Status, Capacity, Frailty (eFI), Frailty (Rockwood), BMI, AKPS, Primary diagnoses (Number of Comorbidities)	✓	
Wellbeing	IPOS	✓	
Quality of Life	EQ-5D-5L	✓	
Symptom Screening Questionnaire	Chronic Breathlessness Survey Breathlessness presence/absence, severity, length Impact of breathlessness Activities forgone due to breathlessness Primary care support for breathlessness		✓

4.2.5.1 Integrated Palliative care Outcome Scale (IPOS)

The IPOS (241) is a validated and reliable 17-item outcome measure, widely used for those with advanced diseases, in either patient or staff-report versions. It is used to assess the *concern due to, rather than severity of*, symptoms over the previous week, and is responsive to change (241). The first question is open ended and allows the participant to report their main problems and is not scored. The next question relates to how much they *have been affected* by ten different physical symptoms (pain, shortness of breath, weakness or lack of energy, nausea, vomiting, poor appetite, constipation, sore or dry mouth, drowsiness, and poor mobility) and is scored from 0 (not at all) to 4 (overwhelmingly). The following questions address emotional symptoms (patient anxiety, family anxiety, depression, and feeling at peace) and communication/practical issues (sharing feelings, information, practical matters) and are also scored from 0 to 4 (although text descriptors may vary for these questions) (241).

The overall IPOS score is the sum of the physical, emotional, and communication items, with a total possible score ranging from 0 to 68. Three subscales can be calculated: physical (ten items scoring up to 40), emotional (four items scoring up to 16), or communication/practical issues (three items scoring up to 12) (241).

4.2.5.2 EuroQol-5D (EQ-5D-5L)

The EQ-5D-5L (242) is a standardised measure of health status and QoL. The EQ-5D-5L includes six questions relating to the patient and how they feel on the day in relation to mobility, self-care, their usual activities, pain, and anxiety and depression. These are scored on five response levels: no problems (1), slight problems (2), moderate problems (3), severe problems (4), or unable to/extreme problems (5). The final question is a visual analogue scale from 0 to 100 which asks the patient to determine their overall current health status on the day. Overall health state can be summarised using an index value, and this is reflective of the health state of the given population of the country/region the patient belongs to. The index value can aid in the calculation of Quality Adjusted Life Years (QALY) which can be used to inform economic and healthcare interventions (242). See section 4.2.8.2 for variables selected for analysis.

4.2.5.3 Chronic Breathlessness Survey

A bespoke chronic breathlessness survey was developed and administered as part of the PACE service evaluation but used exclusively for my PhD research (see Table 4.1).

Development of the survey consisted of peer and supervisor review, assisted by patient and public involvement. A draft was piloted by fellow PhD students, both supervisors (JC and MJ), and the post-doctoral researcher (AH) who had developed some of the questions for a previous survey (2). Once comments on the survey were received, it was amended to reflect any concerns or omissions and sent again to those involved for their follow-up thoughts. Once all questions were agreed on, a final version of the survey was considered complete.

For the purposes of this study, chronic breathlessness was defined as a self-report of breathlessness on most days of the last month similar to a previous study investigating chronic breathlessness in the emergency department (2). Whilst those self-reporting chronic breathlessness within this study are likely to have chronic breathlessness syndrome (7), this was not able to be specifically diagnosed on the use of a screening question alone and no data were gathered from medical records to ascertain optimal treatment of underlying conditions.

4.2.5.4 Medical Records

A number of variables (demographics and other clinical data) were obtained from the patient's medical record. They were:

- Age
- Sex
- Ethnicity
- Relationship status
- Living situation
- Postcode (to estimate the Index of Multiple Deprivation [IMD])
- Smoking status
- Frailty (eFI) (83)

- Frailty (Rockwood Clinical Frailty Scale [CFS] – a clinical measure of frailty in older people, based on clinical judgement) (243)
- Australian Karnofsky Performance Status (AKPS – a measure of performance status) (244)
- Primary diagnosis/other medical conditions

Data collected at the patient's pre-assessment was also obtained from their medical records for inclusion in the PACE service evaluation.

4.2.6 Recruitment and Consent

Participant recruitment took place within usual practice of the ICC. Patients registered with a GP practice in Hull and who were invited to attend for multidisciplinary assessment at the new frailty service (ICC or care home) were reviewed against the inclusion criteria by the clinical team. Patients (see Figure 4.1) were informed about the study at the pre-assessment visit of their multidisciplinary assessment (patient home or care home) and given study information leaflets (See Appendix M for Patient Information Sheet, and Appendix N for Consultee Information Sheet) so they could consider participating in advance of attendance.

On their visit to the ICC for their multidisciplinary assessment, a member of the clinical team asked patients if they were interested in the study. If they were, a member of the research team (HE, SP, UN, or MO) approached said patient to discuss participation and answer any questions they may have about the study. For those with capacity, informed written consent (See Appendix O) was obtained to complete the survey, obtain medical record information, and to be interviewed if appropriate. For those without capacity, a personal consultee (family member or carer) with them at the appointment was asked if, from their knowledge of the patient, if the patient would agree to participate if they did have capacity. If so, written consultee agreement (See Appendix P) was obtained for completion of the survey and to obtain medical record information. Participants (or consultees) were provided with a copy of the study information sheet and signed consent form (a copy of which was also filed in their medical records).

Consenting participants either completed the survey themselves, with the help of a family member/friend, or were supported by a member of the research team if they

wished, and those reporting experiencing chronic breathlessness also completed the associated chronic breathlessness survey. Surveys were completed at a convenient time/break during the patient's multidisciplinary assessment.

If participants were not able to complete the survey on their visit, but consent had been obtained, the remaining survey questions were asked and completed over the phone (by MO) at a mutually agreed time. If a participant was interested but could not complete consent or survey paperwork on the day of their visit, subsequent visits to that participants home were conducted for completion of the surveys. Subsequent visits were completed as soon as possible after the participants visit to the ICC (by MO).

For those participants in care homes a similar process for obtaining consent was used, however, for those who lacked capacity, a nominated consultee (care home member of staff) was appointed who also completed the survey on their behalf.

Care home data were not used in my analysis as this would not reflect usual experiences in the primary care clinical setting. A main difference would be in patient help-seeking behaviour. In a care home this would predominantly be facilitated through care home staff (initiated by staff or the patients' family). However, in those patients at home who wish to seek help for their breathlessness, they would need to do this directly with their primary care health care practitioner (HCP). This is relevant as questions in my survey relate to accessing help in the primary care clinical setting. Follow up data (data from surveys administered at 2-4 weeks and 10-14 weeks after initial recruitment) were not used as I only required a cross-sectional 'snapshot' of information. Care home and follow up data were collected for and used within the PACE analysis.

4.2.7 Ethical Issues Arising From Surveys

Consideration was given to minimising participant burden as much as possible. Patients were introduced to the study at a prior appointment before attending the ICC and were aware a research study was ongoing. Once at the ICC and if deemed appropriate, patients were reintroduced to the study by a member of staff, before being approached by a researcher. Patients were free to decline participation at any point (see section 4.2.3.1 for patient journey flowchart). Patients were able to complete the survey on their own, with a family member, or with a member of the research team. If completed

with a member of the research team, this was conducted quietly and slowly, so the patient was not overburdened with questions. There was also only one screening question for the chronic breathlessness, pain, and unintentional weight loss sections only requiring further questions if they answered the screening question with 'yes'. This minimised questions to answer should they not be relevant to the patient. The survey was conducted when the patient was waiting to see HCPs as part of their assessment, and breaks were taken when needed or when patients were called for appointments.

4.2.8 Variable Selection

A large amount of data collected as part of the PACE service evaluation was only relevant to the service evaluation. As a result, there were a number of variables that were not related to my research questions and were therefore not included in my analysis, for example, medication records were not relevant to me. Further, it was not feasible or practical to include all variables in my analysis.

Variables of interest were selected based on their ability to answer my research questions (see Section 4.1.3).

A number of demographic variables (e.g. age, sex, frailty score - see Table 4.1) were selected in order to answer research question two, which looked at demographic and clinical differences between those with and without chronic breathlessness.

The IPOS shortness of breath variable was used to give a further indication of the level of concern due to shortness of breath, in addition to the chronic breathlessness survey screening question and other related questions. The IPOS anxiety, family anxiety, and depression variables were all selected as they were part of the 'psychological' variables of the IPOS survey and were therefore able to answer research question two, which focused on clinical differences (IPOS scores) between those with and without chronic breathlessness, and research question four, which focused on psychological problems and reduced QoL associated with chronic breathlessness.

The EQ-5D-5L mobility, self-care, usual activities, pain/discomfort, anxiety/depression, health on the day, and index value variables were all selected as they measure QoL. They were therefore able to answer research question three which looked at differences in QoL between those with and without chronic breathlessness. The mobility, self-care,

usual activities, pain/discomfort, and anxiety/depression variables answered research question four, which focused on psychological problems and reduced QoL and chronic breathlessness.

All variables relating to my chronic breathlessness survey were included as these answered research question five, which looked at impact of chronic breathlessness on activities of daily life, and research question six which focused on the care received in the primary care setting.

4.2.8.1 Comorbidities Variable

Data collected from the medical record presented an exhaustive list of past medical history including conditions, surgeries, and treatments. In order to summarise data, categories were developed based on Barnett's multimorbidity count (245), a list of 40 comorbidities developed from a UK General Practice primary care clinical dataset. As there is no standard method for measuring multimorbidity (245), this method was chosen as it most closely reflected the primary care population of my study. Category development was discussed and agreed with one of my supervisors (MJ), who as a Professor of Palliative Medicine, offered clinical judgement and medical knowledge regarding conditions and appropriate categorisation.

The conditions, surgeries, and treatments (obtained from medical records) were listed, and overarching categories were developed according to Barnett and where appropriate, categories were merged or newly developed. Upon categorisation, certain assumptions were made.

First, surgeries or treatments were not counted as part of comorbidity categories unless reflected by related conditions or cause. An assumption was made that the individual would have only received the treatment or surgery due to the condition. For example, valve replacement was considered to be valve disease and counted under 'Heart Disease'; appendicectomy was considered to be appendicitis and counted under 'Non-Malignant Gastrointestinal Conditions'; and cholecystectomy was considered to be cholecystitis and counted under 'Liver-biliary Tract Disease'. A number of other conditions did not match any of the overarching categories and were not counted (for example, dizziness, incontinence, leg cramp, or severe allergies).

Second, where Arthritis was listed, it was assumed this referred to osteoarthritis and was counted under the category of 'Painful condition', which also included Chronic pain, fibromyalgia, and osteoporosis. Where rheumatoid arthritis was specified, this was counted under the category of 'Rheumatoid arthritis, other inflammatory polyarthropathies and systematic connective tissue disorders'.

Third, there were two categories reflecting heart related conditions; 'Heart Disease', including Atrial fibrillation, Ischaemic heart disease, and Myocardial infarction; and 'Heart Failure', including Chronic cardiac failure and Congestive heart failure, in keeping with Barnett's categorisation.

Fourth, a number of conditions did not fit into Barnett's categorisation, so these were grouped with other already developed categories. For example, 'Non-malignant lung disease' included Chronic Obstructive Pulmonary Disease (COPD), Asthma, Bronchiectasis, and Interstitial Lung Disease (ILD); 'Chronic Kidney Disease' included all kidney disorders or disease such as Chronic Kidney Failure or Renal Failure; and 'Blindness and Low Vision' included all blindness or sight related issues such as Glaucoma, Macular Degeneration, and Cataracts.

Finally, other categories were developed to account for a wide range of other conditions not already accounted for by Barnett. For example, 'Blood Disorders' included Thrombocythemia and Monoclonal Gammopathy of Undetermined Significance (MGUS) amongst others; 'Cancer' included Cancers, Lymphomas and Previous Cancers; and 'Neurological Conditions' included Brain Atrophy, Epilepsy, and Multiple Sclerosis.

The total number of comorbidities for each participant was counted as follows: where participants had one or more conditions within each category, the overarching category was counted only once. A total comorbidity count out of 30 (categories) was given for each participant. See Appendix Q for full list of categories and included conditions.

4.2.8.2 Dependent and Independent Variables

In order to answer research question four, 'Is chronic breathlessness associated with psychological problems and reduced quality of life?' (using ORs and binary logistic regression, and chi square analysis), dependent and independent variables were determined.

The chronic breathlessness screening question ‘Have you suffered with breathlessness for most days in the last month?' identified those with chronic breathlessness and was the dependent variable for this study.

The variables shortness of breath (IPOS), anxiety (IPOS), family anxiety (IPOS), depression (IPOS), mobility (EQ-5D-5L), self-care (EQ-5D-5L), usual activities (EQ-5D-5L), pain/discomfort (EQ-5D-5L), and anxiety/depression (EQ-5D-5L) were used as independent variables.

4.2.9 Data Management

Completed and signed consent forms were retained and kept in a safe, secure, locked filing cabinet in an office at the University, in accordance with General Data Protection Regulations (GDPR) and the Data Protection Act (2018). Participants received a copy of their consent form along with one for their medical record. Completed surveys were assigned unique identification numbers for anonymisation and stored as above. Consent forms and other identifying data were stored securely, separately from other study data at the University of Hull.

All participants were assigned a unique anonymised identification number on both paper and electronic records, and this was used on consent forms, surveys, databases, and any further documentation (such as interview transcripts if they took part in the qualitative study of the PhD), for anonymisation.

Three PhD researchers (HE, SP, and UN) were responsible for data collection and entry into the predetermined database. The project manager (MO) also assisted with data collection. Meetings were held regularly between the researchers to make sure data entry was conducted using a consistent approach.

Survey data were entered onto a spreadsheet in Microsoft Excel which was stored on a password protected University portal. The three PhD students responsible for entering the data were all GCP trained and aware of confidentiality and secure research procedures.

4.2.10 Data Cleaning

Once all data were entered into the predetermined database, final agreement was made between the three PhD researchers (HE, SP, and UN) for any outstanding queries regarding data entry. Queries included making sure dates (e.g. date of birth) were entered in the correct format, or that individual PhD survey results were entered correctly (e.g. making sure that some responses on the chronic breathlessness survey were correctly marked as 'N/A' instead of 'No', where relevant). The data were then complete for each PhD student to extract their relevant data and develop their own database.

Following a process of variable selection, included variables were then extracted to my own separate database using SPSS (Released 2020. IBM SPSS Statistics for Windows, Version 27.0. Armonk, NY: IBM Corp). Anonymised data were stored and analysed using this software.

At this point I conducted further cleaning of my own database, including standardising free text variables on my own chronic breathlessness survey data. For example, in question five where respondents described what they have given up or changed because of breathlessness, free text responses such as 'walking' and 'walking club' were standardised to 'Walking'; 'can't look after grandchildren' and 'babysitting', were standardised to 'Looking after grandchildren'; and 'struggles when meeting friends' and 'can't see friends' were standardised to 'Meeting friends'. In question eight when asked how often they see a GP, nurse, or other health professional from their GP surgery about breathlessness, free text responses such as 'as needed' and 'as and when necessary', were standardised to 'As needed'; and 'when it's bad' and 'when needed/severe' were standardised to 'When it's bad'.

I also reorganised the comorbidities variable in my own database, using my own approach, different to that of the other two PhD students (see section 4.2.8.1). This provided an accurate summary and total count of comorbidities for each participant.

Overall, missing data were minimal, and no imputation of missing data occurred, due to the exploratory focus of this dataset. Any imputation would not materially alter conclusions or findings.

4.3 ANALYSIS

Different approaches to analysis were used to answer discrete research questions throughout my thesis. They are outlined below.

4.3.1 Research Questions 1, 2, 3, 5, and 6

Descriptive statistics (frequencies, median, Inter Quartile Range [IQR], or free text summary) were used to answer research questions one, two, three, five, and six (see section 4.1.3). All items on the chronic breathlessness survey were analysed descriptively, along with the individual item scores for shortness of breath (IPOS), anxiety (IPOS), family anxiety (IPOS), depression (IPOS), and all EQ-5D-5L individual item scores.

My survey aims to measure the prevalence of chronic breathlessness in the older, frail population (those attending the ICC for their comprehensive multidisciplinary frailty assessment). The screening question 'Have you suffered with breathlessness for most days in the last month?' identifies those likely to have chronic breathlessness and the binary response (yes/no) is the dependent variable for this study. Those responding "yes" to chronic breathlessness completed the other items in the breathlessness survey which incorporated multiple choice questions and some (questions, 5-7, 9, and 10) included free test responses (Appendix A, Section 3B).

Some pragmatic decisions were needed in order to count different responses to questions. Therefore, questions five ('Have you had to give up or change any of the following **because of your breathlessness**'?), six ('Who do you normally talk to **about your breathlessness**?'), nine ('What treatments **for your breathlessness** have been organised by your GP, nurse, or other health professional from your GP surgery **in addition to your usual treatment (e.g. inhalers or heart tablets**)?'), and ten ('Do you have any of the following conditions?') were scored per the following rule of thumb (in order for analysis to take place). Each question was provided with a selection of answers; each ticked answer was regarded as 'Yes' and other unticked answers were regarded as 'N/A'. 'No' was not an option for these answers. For example, for question five, if a participant ticked 'hobbies' and 'exercise', these answers would be regarded as 'yes' and the other options ('family roles', 'social roles', 'work/volunteer roles', 'sexual activity'

and ‘I have not had to give up or change anything’) were regarded as N/A. These items related to the impact of breathlessness, activities forgone due to breathlessness, and support in the primary care setting for breathlessness (see Appendix A, Section 3B).

4.3.2 Research Question 4

Inferential statistics (Odds ratios, binary logistic regression, and chi square analysis) were used to answer research question four. Odds ratios are useful when using a binary dependent variable (246), such as my outcome of interest, which is determined by the chronic breathlessness screening question ‘Have you suffered with breathlessness for most days in the last month?’ and is answered yes or no. Odds ratios >1 show exposures are associated with higher odds of outcome, and those <1 show exposures are associated with lower odds of outcome (247). The individual item scores for shortness of breath (IPOS), anxiety (IPOS), family anxiety (IPOS), depression (IPOS), mobility (EQ-5D-5L), self-care (EQ-5D-5L), usual activities (EQ-5D-5L), pain/discomfort (EQ-5D-5L), and anxiety/depression (EQ-5D-5L) were used as independent variables.

Where IPOS independent variables needed to be split into two categories for analysis, they were none/mild, and moderate/severe/overwhelming (242, 248), and for a split into three categories they were none/mild, moderate/severe, and overwhelming (see section 4.4.5). The IPOS shortness of breath variable was also split into none/mild, moderate, and severe/overwhelming for a sensitivity analysis (see section 4.4.5.3).

Where EQ-5D-5L independent variables needed to be split into two categories for analysis they were no/slight, and moderate/severe/extreme (28), and for a split into three categories they were no/slight, moderate/severe, and extreme (see section 4.4.5).

My analysis was conducted in four stages.

1. 2x2 contingency tables were used to determine ORs between the dependent variable and each independent variable (see above and section 4.2.8 for information on variables).
2. 2x3 contingency tables were conducted using binary logistic regressions to determine ORs. Chi-square analysis was then used to determine dose response (an increase in OR as severity of variable increases). A clear dose

response demonstrates a simple explanation (246) and association between chronic breathlessness and worsening symptom.

3. A sensitivity analysis was conducted on the shortness of breath (IPOS) variable to support the split of the categories (see above for information on variable categorisation). A binary logistic regression along with Chi-square analysis was conducted to determine dose response.
4. A binary logistic regression was conducted to adjust for age and sex. These variables were added separately to the regression as confounding variables to determine whether they had an impact on the associations found between chronic breathlessness and the independent variables.

Survey data were analysed using SPSS (Released 2020. IBM SPSS Statistics for Windows, Version 27.0. Armonk, NY: IBM Corp).

4.4 RESULTS

In total, 251 participants consented to take part and completed the PACE service evaluation survey. One participant did not answer the chronic breathlessness screening question and one participant was recruited in error (<65); therefore, they were excluded from analysis, leaving a total of 249 participants (see Figure 4.2).

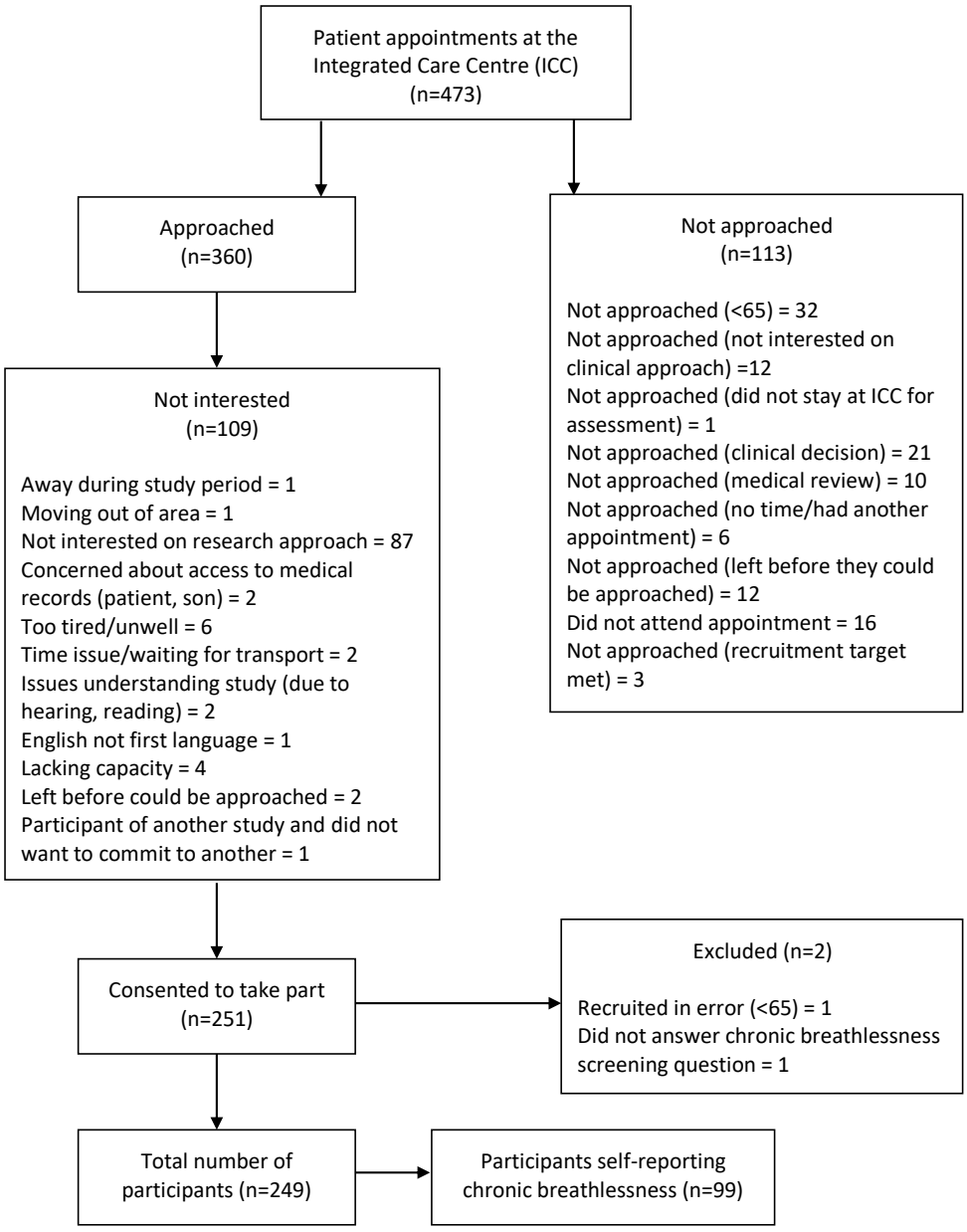

Figure 4.2 Flowchart of Recruitment Process at the ICC

4.4.1 Participant Characteristics

Across the total population, the median (IQR) age was 81 (75-85), and there were 96 men (38.6%) and 153 (61.4%) women. Most participants were white (214/249 [85.9%]), married (120/249 [48.2%]) and living with a spouse/partner (111/249 [44.6%) or alone (113/249 [45.4%]) (see Table 4.2).

Table 4.2 Clinical and Demographic Characteristics of the Populations

Variable	Total Population	Non-Chronic Breathlessness Population	Chronic Breathlessness Population
Age (years)	n = 249	n = 150	n = 99
Missing (%)	0 (0.0)	0 (0.0)	0 (0.0)
Median (IQR)	81.00 (75.00-85.00)	82.00 (76.00-86.00)	80.00 (73.00-84.00)
Sex, n (%)	n = 249	n = 150	n = 99
Men	96 (38.6)	57 (38.0)	39 (39.4)
Women	153 (61.4)	93 (62.0)	60 (60.6)
Ethnicity, n (%)	n = 249	n = 150	n = 99
Missing (%)	16 (6.4)	12 (8.0)	4 (4.0)
White	214 (85.9)	127 (84.7)	87 (87.9)
Mixed/Multiple ethnic groups	18 (7.2)	10 (6.7)	8 (8.1)
Black African/Black Caribbean/Black British	1 (0.4)	1 (0.7)	0 (0)
Relationship Status, n (%)	n = 249	n = 150	n = 99
Missing (%)	31 (12.4)	23 (15.3)	8 (8.1)
Single	7 (2.8)	4 (2.7)	3 (3.0)
Married/Civil Partnership	120 (48.2)	69 (46.0)	51 (51.5)
Separated	2 (0.8)	1 (0.7)	1 (1.0)
Divorced	13 (5.2)	4 (2.7)	9 (9.1)
Widowed	76 (30.5)	49 (32.7)	27 (27.3)
Living Situation, n (%)	n = 249	n = 150	n = 99
Missing (%)	3 (1.2)	2 (1.3)	1 (1.0)
Spouse/Partner	111 (44.6)	65 (43.3)	46 (46.5)
Other Family	18 (7.2)	10 (6.7)	8 (8.1)
Alone	113 (45.4)	72 (48.0)	41 (41.4)
Other	4 (1.6)	1 (0.7)	3 (3.0)
Socioeconomic Deprivation Index (Index of Multiple Deprivation Quintiles), n (%)	n = 249	n = 150	n = 99
Missing (%)	6 (2.4)	5 (3.3)	1 (1.0)
1 (Least Deprived)	21 (8.4)	14 (9.3)	7 (7.1)
2	27 (10.8)	15 (10.0)	12 (12.1)
3	50 (20.1)	30 (20.0)	20 (20.2)
4	51 (20.5)	33 (22.0)	18 (18.2)
5 (Most Deprived)	94 (37.8)	53 (35.3)	41 (41.4)
Median (IQR)	4.00 (3.00-5.00)	4.00 (3.00-5.00)	4.00 (3.00-5.00)

Smoking Status, n (%)	n = 249	n = 150	n = 99
Missing (%)	3 (1.2)	3 (2.0)	0 (0.0)
Yes	29 (11.6)	17 (11.3)	12 (12.1)
No	105 (42.2)	68 (45.3)	37 (37.4)
Former Smoker	112 (45.0)	62 (41.3)	50 (50.5)
Capacity, n (%)	n = 249	n = 150	n = 99
Missing (%)	0 (0.0)	0 (0.0)	0 (0.0)
Yes	239 (96.0)	147 (98.0)	92 (92.9)
No	10 (4.0)	3 (2.0)	7 (7.1)
Frailty (eFI category), n (%)	n = 249	n = 150	n = 99
Missing (%)	16 (6.4)	9 (6.0)	7 (7.1)
No frailty	3 (1.2)	2 (1.3)	1 (1.0)
Mild frailty	7 (2.8)	6 (4.0)	1 (1.0)
Moderate frailty	60 (24.1)	41 (27.3)	19 (19.2)
Severe frailty	163 (65.5)	92 (61.3)	71 (71.7)
Frailty (Rockwood CFS: 1 Very Fit – 9 Terminally Ill), n (%)	n = 249	n = 150	n = 99
Missing (%)	7 (2.8)	4 (2.7)	3 (3.0)
Very fit (1)	1 (0.4)	0 (0.0)	1 (1.0)
Well (2)	3 (1.2)	1 (0.7)	2 (2.0)
Managing Well (3)	13 (5.2)	9 (6.0)	4 (4.0)
Vulnerable (4)	38 (15.3)	26 (17.3)	12 (12.1)
Mildly Frail (5)	100 (40.2)	65 (43.3)	35 (35.4)
Moderately Frail (6)	66 (26.5)	36 (24.0)	30 (30.3)
Severely Frail (7)	20 (8.0)	9 (6.0)	11 (11.1)
Very Severely Frail (8)	1 (0.4)	0 (0.0)	1 (1.0)
Terminally Ill (9)	0 (0.0)	0 (0.0)	0 (0.0)
Median (IQR)	5.00 (5.00-6.00)	5.00 (4.75-6.00)	5.00 (5.00-6.00)
BMI (kg/m^2)	n = 249	n = 150	n = 99
Missing (%)	7 (2.8)	5 (3.3)	2 (2.0)
Underweight (<18.5)	11 (4.4)	4 (2.7)	7 (7.1)
Healthy (18.5-24.99)	53 (21.3)	33 (22.0)	20 (20.2)
Overweight (25-29.99)	74 (29.7)	49 (32.7)	25 (25.3)
Obese (≥30)	104 (41.8)	59 (39.3)	45 (45.5)
Median (IQR)	3.00 (2.00-4.00)	3.00 (2.00-4.00)	3.00 (2.00-4.00)
AKPS (0 [Dead] – 100 [Normal, no evidence of disease])	n = 249	n = 150	n = 99
Missing (%)	0 (0.0)	0 (0.0)	0 (0.0)

Median (IQR)	70.00 (60.00-80.00)	70.00 (60.00-80.00)	60.00 (60.00-80.00)
Number of Comorbidities, n	n = 249	n = 150	n = 99
Missing (%)	0 (0.0)	0 (0.0)	0 (0.0)
Median (IQR)	5.00 (4.00-7.00)	5.00 (4.00-6.00)	5.00 (4.00-7.00)
IPOS_Shortness of Breath, n (%)	n = 249	n = 150	n = 99
Missing (%)	1 (0.4)	1 (0.7)	0 (0.0)
Not at all (0)	103 (41.4)	98 (65.3)	5 (5.1)
Slightly (1)	51 (20.5)	35 (23.3)	16 (16.2)
Moderately (2)	50 (20.1)	14 (9.3)	36 (36.4)
Severely (3)	31 (12.4)	1 (0.7)	30 (30.3)
Overwhelmingly (4)	13 (5.2)	1 (0.7)	12 (12.1)
Median (IQR)	1.00 (0.00-2.00)	0.00 (0.00-1.00)	2.00 (2.00-3.00)
IPOS_Anxiety, n (%)	n = 249	n = 150	n = 99
Missing (%)	1 (0.4)	1 (0.7)	0 (0.0)
Not at all (0)	117 (47.0)	75 (50.0)	42 (42.2)
Occasionally (1)	52 (20.9)	37 (24.7)	15 (15.2)
Sometimes (2)	38 (15.3)	21 (14.0)	17 (17.2)
Most of the time (3)	32 (12.9)	12 (8.0)	20 (20.2)
Always (4)	9 (3.6)	4 (2.7)	5 (5.1)
Median (IQR)	1.00 (0.00-2.00)	0.00 (0.00-1.50)	1.00 (0.00-3.00)
IPOS_Family Anxiety, n (%)	n = 249	n = 150	n = 99
Missing (%)	2 (0.8)	2 (1.3)	0 (0.0)
Not at all (0)	71 (28.5)	44 (29.3)	27 (27.3)
Occasionally (1)	47 (18.9)	37 (24.7)	10 (10.1)
Sometimes (2)	33 (13.3)	16 (10.7)	17 (17.2)
Most of the time (3)	47 (18.9)	26 (17.3)	21 (21.2)
Always (4)	49 (19.7)	25 (16.7)	24 (24.2)
Median (IQR)	2.00 (0.00-3.00)	1.00 (0.00-3.00)	2.00 (0.00-3.00)
IPOS_Depression, n (%)	n = 249	n = 150	n = 99
Missing (%)	1 (0.4)	1 (0.7)	0 (0.0)
Not at all (0)	124 (49.8)	83 (55.3)	41 (41.4)
Occasionally (1)	52 (20.9)	31 (20.7)	21 (21.2)
Sometimes (2)	42 (16.9)	23 (15.3)	19 (19.2)
Most of the time (3)	17 (6.8)	8 (5.3)	9 (9.1)
Always (4)	13 (5.2)	4 (2.7)	9 (9.1)
Median (IQR)	0.50 (0.00-2.00)	0.00 (0.00-1.00)	1.00 (0.00-2.00)

Participants were referred into the ICC as being *at risk* of severe frailty, usually with an eFI of >36; this was determined along with clinical judgement by the primary care practitioner. Therefore, a number of participants were referred with lower eFI scores, however most participants (163/249 [65.5%]) were severely frail. Once at the ICC,

participants were re-evaluated for frailty during their multidisciplinary assessment using the Rockwood CFS and just over one third (86/249 [34.5%]) of individuals scored either Rockwood 6 (moderately frail) or 7 (severely frail) (see Table 4.2).

Only ten participants (4.0%) of the 249 lacked capacity to consent to the survey (and written consultee agreement was obtained – see section 4.2.6 for information on recruitment and consent). The median (IQR) performance status as measured by the AKPS, scored from 0 (dead) to 100 (normal – no evidence of disease), was 70 (60-80). The majority of participants were current (29/249 [11.6%]) or former (112/249 [45.0%]) smokers, almost half (104/249 [41.8%]) were obese, and just over one third (94/249 [37.8%]) were from the most deprived socioeconomic status (as measured by the IMD). Overall, the median (IQR) number of comorbidities was 5 (4-7) (see Table 4.2).

More than one third of the total population were moderately, severely, or overwhelming impacted by shortness of breath (IPOS) over the previous week. Approximately two thirds reported no/mild impact of this symptom (see Table 4.2).

Considering the psychological variables, approximately one third of the total population reported moderate, severe, or overwhelming impact of anxiety or depression over the previous week, with just over half reporting moderate, severe, or overwhelming impact on their family's anxiety (IPOS) over the same time period (see Table 4.2).

4.4.2 Research Question 1 – How common is chronic breathlessness in the older, frail population?

Of the 249 participants to answer the PACE service evaluation survey, 99 self-reported suffering with breathlessness on most days of the last month (chronic breathlessness). This gives a prevalence for chronic breathlessness in the older, frail population, of 39.8% (see Figure 4.3).

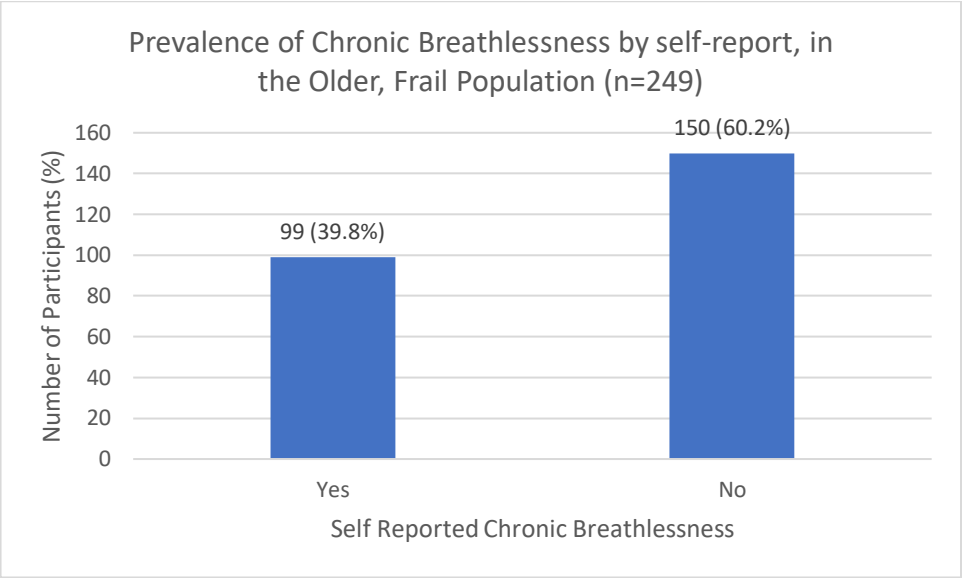

Figure 4.3 Prevalence of Chronic Breathlessness by Self-report

Of the 99 participants that self-reported chronic breathlessness, there were 39 (39.4%) men, and 60 (60.6%) women. Most reported their breathlessness as either level 3 or level 4 on the modified Medical Research Council breathlessness scale (mMRC) (249) (see Table 4.3).

Table 4.3 Chronic Breathlessness Population Characteristics

Variable	Chronic Breathlessness Population
Sex, n (%)	n = 99
Men	39 (39.4)
Women	60 (60.6)
On average over the **past month**, how would you describe your breathlessness? (mMRC scale), n (%)	n = 99
Missing	1 (1.0)
Not troubled by breathlessness except on strenuous exercise (0)	3 (3.0)
Breathlessness when hurrying on the level, or walking up a slight hill (1)	12 (12.1)
Walks slower than most people on the level, or stop after a mile or so, or stop after 15 minutes at your own pace (2)	18 (18.2)
Stops for breath after walking about 100 yards or after a few minutes on level ground (3)	43 (43.4)
Too breathless to leave the house, or breathless undressing (4)	22 (22.2)
Median (IQR)	3.00 (2.00-3.00)
How long have you experienced breathlessness?, n (%)	n = 99
Missing	1 (1.0)
Fewer than 6 months (0)	6 (6.1)
Between 6 months and 1 year (1)	11 (11.1)
Over 1 year (2)	81 (81.8)
Do you have any of the following conditions?, n (%) reporting the following answers	n = 99
Missing	1 (1.0)
COPD	52 (52.5)
Heart Disease	46 (46.5)
Lung Cancer	4 (4.0)
Other Cancer	16 (16.2)
Asthma	22 (22.2)
Other	27 (27.3) – included Diabetes, Angina, Atrial Fibrillation

As shown in Table 4.3, most participants had experienced breathlessness for more than one year (81.8%) or between six months and one year (11.1%). Very few had experienced breathlessness for fewer than six months (6.1%).

Over half of the participants reported having COPD (52.5%), just under half reported heart disease (46.5%), and approximately one fifth reported asthma (22.2%). A fifth reported cancer (20.2%) (of which a small proportion was lung cancer [4%]). Almost a third of participants reported other conditions (27.3%) of which the top three included Diabetes, Angina, and Atrial Fibrillation (see Table 4.3).

4.4.3 Research Question 2 – How do clinical and demographic characteristics compare for older adults with frailty who report chronic breathlessness, and those who do not?

Characteristics of the population were grouped into total population (n=249), non-chronic breathlessness population (n=149), and chronic breathlessness population (n=99).

Differences between those with and without chronic breathlessness can be seen in Table 4.2. On average, those with chronic breathlessness were slightly younger, and had greater socioeconomic deprivation that those without chronic breathlessness. The proportion of those with worse eFI and Rockwood frailty scores, lack of capacity and history of smoking (current or former) was also greater in the chronic breathlessness group. Those with chronic breathlessness had poorer performance status measured by the AKPS and were more commonly obese than those without chronic breathlessness. The number of comorbidities and gender balance were similar between the two groups, as was ethnicity, relationship status, and living situation.

The proportion of those with moderate, severe, or overwhelming impact on shortness of breath as measured by the IPOS was greater in those with chronic breathlessness. Across the psychological variables of the IPOS, there was also a greater proportion of moderate, severe, or overwhelming impact on anxiety, family anxiety, and depression in those with chronic breathlessness, compared to those without.

These results show that the clinical and demographic characteristics differ between those with chronic breathlessness and those without, and that there is a greater

negative impact of shortness of breath and psychological symptoms in those with chronic breathlessness.

4.4.4 Research Question 3 – Does quality of life differ between those with chronic breathlessness and those without?

Characteristics of the population were again grouped into total population, non-chronic breathlessness, and chronic breathlessness population. This can be seen in Table 4.4.

Considering the QoL variables, approximately two thirds of the total population had moderate, severe, or extreme problems with mobility or pain/discomfort (EQ-5D-5L) over the previous week. Approximately half reported moderate, severe, or extreme problems with their usual activities, and one fifth reported moderate, severe, or extreme problems with self-care or anxiety/depression (EQ-5D-5L) over the previous week (see Table 4.4).

The median (IQR) self-reported health on the day (measured between 0 [worst health] and 100 [best health]), was 60 (50 - 80), and the median (IQR) Index Value (overall health state measured between 0 [equivalent to dead] and 1 [full health]) was .674 (.432 - .845) (see Table 4.4).

Table 4.4 Quality of Life Characteristics of the Populations

Variable	Total Population	Non-Chronic Breathlessness Population	Chronic Breathlessness Population
EQ-5D-5L_Mobility, n (%)	n = 249	n = 150	n = 99
Missing (%)	1 (0.4)	1 (0.7)	0 (0.0)
No problems walking about (1)	38 (15.3)	25 (16.7)	13 (13.1)
Slight problems walking about (2)	52 (20.9)	36 (24.0)	16 (16.2)
Moderate problems walking about (3)	73 (29.3)	41 (27.3)	32 (32.3)
Severe problems walking about (4)	72 (28.9)	39 (26.0)	33 (33.3)
Unable to walk about (5)	13 (5.2)	8 (5.3)	5 (5.1)
Median (IQR)	3.00 (2.00-4.00)	3.00 (2.00-4.00)	3.00 (2.00-4.00)
EQ-5D-5L_Self-care, n (%)	n = 249	n = 150	n = 99
Missing (%)	0 (0.0)	0 (0.0)	0 (0.0)
No problems washing or dressing (1)	154 (61.8)	100 (66.7)	54 (54.5)
Slight problems washing or dressing (2)	40 (16.1)	22 (14.7)	18 (18.2)
Moderate problems washing or dressing (3)	35 (14.1)	14 (9.3)	21 (21.2)
Severe problems washing or dressing (4)	12 (4.8)	8 (5.3)	4 (4.0)
Unable to wash or dress (5)	8 (3.2)	6 (4.0)	2 (2.0)
Median (IQR)	1.00 (1.00-2.00)	1.00 (1.00-2.00)	1.00 (1.00-3.00)
EQ-5D-5L_Usual Activities, n (%)	n = 249	n = 150	n = 99
Missing (%)	0 (0.0)	0 (0.0)	0 (0.0)
No problems doing usual activities (1)	78 (31.3)	56 (37.3)	22 (22.2)
Slight problems doing usual activities (2)	49 (19.7)	29 (19.3)	20 (20.2)
Moderate problems doing usual activities (3)	55 (22.1)	29 (19.3)	26 (26.3)
Severe problems doing usual activities (4)	39 (15.7)	21 (14.0)	18 (18.2)
Unable to do usual activities (5)	28 (11.2)	15 (10.0)	13 (13.1)
Median (IQR)	2.00 (1.00-4.00)	2.00 (1.00-3.00)	3.00 (2.00-4.00)

EQ-5D-5L_Pain/Discomfort, n (%)	n = 249	n = 150	n = 99
Missing (%)	0 (0.0)	0 (0.0)	0 (0.0)
No pain or discomfort (1)	55 (22.1)	32 (21.3)	23 (23.2)
Slight pain or discomfort (2)	52 (20.9)	35 (23.3)	17 (17.2)
Moderate pain or discomfort (3)	78 (31.3)	47 (31.3)	31 (31.3)
Severe pain or discomfort (4)	52 (20.9)	30 (20.0)	22 (22.2)
Extreme pain or discomfort (5)	12 (4.8)	6 (4.0)	6 (6.1)
Median (IQR)	3.00 (2.00-4.00)	3.00 (2.00-3.00)	3.00 (2.00-4.00)
EQ-5D-5L_Anxiety/Depression, n (%)	n = 249	n = 150	n = 99
Missing (%)	1 (0.4)	1 (0.7)	0 (0.0)
Not anxious or depressed (1)	141 (56.6)	90 (60.0)	51 (51.5)
Slightly anxious or depressed (2)	54 (21.7)	37 (24.7)	17 (17.2)
Moderately anxious or depressed (3)	30 (12.0)	12 (8.0)	18 (18.2)
Severely anxious or depressed (4)	16 (6.4)	6 (4.0)	10 (10.1)
Extremely anxious or depressed (5)	7 (2.8)	4 (2.7)	3 (3.0)
Median (IQR)	1.00 (1.00-2.00)	1.00 (1.00-2.00)	1.00 (1.00-3.00)
EQ-5D-5L_HealthToday (0 [Worse health] -100 [Best health])	n = 249	n = 150	n = 99
Missing (%)	0 (0.0)	0 (0.0)	0 (0.0)
Median (IQR)	60.00 (50.00-80.00)	67.50 (50.00-80.00)	50.00 (45.00-75.00)
EQ-5D-5L_Index Value (0 [Health state equivalent to dead – 1 [Full health state])	n = 249	n = 150	n = 99
Missing (%)	2 (0.8)	2 (1.3)	0 (0.0)
Median (IQR)	.674 (.432 - .845)	.728 (.473 - .862)	.594 (.393 - .810)

Across the QoL variables of the EQ-5D-5L, there was a greater proportion of moderate, severe, or extreme problems with mobility, self-care, usual activities, pain/discomfort,

and anxiety/depression in those with chronic breathlessness, compared to those without. Furthermore, those with chronic breathlessness had lower self-reported health on the day and lower index values, compared to those without chronic breathlessness.

These results show that QoL is lower in those with chronic breathlessness, compared to those without.

4.4.5 Research Question 4 – Is chronic breathlessness associated with psychological problems and reduced quality of life?

In order to further investigate the psychological (IPOS) and QoL (EQ-5D-5L) variables discussed in research questions two and three, and to answer this research question, analysis using odds ratios (OR) was conducted. An OR is a measure of association between an exposure (i.e. anxiety) and an outcome (i.e. chronic breathlessness). Hence, the likelihood of experiencing, for example, moderate/severe/overwhelming anxiety, in the chronic breathlessness group compared to the non-chronic breathlessness group.

As a reminder, for this analysis, IPOS variables were dichotomised into none/mild, and moderate/severe/overwhelming, and EQ-5D-5L variables were dichotomised into no/slight, and moderate/severe/extreme.

4.4.5.1 Step 1 – 2x2 ORs (Contingency Tables)

As can be seen in Table 4.5, the OR for chronic breathlessness and shortness of breath (IPOS) is 30.88 (95% CI 15.21 – 62.67). This means that those people who self-reported chronic breathlessness are 30.88 times more likely to experience moderate/severe/overwhelming impact of shortness of breath (IPOS) than those without chronic breathlessness. This finding supports the construct validity of the chronic breathlessness screening question; this question was effective in identifying the chronic breathlessness population.

Table 4.5 2x2 Odds Ratios

Independent Variable	n (%)	OR	95% CI	
			Lower	Upper
IPOS Shortness of Breath Variable				
IPOS Shortness of Breath	248 (99.6)	30.88*	15.21	62.67
IPOS Psychological Variables				
IPOS Anxiety	248 (99.6)	2.23*	1.29	3.85
IPOS Family Anxiety	247 (99.2)	2.03*	1.20	3.41
IPOS Depression	248 (99.6)	1.94*	1.12	3.39
EQ-5D-5L Quality of Life Variables				
EQ-5D-5L Mobility	248 (99.6)	1.67	0.97	2.88
EQ-5D-5L Self Care	249 (100.0)	1.63	0.89	2.99
EQ-5D-5L Usual Activities	249 (100.0)	1.78*	1.06	2.96
EQ-5D-5L Pain/Discomfort	249 (100.0)	1.19	0.71	1.99
EQ-5D-5L Anxiety/Depression	248 (99.6)	2.63*	1.42	4.90

OR=Odds Ratio, CI=Confidence Interval
*Significant result (CIs do not cross the point of no difference of 1)

In addition, those with chronic breathlessness are approximately twice as likely to experience significant anxiety, family anxiety, and depression than those without chronic breathlessness.

Further, those with chronic breathlessness are about 1.5 times as likely to experience significant mobility issues, self-care issues, and problems with usual activities, approximately 1.2 times as likely to experience significant pain/discomfort, and almost three times as likely to experience significant anxiety/depression than those without chronic breathlessness.

The variables measuring mobility (EQ-5D-5L), self-care (EQ-5D-5L), and pain/discomfort (EQ-5D-5L) did not report a significant result but indicated higher odds of experiencing these factors negatively in those with chronic breathlessness, compared to those without.

4.4.5.2 Step 2 – 2x3 ORs (Binary Logistic Regression and Chi-Square Analysis)

As can be seen in Table 4.6, the OR for chronic breathlessness and shortness of breath (IPOS) shows that there is a “dose response” (increase in OR as impact of shortness of breath increases), and therefore those individuals who self-reported chronic

breathlessness are more likely to have more severe impact of shortness of breath. For this variable, there is a statistically significant dose response in the OR (χ^2 = 106.93, p < .01) (see Table 4.6).

Table 4.6 2x3 OR and Chi-Square for Dose Response

Independent Variable	n (%)	OR	95% CI Lower	95% CI Upper	Chi-square linear-by-linear association	P for linear trend
IPOS Shortness of Breath	248 (99.6)					
Overwhelming		76.00	9.39	615.23	106.93	0.000*
Moderate/Severe		27.87	13.49	57.56	-	-
None/Mild		1	-	-	-	-
IPOS Anxiety	248 (99.6)					
Overwhelming		2.46	0.64	9.50	7.83	0.005*
Moderate/Severe		2.20	1.25	3.89	-	-
None/Mild		1	-	-	-	-
IPOS Family Anxiety	247 (99.2)					
Overwhelming		2.10	1.06	4.16	6.03	0.014*
Moderate/Severe		1.98	1.10	3.56	-	-
None/Mild		1	-	-	-	-
IPOS Depression	248 (99.6)					
Overwhelming		4.14	1.22	13.98	7.39	0.007*
Moderate/Severe		1.66	0.91	3.02	-	-
None/Mild		1	-	-	-	-
EQ-5D-5L Mobility	248 (99.6)					
Extreme		1.32	0.40	4.37	2.38	0.123
Moderate/Severe		1.71	0.99	2.96	-	-
No/Slight		1	-	-	-	-
EQ-5D-5L Self-Care	249 (100.0)					
Extreme		0.57	0.11	2.87	1.03	0.310
Moderate/Severe		1.93	1.01	3.66	-	-
No/Slight		1	-	-	-	-
EQ-5D-5L Usual Activities	249 (100.0)					
Extreme		1.75	0.77	4.02	3.86	0.049*
Moderate/Severe		1.78	1.03	3.08	-	-
No/Slight		1	-	-	-	-
EQ-5D-5L Pain/Discomfort	249 (100.0)					
Extreme		1.68	0.51	5.55	0.72	0.398
Moderate/Severe		1.15	0.68	1.95	-	-
No/Slight		1	-	-	-	-
EQ-5D-5L Anxiety/Depression	248 (99.6)					
Extreme		1.40	0.31	6.44	7.05	0.008*
Moderate/Severe		2.91	1.50	5.63	-	-
No/Slight		1	-	-	-	-

*Significant at p<.01 (IPOS Shortness of Breath, IPOS Anxiety, IPOS Depression, EQ-5D Anxiety/Depression) or p<.05 (IPOS Family Anxiety, EQ-5D Usual Activities) level

Individuals with chronic breathlessness are more likely to have more severe impact of anxiety, family anxiety, and depression, than those without chronic breathlessness, with a statistically significant dose response for these variables (see Table 4.6).

Those individuals with chronic breathlessness are also more likely to suffer with more severe problems with usual activities and anxiety/depression, up to the moderate/severe category, with a statistically significant dose response. However, these two results demonstrate a plateau effect at the moderate/severe groups (see Table 4.6). This means that these two variables suggest there may be a non-linear relationship, but this could be due to group size in the moderate/severe, and overwhelming categories.

Three variables did not report a statistically significant dose response; they were Mobility (EQ-5D-5L), Self-care (EQ-5D-5L), and Pain/Discomfort (EQ-5D-5L) (see Table 4.6). This means that there may not be an observable association between chronic breathlessness and more *extreme* mobility, self-care, or pain/discomfort.

These results support the previous results, as the same variables reported statistical significance across both the 2x2, and 2x3 analyses.

4.4.5.3 Step 3 - Sensitivity Analysis

A sensitivity analysis was conducted on the shortness of breath (IPOS) variable to support the previous split of the categories. In this sensitivity analysis, the variable was split into none/mild, moderate, and severe/overwhelming (see Table 4.7).

A statistically significant dose response was found in the OR ($\chi^2 = 117.27$, $p < .01$). This is similar to the dose response found in Table 4.6 and supports the use of the previous none/mild, moderate/severe, and overwhelming categories (Table 4.6).

Table 4.7 Sensitivity Analysis

Independent Variable	n (%)	OR	95% CI Lower	95% CI Upper	Chi-square linear-by-linear Association	P for linear Trend
IPOS Shortness of Breath	248 (99.6)					
Severe/Overwhelming		133.00	29.94	590.91	117.27	.000*
Moderate		16.29	7.54	35.17	-	-
None/Mild		1	-	-	-	-

*Significant at p<.01

4.4.5.4 Step 4 – Confounding Variables

To account for the impact of other variables, a binary logistic regression was used to adjust for age (see Table 4.8) and sex (see Table 4.9) (separately). Results showed that the dose response for adjusted ORs (age and sex) is similar to the dose response in the unadjusted ORs, supporting the previous 2x3 OR results. Therefore, age or sex does not confound the relationship between chronic breathlessness and each of the independent variables.

Table 4.8 Binary Logistic Regression Unadjusted and Adjusted Odds Ratios for Age

Independent Variable	OR	95% CI Lower	95% CI Upper	Chi-square linear-by-linear Association	Chi-square P for linear trend (Sig.)	Adjusted OR (Age)	95% CI Lower	95% CI Upper	P value (Sig.)
IPOS Shortness of Breath									
Overwhelming	76.00	9.39	615.23	106.93	0.000*	87.79	10.40	741.04	0.000
Moderate/Severe	27.87	13.49	57.56	-	-	30.04	14.06	64.21	0.000
None/Mild	1	-	-	-	-	1	-	-	-
IPOS Anxiety									
Overwhelming	2.46	0.64	9.50	7.83	0.005*	2.34	0.60	9.13	0.220
Moderate/Severe	2.20	1.25	3.89	-	-	2.03	1.14	3.62	0.017
None/Mild	1	-	-	-	-	1	-	-	-
IPOS Family Anxiety									
Overwhelming	2.10	1.06	4.16	6.03	0.014*	2.02	1.02	4.02	0.044
Moderate/Severe	1.98	1.10	3.56	-	-	1.84	1.02	3.34	0.044
None/Mild	1	-	-	-	-	1	-	-	-
IPOS Depression									
Overwhelming	4.14	1.22	13.98	7.39	0.007*	3.99	1.17	13.59	0.027
Moderate/Severe	1.66	0.91	3.02	-	-	1.59	0.87	2.90	0.131
None/Mild	1	-	-	-	-	1	-	-	-
EQ-5D-5L Mobility									
Extreme	1.32	0.40	4.37	2.38	0.123	1.14	0.34	3.87	0.830
Moderate/Severe	1.71	0.99	2.96	-	-	1.60	0.92	2.79	0.099
No/Slight	1	-	-	-	-	1	-	-	-
EQ-5D-5L Self-Care									
Extreme	0.57	0.11	2.87	1.03	0.310	0.54	0.11	2.78	0.464
Moderate/Severe	1.93	1.01	3.66	-	-	1.67	0.85	3.27	0.137
No/Slight	1	-	-	-	-	1	-	-	-

EQ-5D-5L Usual Activities									
Extreme	1.75	0.77	4.02	3.86	0.049*	1.61	0.70	3.74	0.266
Moderate/Severe	1.78	1.03	3.08	-	-	1.67	0.96	2.91	0.071
No/Slight	1	-	-	-	-	1	-	-	-
EQ-5D-5L Pain/Discomfort									
Extreme	1.68	0.51	5.55	0.72	0.398	1.26	0.37	4.38	0.711
Moderate/Severe	1.15	0.68	1.95	-	-	1.09	0.64	1.85	0.764
No/Slight	1	-	-	-	-	1	-	-	-
EQ-5D-5L Anxiety/Depression									
Extreme	1.40	0.31	6.44	7.05	0.008*	1.39	0.30	6.45	0.676
Moderate/Severe	2.91	1.50	5.63	-	-	2.70	1.38	5.27	0.004
No/Slight	1	-	-	-	-	1	-	-	-

*Significant at p<.01 (IPOS Shortness of Breath, IPOS Anxiety, IPOS Depression, EQ-5D Anxiety/Depression) or p<.05 (IPOS Family Anxiety, EQ-5D Usual Activities) level

Table 4.9 Binary Logistic Regression Unadjusted and Adjusted Odds Ratios for Sex

Independent Variable	OR	95% CI Lower	95% CI Upper	Chi-square linear-by-linear Association	Chi-square P for linear trend (Sig.)	Adjusted OR (Sex)	95% CI Lower	95% CI Upper	P value (Sig.)
IPOS Shortness of Breath									
Overwhelming	76.00	9.39	615.23	106.93	0.000*	76.40	9.42	619.49	0.000
Moderate/Severe	27.87	13.49	57.56	-	-	27.92	13.51	57.70	0.000
None/Mild	1	-	-	-	-	1	-	-	-
IPOS Anxiety									
Overwhelming	2.46	0.64	9.50	7.83	0.005*	2.48	0.64	9.59	0.190
Moderate/Severe	2.20	1.25	3.89	-	-	2.21	1.25	3.91	0.006
None/Mild	1	-	-	-	-	1	-	-	-
IPOS Family Anxiety									
Overwhelming	2.10	1.06	4.16	6.03	0.014*	2.10	1.06	4.15	0.033
Moderate/Severe	1.98	1.10	3.56	-	-	1.98	1.10	3.56	0.022
None/Mild	1	-	-	-	-	1	-	-	-
IPOS Depression									
Overwhelming	4.14	1.22	13.98	7.39	0.007*	4.12	1.22	13.93	0.023
Moderate/Severe	1.66	0.91	3.02	-	-	1.69	0.92	3.09	0.088
None/Mild	1	-	-	-	-	1	-	-	-
EQ-5D-5L Mobility									
Extreme	1.32	0.40	4.37	2.38	0.123	1.32	0.40	4.39	0.653
Moderate/Severe	1.71	0.99	2.96	-	-	1.71	0.99	2.96	0.057
No/Slight	1	-	-	-	-	1	-	-	-
EQ-5D-5L Self-Care									
Extreme	0.57	0.11	2.87	1.03	0.310	0.57	0.11	2.89	0.496
Moderate/Severe	1.93	1.01	3.66		-	1.92	1.01	3.66	0.046
No/Slight	1	-	-	-	-	1	-	-	-

EQ-5D-5L Usual Activities									
Extreme	1.75	0.77	4.02	3.86	0.049*	1.81	0.78	4.19	0.167
Moderate/Severe	1.78	1.03	3.08	-	-	1.80	1.04	3.12	0.036
No/Slight	1	-	-	-	-	1	-	-	-
EQ-5D-5L Pain/Discomfort									
Extreme	1.68	0.51	5.55	0.72	0.398	1.72	0.51	5.73	0.381
Moderate/Severe	1.15	0.68	1.95	-	-	1.16	0.69	1.96	0.582
No/Slight	1	-	-	-	-	1	-	-	-
EQ-5D-5L Anxiety/Depression									
Extreme	1.40	0.31	6.44	7.05	0.008*	1.44	0.31	6.63	0.641
Moderate/Severe	2.91	1.50	5.63	-	-	3.00	1.54	5.86	0.001
No/Slight	1	-	-	-	-	1	-	-	-

*Significant at p<.01 (IPOS Shortness of Breath, IPOS Anxiety, IPOS Depression, EQ-5D Anxiety/Depression) or p<.05 (IPOS Family Anxiety, EQ-5D Usual Activities) level

4.4.6 Research Question 5 – What is the impact of chronic breathlessness on activities of daily life?

Almost all participants who reported chronic breathlessness (n=99) stated that breathlessness impacted negatively on their daily lives (22 [22.2%] stated it impacted them ‘always’ and 64 [64.7%] stated it was ‘very often’, ‘often’ or ‘sometimes’). Very few (11 [11.1%]) said that breathlessness ‘rarely’ or ‘never’ affected their day-to-day activities (see Table 4.10).

Table 4.10 Impact of Chronic Breathlessness on Activities of Daily Life Descriptive Statistics

Variable	Chronic Breathlessness Population
Does your breathlessness affect your normal day-to-day activities?, n (%)	n = 99
Missing	2 (2.0)
Never (0)	7 (7.1)
Rarely (1)	4 (4.0)
Sometimes (2)	29 (29.3)
Often (3)	15 (15.2)
Very Often (4)	20 (20.2)
Always (5)	22 (22.2)
Median (IQR)	3.00 (2.00-4.00)
Do you feel anxious or depressed **because of your breathlessness**?, n (%)	n = 99
Missing	2 (2.0)
Never (0)	32 (32.3)
Rarely (1)	15 (15.2)
Sometimes (2)	25 (25.3)
Often (3)	10 (10.1)
Very Often (4)	10 (10.1)
Always (5)	5 (5.1)
Median (IQR)	2.00 (0.00-3.00)
Have you had to give up or change any of the following **because of your breathlessness**?, n (%) reporting the following answers	n = 99
Missing	2 (2.0)
Hobbies	36 (36.4) - included Gardening, Walking, Fishing
Exercise	38 (38.4) – included Walking, Exercises, Biking/Cycling
Family Roles	30 (30.3) – included Looking after grandchildren/babysitting, Looking after family, Shopping
Social Roles	22 (22.2) – included Meeting friends, Going out with family, Can't go out on own
Work/Voluntary Roles	9 (9.1) - included Charity work, Community centre volunteering, Housework/gardening
Sexual Activity	12 (12.1)
Not Give Up or Changed Anything	33 (33.3)

Only thirty-three participants (33.3%) reported that they did not give up or change anything because of their breathlessness. Thirty-eight (38.4%) gave up or changed their exercise, including walking, general exercising, or biking/cycling. Thirty-six (36.4%) gave up or changed their hobbies, for example, gardening, walking, or fishing. Thirty (30.3%) had to give up or change their family responsibilities which often involved looking after grandchildren/babysitting, looking after family, or shopping. Twenty-two gave up or changed social activities such as meeting friends or going out with family; others were no longer able to go out on their own because of their breathlessness. Twelve (12.4%) participants reported that they gave up or changed their sexual activity due to breathlessness, and nine (9.3%) had to give up or change their work or voluntary commitments; this included charity work, community centre volunteering, or housework/gardening (see Table 4.10).

Over half (50 [50.6%]) stated that they felt anxious or depressed *because* of their breathlessness 'always', 'very often', 'often', or 'sometimes'. Of these participants, five (5.1%) reported feeling like this all of the time. Forty-seven (47.5%) participants stated that they 'rarely' or 'never' felt anxious or depressed *because* of their breathlessness, however this may be because they did not feel anxious or depressed at all, or because they attributed the cause of their anxiety or depression elsewhere (see Table 4.10).

Overall, we can see that chronic breathlessness has a serious impact on activities of daily living in the older, frail population.

4.4.7 Research Question 6 – What support do older, frail adults experiencing chronic breathlessness get, in the primary care setting?

Participants self-reporting chronic breathlessness (n=99) reported talking to a variety of professionals or other individuals about their breathlessness (see Figure 4.4). Most respondents (53 [53.5%]) reported talking to a GP, 24 (24.2%) talked to a practice nurse and 14 (14.1%) spoke to a Heart Failure Specialist Doctor about their breathlessness. Outside of the medical profession almost half spoke to family/friends (44 [44.4%]). As can be seen in Figure 4.4, very few participants reported speaking to other health care professionals. Twelve respondents (12.1%) *did not talk to anyone at all* about their breathlessness. Only six (6.1%) stated that they talked to 'other' people, and this

included Other consultants/specialist clinics, Physiotherapists, and, on one occasion, God.

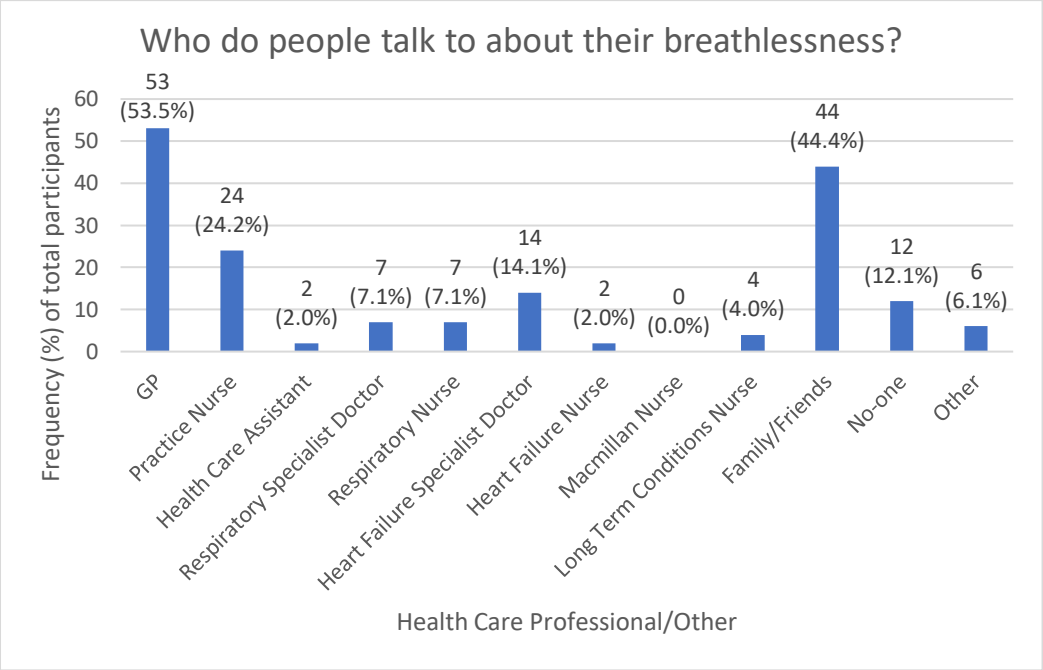

Figure 4.4 Who Participants Speak to About Their Breathlessness

One fifth of participants report seeing a health professional from their GP surgery *about their breathlessness* on a yearly basis, with less attending every six, or three months. Very few participants reported attending every month or week (see Table 4.11). Participants reported (in a free text box) 'other' frequencies at which they saw a health professional at their GP surgery *about their breathlessness*, and the top responses included 'never', 'as needed', 'don't', or 'when it's bad' (see Table 4.11).

Table 4.11 Support in the Primary Care Setting Descriptive Statistics

Variable	Chronic Breathlessness Population
Roughly, how often do you see a GP, nurse, or other health professional from your GP surgery **about your breathlessness**?, n (%)	n = 99
Missing	2 (2.0)
Not Applicable	4 (4.0)
Every week (0)	3 (3.0)
Every month (1)	4 (4.0)
Every three months (2)	14 (14.1)
Every six months (3)	17 (17.2)
Yearly (4)	20 (20.2)
Other (5)	35 (35.4) – included Never (5 [5.1]), As needed (5 [5.1]), Don't (3 [3.0]), When it's bad (2 [2.0])
Median (IQR)	4.00 (3.00-5.00)
Does your GP, nurse, or other health professional from your GP surgery ask you about how breathlessness **affects your daily life**?, n (%)	n = 99
Missing	2 (2.0)
Not Applicable	3 (3.0)
Yes (0)	22 (22.2)
No (1)	63 (63.6)
Not Sure (2)	9 (9.1)
What treatments **for your breathlessness** have been organised by your GP, nurse, or other health professional from your GP surgery **in addition to your usual treatment (e.g. inhalers or heart tablets)**? (tick all that apply), n (%) reporting the following answers	n = 99
Missing	1 (1.0)
Pulmonary Rehabilitation	6 (6.1)
Breathing Exercises	10 (10.1)
Handheld Fan	6 (6.1)
Anxiety Treatment	3 (3.0)
Psychological Treatment	1 (1.0)
Morphine Like Medications	1 (1.0)
Oxygen	10 (10.1)
Other	68 (68.7) – included Inhalers (22 [22.2]) Nothing (34 [34.3])

Despite serious limitations on activities of daily living, *only about one fifth* (22.2%) of participants reported that their health professional asked about the impact of breathlessness on their daily life, with over two thirds (63.6%) stating they were not asked (see Table 4.11).

Very few treatments for breathlessness in addition to usual treatment were organised by health professionals at the participants' GP surgery, with *only four* (4%) participants reporting any anxiety or psychological treatment being organised (see Table 4.11).

Participant responses suggest that the older, frail population experience limited support for their chronic breathlessness in the primary care setting, in spite of its serious impact upon quality of life, psychological factors, and their activities of daily living.

4.5 DISCUSSION

Almost 40% of older adults with frailty attending a holistic assessment in an integrated care clinic self-reported chronic breathlessness. Compared to those without, those with chronic breathlessness were younger, more socioeconomically deprived, more commonly past or current smokers, had poorer AKPS performance scores, had worse frailty scores, and were more obese. Of those with chronic breathlessness, most had breathlessness for at least six months, mostly reported mMRC scores of level 3 or 4, and predominantly had COPD or heart disease.

Those with chronic breathlessness were more likely to experience moderate/severe/overwhelming impact of shortness of breath (IPOS), anxiety (IPOS), family anxiety (IPOS) and depression (IPOS) than those without. Additionally, they were more likely to experience moderate/severe/extreme issues with mobility (EQ-5D-5L), self-care (EQ-5D-5L), usual activities (EQ-5D-5L), pain/discomfort (EQ-5D-5L), and anxiety/depression (EQ-5D-5L) than those without chronic breathlessness. These associations were independent of age and sex.

Those with chronic breathlessness were impacted on a day-to-day basis, and often felt anxious or depressed and often had to give up or change various activities because of it.

General practitioners were named as the most common health professional that participants discussed their breathlessness with, however, some talked to no-one at all.

Some saw their GP or other health professional on a yearly basis about their breathlessness, whilst others never attended or did so only when it was bad. Few participants reported health professionals asking about the impact of breathlessness on daily life, and very few breathlessness specific treatments were received.

4.5.1 Chronic breathlessness Prevalence in the Older, Frail Population

My study indicates that the prevalence of chronic breathlessness in the older, frail population is 39.8%. This is considerably higher than in the general population where the Health Survey for England 2011 (59) determined a prevalence of 15% for males and 26% for females, and in Australia where the prevalence is 9% (6). General population studies of older adults estimate the prevalence of breathlessness to be between 25% and 31% depending on the age cut-off for older age, and the question used to identify breathlessness (78-80). Therefore, my findings show that the prevalence of chronic breathlessness in older adults with frailty appears to be higher than in the general population of older adults.

This is important when we consider the added implications and adverse outcomes of frailty in older adults (83, 84). The serious impact of chronic breathlessness and the limited treatments offered could understandably lead to poorer health outcomes which need to be addressed in this population.

The prevalence of frailty in those over 65 is 10% and increases with age (81). Older, frail individuals have increased risk of adverse outcomes such as falls, disability, long-term care, hospitalisation and mortality (83, 84). The older, frail population is already associated with higher health care utilisation and poorer health outcomes (63). Therefore, serious consideration needs to be given to the supportive care needs of the subset of this population who also have chronic breathlessness, and who are likely to be more at risk of poorer health outcomes. A study examining the prevalence and predictors of frailty in those ≥40 with fibrotic interstitial lung disease (ILD) in a specialised clinic, found that not only is frailty highly prevalent within this population, but it is also strongly and independently associated with severity of breathlessness (86). An Australian study in the adult population (10,072 respondents, of which 30% were ≥60 years of age) found there is a considerable burden of breathlessness among those with

and without respiratory or heart conditions, contributing to overall health (62). Similarly, a study looking at symptom-burden in people with frailty and chronic kidney disease also found that those with frailty (225/353, mean age of 77.7 years) had higher odds of experiencing breathlessness compared to the non-frail participants (87).

Older, frail individuals, also suffering with chronic breathlessness are likely to have complex chronic health problems, which in turn will generate more negative, long-term outcomes. As QoL and function worsen for those with chronic breathlessness (28), taking into account any potential complexities of frailty (such as fatigue, unexplained weight loss, or falls (84) for example) is necessary in order to provide well rounded care.

The increased prevalence and negative consequences of chronic breathlessness in older frail individuals, means that this population needs more targeted support related to breathlessness and its negative health outcomes.

4.5.2 Chronic Breathlessness and the Impact of Psychological and Quality of Life Factors

4.5.2.1 Psychological Factors

Older, frail adults who reported chronic breathlessness experience more psychological problems (anxiety and depression) than those without chronic breathlessness. These are important findings and support previous research which shows that anxiety and depression are increased in those with chronic breathlessness (8, 19), and in the older, frail populations (90).

Anxiety and depression are common in conditions where breathlessness is a symptom, such as COPD, and this relates to increased disability and morbidity, leading to impaired QoL (14). My findings add to evidence that chronic breathlessness is associated with anxiety, depression, and coexisting anxiety/depression reported in a recent online cross-sectional survey looking at these factors across the adult population (19). Anxiety, depression, and coexisting anxiety/depression were present in 6%, 2.7%, and 6.1% of the study population, respectively. Whilst this survey was of the whole adult population, there are similar results in elderly adults in the last year of life, where anxiety and depression are strongly associated with restricting breathlessness (20). A further study also found that breathlessness and depression were mutually associated in those ≥65

with chronic conditions, and that onset, persistent, or worsening breathlessness can increase the risk of depression, or vice-versa (250).

Anxiety and depression are common in older people (251). Data drawn from an epidemiological study (≥65 years) in the USA showed that self-reported shortness of breath was a significant predictor of depression at three year follow up (18). Both anxiety and depression are also associated with pre-frail and frail adults ≥60, where the likelihood of these symptoms is higher once frailty develops (90).

As well as worse psychological outcomes amongst older frail people with chronic breathlessness, my results show that family members of those with chronic breathlessness had twice the odds of experiencing anxiety compared to those without chronic breathlessness. My findings also support broader research which has shown that both patients and family members report breathlessness to be distressing (1); we can see an increased focus in the literature about impact on caregivers in the care and treatment of others' health conditions (252). Both family and friends providing informal care can take on a lot of responsibilities around symptom management, along with practical and emotional support (51). An increase in physical duties, emotional support and treatment plans can impact those family and friends providing informal care physically, emotionally, and socially, leading to poorer physical and mental health (45).

Due to the prevalence of anxiety and depression in those older, frail individuals suffering with chronic breathlessness, and the impact this has on family members, there is an urgent need to better support this population and their carers. Recent literature has called for a holistic/person-centred care approach to chronic breathlessness management (32, 253, 254), which may reduce patient distress and psychological symptoms in those with advanced disease (253).

4.5.2.2 Quality of Life

Chronic breathlessness is associated with poorer QoL (28) and findings from my survey show that chronic breathlessness is also associated with impairment in mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. This indicates that as chronic breathlessness worsens, people limit their daily functions and activities in order to avoid the symptom and its negative effects. This leads to more time in the home and

ultimately becoming housebound (26). A study assessing health-related quality of life (HRQoL) in the adult population conducted by at home surveys as part of the Australian Health Omnibus Survey (26), found that those with chronic breathlessness had reduced physical and mental component scores on the SF-12 (a 12 item health questionnaire). Results show that HRQoL worsened with severity of chronic breathlessness. Older age also indicated greater impact of chronic breathlessness on HRQoL (26).

A recent population based survey aimed to assess QoL and duration of breathlessness in adults (28). The mMRC, EQ-5D-5L, and SF-12 were used to measure breathlessness and QoL. Results showed that those reporting moderate to extreme scores on each of the EQ-5D-5L dimensions (mobility, self-care, usual activities, pain, and anxiety/depression) had higher proportions of mMRC ≥1, compared to those reporting mMRC 0. Greater severity of chronic breathlessness was associated with lower mobility, activity, and pain; however, self-care and anxiety/depression were more impaired in those with more severe breathlessness (mMRC 4). Even though this study includes adults of all ages (and not just older adults), the findings are consistent with mine in that those with chronic breathlessness had greater odds of experiencing moderate to extreme scores on each of the five dimensions of the EQ-5D-5L. However, in my data, ORs for mobility, self-care, and pain/discomfort were not statistically significant. Whilst these findings may not be significant, they are still likely to be important to people experiencing these negative effects. As indicated in the above study (28), breathlessness scores may need to be very severe for mobility and self-care to be impacted to such a degree, and participants within my study may not have perceived their symptoms at such a level (22.2% reported mMRC level 4). It could be that participants actively reduce or avoid physical activities in order to limit any breathing discomfort and that this leads to an underestimation of their breathlessness severity or activity related discomfort (255). Older people with greater impaired function, physical ability, and frailty may be subject to physical limitations (89). For the older, frail population suffering with chronic breathlessness (as one of many possible conditions or symptoms), it is conceivable that a general reduction in physical activities has occurred due to overall health decline. Therefore, older, frail individuals may not perceive higher levels of symptom severity.

Data from my study supports evidence showing the health and social implications for the older frail adult with chronic breathlessness; in particular, increased negative

psychological impact (19) and poorer QoL (28). This could also lead to increased healthcare utilisation and overall decline in health. Therefore, these factors must be considered within general health care by screening for both anxiety and depression in those older frail adults with chronic breathlessness, in the primary care setting. Previous research has validated a quick, ten-minute, self-administered screening tool for depression in those with COPD, to use in an outpatient setting (Brief Assessment Schedule Depression Cards [BASDEC]) (256). Such tools can be given to patients before primary care appointments for discussion in the clinical setting. This would aid the identification of anxiety or depression and could help facilitate discussions about their overall health needs, including treatment and management. Interventions to target anxiety and depression in those older frail adults with chronic breathlessness could be beneficial to their QoL.

4.5.3 Impact of Chronic Breathlessness on Daily Life

Older adults with frailty self-reporting chronic breathlessness experience poorer quality of life and greater psychological impact compared to those without chronic breathlessness, and commonly give up or change their hobbies/activities because of their breathlessness. This shows us the serious negative impact chronic breathlessness has on the general, day to day activities of older adults with frailty; an understanding about this population that has not yet been obtained from prior research.

Regular, every day activities are often difficult to complete for those with chronic breathlessness. A qualitative study of those with idiopathic pulmonary fibrosis (IPF) found that breathlessness was extremely distressing, which prevented or minimised physical activities; simple tasks such as brushing teeth or carrying groceries were more exerting (11). This study was in the adult population but included those aged between 44 and 82. A meta-synthesis of qualitative research exploring the experiences of those with advanced COPD also found that simple everyday tasks (such as walking from one room to another or going to the toilet) were restricted heavily by breathlessness (21). A study investigating breathlessness in community-dwelling adults ≥70 found that more than half experienced breathlessness sufficient to restrict activity (half a day in bed or cut down on regular activities) in their last year of life (20). In the general adult population, chronic breathlessness is related to reductions in QoL, particularly those

areas related to mobility, activities of daily living and pain; self-care was only impacted by the most severe breathlessness (28). In addition, a study looking at breathlessness within older people living in their own home found that breathlessness had substantial impact on function and QoL, where mobility was most affected (13).

In order to prevent further breathlessness, individuals report changing or giving up their activities. Data obtained as part of my PhD show a wide range of these activities, such as gardening, walking, biking, looking after family/grandchildren, shopping, meeting friends, charity work and sexual activity. My results support the first study to describe activities forgone due to chronic breathlessness (31). Whilst in the general population, this study found that as breathlessness worsens, individuals give up a wide range of activities, such as sports (bike riding), gardening, caregiving responsibilities, shopping, visiting friends, sexual activities, and work commitments. These activities mirror those mentioned within my study. Further research including a qualitative analysis of adults between the ages of 54 and 86, described the impact of chronic breathlessness on their daily activities (257). Limitations were shown for activities such as showering and cleaning, and it was found that planning and practical considerations for leaving the house had become difficult; this included social outings and medical appointments due to the physical burden of getting there (257).

An increase in breathlessness is a key factor in the limitation of daily physical activities in COPD patients (258) where lower physical activity, increased breathlessness, fatigue and kinesiophobia (fear of movement), correlated with worsening activities of daily living and QoL (259). In patients with advanced and terminal illnesses, attempts to reduce breathlessness by limiting physical activity led to sedentary behaviours, which in turn decreased physical fitness (deconditioning), and increased anxiety and depression, leading to an overall diminished QoL (1).

Ultimately these limitations on social activities, hobbies and self-care can be viewed as a shrinking life world (260) or life space (31). This can lead to social isolation, which for the older adult with frailty could be detrimental, particularly if they do not speak to anyone about their breathlessness and continue to reduce their activities. Activities forgone may also preclude those individuals from any of the health benefits such activities (such as exercise) may provide. A study of older adults in Japan found that objectively measured outdoor time was associated with both physical and psychological

function, through the use of physical activity (261). Older adults are already at greater risk of experiencing social isolation or loneliness (34), and this can increase the risk of hospital admission in those with respiratory disease (35).

We can see that individuals with chronic breathlessness are suffering on a daily basis, ultimately limiting their activities and engagement with the world around them. Data from my PhD study show that practitioners enquire about the impact breathlessness has on an individual's daily life in only one fifth of cases (research question six), and that half of the participants report being anxious or depressed *because of their breathlessness*. These findings – increased psychological impact and practitioners not actively asking about chronic breathlessness – emphasise the importance that chronic breathlessness and its associated effects are going unaddressed, in spite of the available treatments.

Identifying the *impact of this symptom* on the individual can help to promote understanding, self-management, and symptom management strategies. However, the utilisation of effective management techniques lies ultimately in the successful identification and assessment of chronic breathlessness in the first place, considering the *impact* of this symptom. This can be effectively and systematically conducted within health care settings, by opening a dialogue between practitioner and patient, whereby the practitioner asks, 'How does breathlessness impact your daily life?" or 'Have you had to give up or change anything because of breathlessness?'. A previous systematic review (27) describing the widespread effects of breathlessness highlighted the importance of the practitioner focusing on the symptom as well as the disease.

4.5.4 Chronic Breathlessness Support in Primary Care

More than half of my participants with chronic breathlessness identified their GP as the health professional they would normally talk to about their breathlessness, however, approximately 12% reported talking to no-one. A large proportion of respondents (20 [20.2%]) saw their practitioner only once a year about breathlessness, while others reported not seeing a GP or health professional at all (Never – 5 [5.1%], Don't - 3 [3.0]) or only going 'as needed' (5 [5.1%]) or 'when it's bad (2 [2.0%]). Some participants reported that they went to see their GP about their breathlessness monthly (4 [4.0%]) or even weekly (3 [3.0%]), indicating the serious nature of their breathlessness, and that

their GP was the professional they chose to speak to. Only one fifth of participants reported that their health professional asked about the impact chronic breathlessness had on their lives, and very few participants reported receiving any breathlessness targeted treatments or interventions.

These findings support suggestions that chronic breathlessness is an 'invisible' symptom; not understood by family and friends or even health care professionals (105, 106). Patients may often be comfortable at rest and therefore any effects of breathlessness are not obvious (106). Practitioners seldom ask about breathlessness, and patients do not routinely report it (107), perhaps because they are not afforded the opportunity, and when they are, their breathlessness may be less noticeable and the patient may feel it has no legitimacy (106, 107). Practitioners may often only treat underlying conditions with disease-targeted treatments, but chronic breathlessness still remains invisible and is *not additionally* treated in spite of available treatment options. If it is noticed, it is seen as an inevitable side effect of the clinical condition (107). This is problematic for the chronic breathlessness population as they are not receiving the symptom targeted treatment and management that they need.

There are effective breathlessness related interventions available (pharmacological and non-pharmacological). These include opioids (1), oxygen (123), pulmonary rehabilitation (1), breathlessness services (253), or the handheld fan (1), however many appear underutilised. My findings support the need for increased awareness and use of breathlessness related interventions, as only 10 (10.1%) participants received any breathing exercises, 10 (10.1%) received oxygen, six (6.1%) received a handheld fan, and six (6.1%) received pulmonary rehabilitation. These data are especially surprising when over half of the participants (52 [52.5%]) with chronic breathlessness reported having COPD. The Quality and Outcomes Framework (QOF) in English primary care offers payments if those with COPD and mMRC ≥3 are offered pulmonary rehabilitation (199). Given that two thirds (65 [65.6%]) of the participants who self-reported chronic breathlessness in this study also reported mMRC level ≥3, it is particularly surprising that more participants did not report being offered pulmonary rehabilitation. If this had been offered and received, participants may not have perceived the offer as treatment for breathlessness, but as treatment for COPD or to increase mobility.

Ultimately, identification and assessment of chronic breathlessness is paramount, otherwise this debilitating symptom will go unnoticed and unmanaged, with increased implications for the wider health system. This is particularly relevant for the older, frail population who are already at increased risk of adverse health outcomes (83, 84).

4.6 STRENGTHS AND LIMITATIONS

There are several strengths to the present study. Firstly, my study included the use of standardised assessment tools (IPOS, EQ-5D-5L) for data collection. Secondly, the association between the results of my chronic breathlessness screening question and the shortness of breath (IPOS) question supports construct validity. The screening question was effective in identifying chronic breathlessness in the older, frail population. Thirdly, cross-sectional studies are suitable to estimate the prevalence of a particular disease/behaviour within a population (174) and this study determined the prevalence of chronic breathlessness in the older, frail population. Finally, a number of findings of this survey are consistent with other research and are therefore likely to be applicable to other older, frail populations.

However, the cross-sectional nature of this study is also a limitation as data are only collected at one snapshot in time, and therefore only *associations* between exposures and outcomes, and not *causation*, can be determined. Finally, survey questions were self-reported and as discussed above, some individuals may under report symptoms due to a decrease in physical activities which limits breathlessness (255). This could be the case in the older, frail population who may be subject to reduced function and physical ability (89).

4.7 RECOMMENDATIONS FOR CLINICAL PRACTICE AND RESEARCH

The findings of this aspect of my PhD study have several recommendations.

Firstly, chronic breathlessness needs to be systematically and routinely identified within clinical practice (particularly primary care) for the older, frail adult. The implementation of a simple, single screening question (such as my breathlessness survey screening question - 'Have you suffered with breathlessness for most days in the last month?')

within the patient consultation would be useful for identification of people with chronic breathlessness. Other outcome measures such as the IPOS could then be incorporated into primary care clinical practice, to provide a further assessment of the impact of breathlessness. The first part of the IPOS assesses how much an individual has *been affected by* a series of ten symptoms over the past week. I found that the IPOS (measuring *impact*) could give more useful information – understanding how an individual deals with a symptom – and may be more important than other outcome measures that determine severity (such as the EQ-5D-5L). The IPOS is patient-centred, short, quick, and easy, and could even be given to all patients while waiting to see their practitioner, along with an explanation of what it was and why they were being asked to do it. This could aid discussion in the clinical encounter and help to identify negative psychological and QoL outcomes in those older, frail adults with chronic breathlessness. This would allow more symptom targeted interventions to be discussed between patient and practitioner, therefore enabling effective management strategies to be employed. Therefore, systematic, and routine assessment of chronic breathlessness is necessary within primary care.

Secondly, as breathlessness worsens, so too does QoL. Therefore, impact of chronic breathlessness also needs to be considered. Clinicians need to ask directly how chronic breathlessness affects the daily life of the patient or have discussions about what they have changed or given up due to chronic breathlessness. This can help clinicians understand patient priorities, and in doing so, symptom targeted interventions and management can be organised without delay.

Thirdly, anxiety and depression are prevalent within chronic breathlessness and older, frail populations. Therefore, routine screening for anxiety and depression should also be considered within primary care for those older, frail adults with chronic breathlessness.

Further research could validate the use of my screening question (‘Have you suffered with breathlessness for most days in the last month?’), to screen older, frail adults for chronic breathlessness in the primary care setting.

Additionally, future research could investigate whether improvements in identification of chronic breathlessness (through use of the above screening question) leads to improved management of breathlessness and health outcomes such as psychological concerns and quality of life. This raises further questions about whether improved

identification could lead to better symptom specific management, or perhaps decrease acute-on-chronic breathlessness episodes.

4.8 SUMMARY CONCLUSIONS

My findings show that almost 40% of older, frail adults attending a holistic assessment in an integrated care clinic self-reported chronic breathlessness. The older, frail adult with chronic breathlessness is more likely to experience negative psychological impact and poorer QoL, often giving up activities due to their breathlessness. Within the primary care environment, patients report talking to their GP about their breathlessness but some talk to no-one. Attendance at primary care for this symptom was infrequent, and patients report that HCPs rarely ask about the impact of breathlessness. Few breathlessness specific treatments were received.

Within primary care, there appears to be missed opportunities for chronic breathlessness to be systematically and actively identified and assessed within the older, frail population. Active identification and assessment could avoid adverse psychological consequences and help to deliver targeted interventions. This is particularly relevant given the recently named chronic breathlessness syndrome where recognition is paramount to address an often neglected symptom (7).

In the next chapter I will explore further the psychological impact of living with chronic breathlessness, and older, frail adults, their carers, and practitioners' experiences of identification and assessment of this symptom in the primary care setting.

CHAPTER 5 - THE WIDESPREAD IMPACT OF LIVING WITH CHRONIC BREATHLESSNESS, AND EXPERIENCES OF IDENTIFICATION AND ASSESSMENT OF THIS SYMPTOM IN AN OLDER, FRAIL POPULATION IN PRIMARY CARE: METHODS AND RESULTS

5.1 INTRODUCTION

5.1.1 Chapter Rationale

In chapter four (Quantitative Component), I identified that almost 40% of older, frail adults attending a holistic assessment centre self-reported chronic breathlessness. People with chronic breathlessness were more impacted by psychological concerns and poorer QoL, and more likely to give up hobbies/activities because of their chronic breathlessness, than those who did not self-report chronic breathlessness. Participants mostly reported little support from the primary care setting apart from some examples of good practice with health care practitioners enquiring about the impact of chronic breathlessness. Additionally, very few breathlessness related interventions (e.g. hand-held fan, pulmonary rehabilitation) were reported from patients.

As well as quantitative indicators such as the high prevalence of chronic breathlessness and the missed opportunities for identification, I was also keen to explore psychological impact and experiences of support and management in the primary care setting in more detail. Therefore, in this aspect of my PhD, I explored the psychological impact of living with chronic breathlessness, and older, frail adults, their carers, and practitioners' experiences of identification and assessment of this symptom in the primary care setting.

In this chapter I present the methods and findings of the qualitative component of my mixed-methods study (See Chapter 2: Methodology).

5.1.2 Aims

1. To explore the psychological impact of living with chronic breathlessness in frail older adults and their carers.
2. To explore and understand how older adults with frailty, their carers, and practitioners experience identification and assessment of chronic breathlessness in the primary care setting.

5.1.3 Research Questions

1. How does chronic breathlessness affect psychological wellbeing of older adults with frailty?
2. How do older adults with frailty, their carers', and practitioners experience identification and assessment of chronic breathlessness in the primary care setting?

5.1.4 Objectives

To explore, in the context of the primary care setting, with older adults with frailty, their carers and practitioners:

1. The psychological impact of chronic breathlessness on the older adults with frailty and their carer, in the context of:
    a. Their history of breathlessness, broader impact of breathlessness
2. The effect of chronic breathlessness on overall quality of life of the older adults with frailty and their carer, considering:
    a. Adaptations of activities and other self-management strategies for breathlessness
3. The lived experience in the identification and assessment of chronic breathlessness in the primary care setting, considering:
    a. Patient and carer interaction with primary health care practitioners and services regarding the symptom of breathlessness; views regarding the legitimacy of breathlessness as a reason to consult and how best to address this; and views about chronic breathlessness definitions.

5.2 METHODS

5.2.1 Study Design

A qualitative study using semi-structured in-depth interviews embedded within a larger service evaluation (See Chapter 4: Quantitative Component) was conducted.

5.2.2 Study Setting

Primary care/community based: Service evaluation data were collected at the Integrated Care Centre (ICC); participants were community-dwelling older adults being assessed in a community-based integrated care centre as day cases. Interviews were then conducted in the community (patients' home).

5.2.3 Participants

5.2.3.1 Inclusion and Exclusion Criteria

To be eligible for interview, adults with frailty must have participated in the PACE study who self-reported chronic breathlessness ('breathlessness for most days of the last month') on the screening questionnaire (See Chapter 4: Quantitative Component) along with their carers, and who had mental capacity to provide their own consent.

Consenting health care practitioners (HCPs) who worked in primary care (either at the Integrated Care Centre [ICC] or at an ICC-associated primary care practice) were also eligible to take part.

Failure to meet these criteria led to exclusion.

5.2.4 Ethics/HRA Approval

My study received ethical approval as an embedded component of the PACE project, from the Hull York Medical School (Ref 1825; 3rd October 2018), and NHS Research Ethics Committee (IRAS Project ID 250981; 22nd March 2019).

5.2.5 Sampling, Recruitment and Consent

Seventy-six of the 249 survey respondents self-reporting chronic breathlessness indicated willingness to participate in an interview (as part of the PACE survey). I used purposive sampling of this group according to sex (female/male) and mMRC (modified Medical Research Council breathlessness scale) score (1/2 or 3/4) as shown in Table 5.1.

Table 5.1 Patient Purposive Sampling Grid

Sampling Criteria	Interviews Planned
mMRC 1/2*	10
mMRC 3/4*	10
Female	10
Male	10
Carer Present	5
No Carer Present	15
Total patient interviews	20

**mMRC 1 - Breathlessness when hurrying on the level, or walking up a slight hill*
mMRC 2 – Walks slower than most people on the level, or stop after a mile or so, or stop after 15 minutes at your own pace
mMRC 3 – Stops for breath after walking about 100 yards or after a few minutes on level ground
mMRC 4 - Too breathless to leave the house, or breathless undressing

Eligible patients according to the sampling grid (see Table 5.1) were contacted via telephone and reminded of their involvement in the PACE study and asked if they were still willing to participate in an in-depth interview. At this point they were free to decline involvement, or if they still expressed interest in participating, a preferred time for interview at the patient's home was agreed. At this point, participants were asked if they had a carer (family member/friend) who may also wish to be involved with the interview. If so, and available to confirm, their participation was agreed in principle. On the day of the interview and prior to data collection, participant information sheets (Appendix R) were given with the opportunity to ask questions, and informed consent forms (Appendix S) - which included consent to use an audio-recording device - were signed.

A convenience sample of HCPs working at the ICC (who also worked in primary care) were initially contacted via email or in person with appropriate participant information

sheets (Appendix T) and notified about my PhD study. Four HCPs were recruited to take part in an interview and a mutually agreed time and place was established for this to occur. Three interviews were conducted over the telephone, and one in person at Hull York Medical School. For those who participated in telephone interviews, informed consent forms (Appendix U) were emailed in advance and signed and returned electronically prior to interview. For those interviews in person, informed consent forms (Appendix U) were signed on the day but prior to data collection. For all HCP interviews, opportunities to ask questions were given prior to consent.

One of the HCPs recruited from the ICC provided links with his primary care practice (snowball sampling) where the rest of the practitioner recruitment (six interviews) took place. I arranged a visit where the aforementioned HCP introduced me to a number of others who were interested in participating. I provided information sheets and arranged a time and place (the primary care practice) to conduct the interview, which were all face to face. Consent forms were obtained prior to interview.

Purposive sampling of 20 patients, and a convenience sample of five carers and 10 HCPs were recruited. Five patient interviews were dyads of both patient and carer. Purposive sampling of patients according to predetermined criteria applicable to the research allowed for maximum variation in participants. The concept of data saturation – when no new themes or codes emerge from the data – was not considered a useful concept in relation to my data collection (recently discussed by Braun and Clarke) (184). My specific area of focus meant the number of interviews conducted provided sufficient information power (185), and was also practical within the scope of a PhD.

To the best of my knowledge, none of the HCPs involved in this study were involved with the care of the interviewed patients.

5.2.6 Data Collection

5.2.6.1 Topic Guide Development

Topic guides (one for patients/carers [Appendix B] and one for HCPs [Appendix C]) were developed to direct the interviews. My questions were open ended and flexible, allowing for in-depth answers and the emergence of information which was both relevant to the topic and meaningful to the participant. Each interview allowed for

iterative development to the topic guide (adding new questions/prompts if needed). The topic guide was developed through discussions with my supervisors and advisors including patient and public representatives (see section 5.2.6.2), but also driven by gaps in the literature. A separate topic guide was developed for patients/carers, and for HCPs.

The patient/carer topic guide (See Appendix B) included questions and prompts relating to my research questions such as the psychological impact of breathlessness, history and broader impact of breathlessness, experiences of encounters with HCPs, identification/assessment, treatment and management of breathlessness, how well HCPs understand breathlessness, whether breathlessness is taken seriously, ease of discussing breathlessness, legitimacy of taking symptom of breathlessness to HCP, barriers/facilitators to discussing breathlessness, what is important in the way HCPs listen/help, reasons for not seeing HCPs, and thoughts on chronic breathlessness syndrome terminology.

The HCP topic guide (see Appendix C) included questions and prompts relating to HCP experiences when consulting with someone with chronic breathlessness, how they proceed in the clinical encounter (identification/assessment, treatment, and management), ease of discussing breathlessness, and knowledge/thoughts on impact of breathlessness on patients and others. It also included questions/prompts relating to use of outcome measurements, how do HCPs feel when presented with a person with chronic breathlessness, training, understanding and impact of breathlessness, and thoughts on the usefulness of chronic breathlessness syndrome terminology and the use of this with patients.

Views regarding the terminology and application of the recently named chronic breathlessness syndrome (7) were also sought from patients, carers, and HCPs. This was done to understand whether the concept of a delineated syndrome would make chronic breathlessness more visible, thereby raising awareness and access to support or treatment for this symptom within primary care. This could influence practitioners' recognition of the symptom, and impact patients and carers psychological morbidity. The views from patient or carer populations about chronic breathlessness syndrome terminology have not yet been published.

5.2.6.2 Patient and Public Involvement and Review of Topic Guide

Topic guides were reviewed by two Patient and Public Involvement (PPI) groups: the first was an older adult's support group at the Ings Resource Centre, Hull (21/02/19) with approximately 12 participants, and the second was the Trans Humber PPI Group at Castle Hill Hospital, Hull (19/03/19) with approximately eight participants. Both groups included people over 60 years of age. They reviewed the topic guides and provided feedback regarding how understandable the questions were and whether they made sense for the intended population. Advice going forward was to make sure language was simple and easy to understand, directly to a lay audience.

Once PPI was complete, topic guides were reviewed and discussed by supervisors and other advisors before refinement of the final version. Slight alternations were made to the topic guides as interviews progressed using an iterative approach.

5.2.6.3 Interviews

Interviews with patients were conducted between 05/06/19 and 30/09/19 and lasted between 17 minutes and 2 hours 20 minutes. HCP interviews took place between 08/08/19 and 09/03/20 and lasted between 26 minutes and 55 minutes. All consent forms included consent to use an audio-recording device.

Field notes were made after each interview to document initial thoughts and observations about the interview. This helped to identify emerging topics for discussion and allowed questions for future participants to be considered. Field notes are considered an important function of qualitative research, providing detailed contextual descriptions (262).

I used a process of continuous reflection throughout data collection with the use of a field diary where I noted my thoughts about each interview. I also held discussions with my supervisors about content and questions of interviews; these occurred after patient interview three and ten, and practitioner interview one.

5.2.7 Ethical Issues Arising From Interviews

As the PACE survey also collected data for two other PhD students prior to conducting interviews about their own topic of interest (SP – adverse effects from pain medications, and UN – unintentional weight loss), consideration was given if a participant was eligible to take part in more than one interview. At this point, relevant participants were discussed between the researchers and agreement was made about who should contact them for involvement in their study. If deemed appropriate and not considered too burdensome, a participant was asked if they were willing to take part in another interview about a different topic. If agreed, the other researcher then made contact. This happened once where one of my participants had been interviewed by SP, a number of weeks previously.

For patient interviews, the patient chose the location, and these were all conducted in their homes. For the older, frail population it was practical for me, the researcher, to travel to them and would also help maintain their individual comfort. Breaks were taken when needed, considering those individuals suffered with chronic breathlessness and may be experiencing breathlessness at the time of interview. Consideration was given to the content of the topic guide which may have invoked emotional reactions from patients or carers, and breaks were offered throughout in order to minimise participant burden, especially when experiencing breathlessness. If I, as the researcher felt at all affected by any of the issues during the interview, I sought guidance and support from my supervisor and/or peers.

For HCPs, interviews were offered in person or over the phone to minimise time lost from their workday. Those conducted in person (Hull York Medical School or in the clinical environment) were often more restricted by time; often the interview was conducted in breaks during clinical hours or in the HCP's lunch break. Therefore, some interview questions had to be prioritised, for instance asking each main question with fewer follow ups where time did not allow for more prompts.

All participants (patients, carers, and HCPs) were made aware that they could stop the interview and withdraw from the study at any point should they wish to.

5.2.7.1 Bias

Risk of selection bias was considered throughout my participant recruitment. Views obtained came from a single site in context of the PACE service evaluation and therefore may not be representative of HCPs. Practitioners interviewed were either: GPs with extended roles in frailty working at the Jean Bishop Integrated Care Centre, but also practiced as a GP or a locum doctor in different primary care surgeries; the rest of the practitioners were recruited through the surgery of one of these GPs. It is likely that the GPs who worked at the Jean Bishop Integrated Care Centre may have more skills and qualifications (given their extended role in frailty), than the rest of the practitioners. Most practitioners had similar views about holistic care and treatment of patients. Therefore, selection bias is likely to have occurred within the practitioner recruitment, considering their interest, engagement, and general higher skill set; this may impact on their care and standards of practice amongst patients.

There was minimal selection bias within the patient population. Purposive sampling was used to select participants for interview who matched certain criteria, for instance, similar numbers of male and female along with similar numbers of varying degrees of breathlessness. Those willing to provide consent for interview were therefore a self-selecting group.

Qualitative research typically involves the focused study of a group of individuals who share experiences; findings (showing depth rather than breadth) are therefore concentrated on the contextual significance of the particular phenomenon being studied (173). Thus, whilst the main purpose of qualitative research is not to produce generalisable findings, it is notable that my findings are consistent with findings reported elsewhere and therefore are likely to be applicable to other populations of older, frail adults.

5.2.7.2 Reflexivity

My own reflexivity and bias have been considered throughout this study. My background within the health sector (within research and psychology fields) has allowed me to use my understanding of the impact of long-term health conditions, alongside listening and communication skills, when interviewing patients/carers. Here, I have been

able to objectively listen and appreciate the experiences of others, being patient and respectful to research participants. Further, I reflected on my interviewing skills through discussions with supervisors and other colleagues once I had completed a number of interviews. During analysis, double coding of two interviews also occurred which helped minimise bias. Detailed discussion regarding emerging themes and overall results was also held with supervisors. These steps all helped enrich interpretation of the data.

5.2.8 Data Management and Cleaning

Consent forms were stored in a safe, secure, and locked filing cabinet in an office at the University of Hull, in accordance with General Data Protection Regulations (GDPR) and the Data Protection Act (2018). Participants were also provided with a copy of their consent form for their own personal record. All participants were assigned a unique anonymised participant number (for patients, this was in addition to their anonymised PACE ID) on both paper and electronic records (used on consent forms and interview transcripts).

I was solely responsible for data collection and transcription. Interviews were recorded with the use of a Dictaphone (Olympus Digital Voice Recorder WS-853) and were immediately transferred to a password protected USB upon return to the workplace or home, and then deleted from the Dictaphone. Interviews were transcribed verbatim into Microsoft Word, saved on the password protected USB under their unique participant number, and their content was anonymised (identifiable information removed, e.g. names/services/locations, and replaced with generic terms, e.g. 'husband', 'Location 1'). A list of anonymised words was created in Microsoft Word, and also saved on the password protected USB, separate to the location of the interviews. Anonymised transcripts were imported into NVivo 12 for analysis; NVivo files were saved on a password protected University portal. Audio recordings and transcripts were deleted from the USB once securely stored on a password protected University portal.

5.3 ANALYSIS

5.3.1 Thematic Analysis

Interviews were analysed using Thematic Analysis as described by Braun and Clarke (154). This follows six iterative steps: 1) Familiarisation with the data; 2) Generating initial codes, 3) Searching for themes; 4) Reviewing themes; 5) Defining and naming themes; and 6) Producing the report. This included transcribing and reading each interview to familiarise myself with its contents (step 1), then coding interesting features of the data across all interviews (step 2).

An inductive and deductive approach to coding was used in order to develop themes. The deductive approach used codes which were mapped onto pre-existing conceptual frameworks; in this case the frameworks of Total Dyspnoea (137) and Breathing Space (27) (for more detail see section 2.3: Conceptual Frameworks). An inductive approach was used to code the data to demonstrate views and experiences from participants. Both approaches (inductive and deductive coding) were used here in order to develop new insights from participants, and to build on existing knowledge (183). Initially, I coded two transcripts (one patient and one practitioner) which were also coded by a secondary, independent coder (AH). These codes were then discussed to determine agreement/disagreement, whereupon a coding framework was developed. I then used this framework to code the remaining 28 transcripts. Once all coding was complete, I arranged codes into relevant descriptive themes (step 3), then reviewed and refined those themes with supervisors (step 4). I then returned to the data to check and finalise (including naming) the analytic themes (step 5) and began writing the final analysis (step 6) (154). A reflexive thematic analysis approach was used where engagement with the data and analysis was both reflective and reflexive, considering the development and generation of codes and themes throughout the analytic process (181).

5.4 RESULTS

5.4.1 Participant Characteristics

In total, 35 participants took part in the in-depth interviews. Twenty of these were patients, five of which included a carer (four were spouses and one was a child of patient participants), and 10 were HCPs.

Of the patient interviews, there were nine females and 11 males, eight of whom had mMRC scores of 1 or 2, and 12 with mMRC scores of 3 or 4. Two were conducted as a joint interview as both husband and wife were study participants, both with experience of breathlessness themselves and of caring for their spouse. Patient and carer characteristics can be seen in Table 5.2 (demographic data were collected as part of the PACE study).

The HCPs interviewed (mean age 43 [IQR 39 – 48], range 32 - 52; mean years of practice 15 [IQR 7 - 22], range 4 - 32) were four General Practitioners with Extended Roles (GPwER) in frailty (recruited from the ICC), one General Practitioner (GP), three Advanced Clinical Practitioners (ACPs), one Respiratory Practice nurse, and one Practice Nurse (recruited from one primary care practice).

Table 5.2 Patient Characteristics

Participant Characteristic	**Total patient population, n=20**
Sex, n	
Female	9
Male	11
Age (years)	
Median (IQR)	78.5 (71.5-83.0)
Range	68-92
Number of comorbidities	
Median (IQR)	6 (4.25-7.0)
Range	3-10
Types of medical conditions*	
Most common types of medical conditions *(does not add up to 20 as patients had >1 comorbidity)*	Heart disease – 16 Non-malignant lung disease (e.g. COPD, Asthma, Pulmonary Fibrosis) – 14 Diabetes - 11 Heart failure – 10
Smoking Status, n	
Yes	1
No	7
Ex	12
Living Status, n	
Alone	7
With spouse	11
With ex-spouse	1
Sheltered Living (Alone)	1
Interview with carer, n	
Yes	5
No	15
Carer relationship to patient	
Spouse	4
Child	1

**Conditions categorised as per comorbidities in Chapter 4: Quantitative Component*

5.4.2 Findings

Four main themes (and sub-themes) were developed (See Table 5.3). See Appendix V for themes and included codes.

Table 5.3 Themes and Sub-themes

Qualitative Theme	Sub-themes
Theme 1: The Widespread Impact of Chronic Breathlessness on Patients and Carers	-
Theme 2: Barriers to Optimal Health-Seeking Behaviour and the Identification of Chronic Breathlessness	• Experiences of identification/assessment • Experiences of barriers to effective identification of chronic breathlessness • Use of 'chronic breathlessness syndrome' terminology
Theme 3: Variations in the Clinical Management of Chronic Breathlessness	• Variations in treatment and management • Examples of good practice
Theme 4: The Need for Education and Information about Chronic Breathlessness	• Practitioner's knowledge and expectations of care regarding chronic breathlessness • Patient's knowledge and expectations of care regarding chronic breathlessness

5.4.2.1 Theme 1 – The Widespread Impact of Chronic Breathlessness on Patients and Carers

This theme reflects the widespread impact that chronic breathlessness has on the older frail adult, and their carer, and, in particular, on their psychological wellbeing.

Most patients reported that they had experienced long-term chronic breathlessness (several years), with only a few reporting recent onset of the symptom (within the last year). Most reported a general worsening of their breathlessness over time. Patients reported psychological effects such as depression, anxiety, stress, and fear as a result of chronic breathlessness.

"Well it, sometimes it makes me, real down but I don't try and get, you know what I mean I try and pick myself up and that and think oh well, it's, it's the condition, you've gotta get on with it so" (Patient 1, Female, 70 years)

"I think I just feel, feel worn out you know you feel…..I think it's a frightened feeling really frightened you know if you-you're gasping for your breath you're, you start to, it's a bit bit, bit of a fearful feeling really I think" (Patient 12, Male, 87)

Similarly, carers describe the psychological impact that looking after their relative with chronic breathlessness had on their own lives, reporting feeling frightened, useless, worried, stressed, and overwhelmed.

Interviewer: "How did you feel in that moment when you thought she wasn't gonna be able to breathe, properly, or when you were really panicked?"

Carer: "I was I was completely useless…it's like when [participant] fell in the bathroom…you feel completely, you can't do anything I mean what can you do? You know your, your, your partner's there breathing I had the window open with the wafting at, was trying to get some air and, and and that's when I said, what three in the morning it was, come on in I'm gonna ring, I'm gonna ring an ambulance because she's gonna, she looks if she's gonna die she was (inhales sharply) gasping…And so, it was I was just, you just feel useless. You know it's like, at the time of childbirth you're stuck out of the room when, when when when…you were stuck out the room and you, you did the pacing you know you're just, useless". (Carer 2, Husband of Patient 9)

Patients also reported negative physical effects such as restricted movement or giving up/restricting activities because of their breathlessness. HCPs expressed similar views about patient physical abilities, demonstrating a downwards vicious spiral.

So, of recent erm, of recent times, erm, it's very debilitating, in one sense. Although I can walk about, and I'm fine, I can't stand, because standing won't hold my, my breath won't hold my stance, and erm, I can't get about, without help. So it's, you know it's extremely…debilitating". (Patient 3, Female, 69)

"I could even dance, you know a few years ago I could, even with me inhaler I could, I've got this and I could still get up and dance and you, for a few years now I haven't been able to do that when I've gone out, yeah". (Patient 7, Female, 83)

"Well they just keep they just restrict their life further and further, 'cause they worry more and more about their breathlessness and you know they think if I do that I'm gonna be breathless, if I do that I'm gonna be breathless so, it just erm, it they they gradually sort of their world kind of shrinks doesn't it, they they used to be able to walk down to the shops, now they can't so they only get halfway so they don't bother. And then because they're not doing anything or exercising they they can do less so then they're stuck in the house. And and it's just a downward spiral basically". (HCP 1, GPwER)

Patients also expressed there was a negative social impact resulting from chronic breathlessness. This included not being able to contribute to family activities such as looking after grandchildren, not getting out much or on their own, or stopping hobbies and social activities. One participant expressed how they felt their entire world had changed.

"I can't get out on my own. Because if we er, get a taxi anywhere, my friends have got to come with me. And help me in and out". (Patient 8, Male, 92)

Carer: "It impacts on the family as well 'cause we've got two small grandchildren now and, when they're, playing in the garden and, you know that…".

Patient: "Oh I can't go out with them, hm".

Carer: "You know what I mean, so there is an impact, an an ongoing impact that way so. You know 'cause if we sometimes if we go and we have had a bit of fun time with them…"

Patient: "Oh I can't I can't breathe".

Carer: "…so…they're different things you don't, quantify it until it happens to be honest". (Patient 9, Female,71 and Carer 2, Husband of Patient 9)

"Erm, I feel, to say, er…I just I just say say I'm living in a no world now. There's no decent food, there's no alcohol, there's no sex, there's no driving, you know. Everything is a no". (Patient 15, Male, 78)

Despite the widespread impact of their breathlessness, many patients preferred not to share their feelings about the effects of chronic breathlessness with family/friends, in order to avoid upsetting others.

"I'm er, thinking of meself as well as er, I aren't gonna be bothering anybody anything if you know what I mean. I hate, bothering anybody". (Patient 14, Female, 83)

"No. Erm, even you know our children are in their fifties now. But they're still our children. And, er you know it is silly I know, but, you want to protect them still. Which I know is silly. So, you don't tend to tell them about your ailments and, unless it's…Er so you know, it's not something as a family, we would talk about…unless there was an emergency. And then we would". (Carer 4, Wife of Patient 15)

5.4.2.2 Theme 2 – Barriers to Optimal Health-Seeking Behaviour and the Identification of Chronic Breathlessness

This theme reports the varied forms of identification and assessment used by practitioners and patients in the management of chronic breathlessness. The theme goes on to highlight the barriers to effective identification of chronic breathlessness in the primary care setting in terms of patient health-seeking behaviour, practitioner behaviour and response, and challenges of dealing with chronic conditions. Consideration is also given to the definition 'chronic breathlessness syndrome' and how this could impact the visibility of chronic breathlessness.

5.4.2.2.1 Experiences of Identification/Assessment

Both patients and HCPs report various forms of identification and assessment taking place, from nothing at all, to general observation, to detailed assessment (usually for people with COPD; this may be because specific criteria are stipulated in the Quality and Outcomes Framework [QOF] incentive payments in English primary care). However, the focus appears to be mainly in assessing the cause of breathlessness in disease terms (e.g. ordering further tests such as lung function, x-rays), rather than understanding the severity and impact of breathlessness itself and using this assessment to direct specific interventions.

Interviewer: "…what kinds of tests did they do at the time, did they do anything to test your breathlessness?"

Patient: "No, no".

Interviewer: "Nothing at all?"

Patient: "No they didn't, no". (Patient 7, Female, 83)

"I use the GOLD [Global Initiative for Chronic Obstructive Lung Disease] erm, guidance, so I'm looking at CAT [COPD Assessment Test] scores, MRC scores, I'm looking at erm, you know how many exacerbations they've had, how many hospital admissions they've had". (HCP 8, Respiratory Practice Nurse)

"Oh no this was I went for the, for the cough. Cough, I literally went for the cough. And I mentioned the breathlessness at the same time you see. And, so she sent me for the x-ray". (Patient 5, Male, 83)

There were some examples of good practice regarding attention to the symptom itself. Some HCPs report asking about the impact of breathlessness or having open, holistic chats with the patient.

Interviewer: "And does it ever come up about erm, the impact that breathlessness has on their life, is that something that you discuss with a patient?"

HCP: "Yeah yeah…I suppose I've always done that yeah. Er around things like, you know what does it stop-it is the first question I ask you what does it stop you doing, what could you do, before you were breathless that you can't do now, erm, and that brings out, a lot of the, the sort of, problems that they're getting and and and how it's impacted them. Erm, and often you know if they're with a, a carer or a, a relative or whatever they're they're usually quite happy to tell you what they, they can and can't do now".

Interviewer: "Yeah. So the carer would often speak up at this point as well?"

HCP: "…most of the time in general practice it's usually have people come in twos. Erm, and and they've both usually got their own agendas, so yeah, they're usually quite happy to speak up". (HCP 1, GPwER)

HCPs felt confident that important issues about breathlessness would be volunteered unprompted by the patient, even if not asked directly about day-to-day impact of breathlessness, that is, if it was a concern for the patient, then they would tell the HCP. However, some patients reported that they are not asked about the impact of breathlessness – and do not volunteer this information, perhaps as they expect the practitioner to ask.

Interviewer: "Do you ask specifically about how their breathlessness impacts their life, and, what they have…what they might have had to give up or anything like that, or specifics?"

HCP: "Well erm…it depends, most patients indirectly when you're asking them they they they give you that anyway so, err it it invariably, if you start it off openly and they get chatting, within the first couple of minutes they've basically told you what they can't do and what they miss doing, and then er it I…probably get a bit at the end but er, most, if they're coming presenting with that or that is one of their side problems, within their, informal holistic chat they've basically… it seems fairly forthcoming in most patients that they come out with it. I don't know whether other people, have, said the same but I think…it's one of those things that they it impacts so profoundly on their life, and their

quality of life and affects them, it can't help but come out when you're asking about how they are and what things have happened…it's life changing so they're, it's normally out there fairly quick". (HCP 3, GPwER)

Interviewer: "Do they ever ask about how breathlessness impacts your life and how it, makes you feel and things like that do they ask questions like that?"

Patient 12: "No they, they never do really no".

Patient 11: "No not really no they just seem to do these tests…" (Patient 11, Female, 88 and Patient 12, Male 87 – married couple)

In general, few HCPs report using outcome measures such as the mMRC. Where these were used, they were used by nurses or advanced clinical practitioners as part of chronic disease management (such as COPD reviews). For non-respiratory causes of breathlessness such as heart failure, breathlessness outcome measures were not systematically used by HCPs.

"…so there's the New York Heart Failure erm, rating that we use for breathlessness in heart failure, erm but, (exhale) but do we use it routinely in primary care we probably don't is the honest answer". (HCP 4, GPwER)

"And I must admit the, MRC breathlessness scale is probably something that I don't use quite as often as I should do". (HCP 5, ACP)

HCP: "I like to use the, MRC breathlessness scale 'cause I like the, I like the descriptions on that 'cause I think that's quite…to the point, and an easy read".

Interviewer: "Is that with every patient that you would do that or is that just, depending on the patient?"

HCP: "I do it with every COPD patient. Yeah I don't use it with asthma or anything". (HCP 10, Practice Nurse)

"I think you just erm, you know you're you're asking about what they can manage to do, you're…asking about the MRC score is a good way of…leading into it, erm…and I think the depression score is an important thing cos erm, you know quite often, and the CAT score because you're you're, finding out a little bit more about, how that's affecting them emotionally and also, erm how it's affecting their quality of life so, you know those assessments are, ve-very important as well. It gives you a bit of a more of a, rounded picture". (HCP 8, Respiratory Practice Nurse)

5.4.2.2.2 Experiences of Barriers to Effective Identification of Chronic Breathlessness

Notwithstanding the various forms of identification and assessment of chronic breathlessness, there are broader challenges of managing this symptom in primary care. HCPs report that chronic breathlessness is common in primary care but is difficult to manage.

"Erm, er 'cause it's one of those symptoms that really quite erm…er, it is quite difficult to manage". (HCP 1, GPwER)

"Well, you know it's a common presenting complaint in primary care" (HCP 4, GPwER)

For the older, frail adult, breathlessness is often one of many symptoms and may not always be prioritised, therefore not brought up in the primary care environment perceived by patients as pressured and time constrained. In addition, patients may only report chronic breathlessness in moments of crisis, or as a by-product of another symptom (e.g. cough).

"And the thing is as well I think…because of all the, ailments [patient's] got, I think the breathing, is the bottom of the pile. So if we can get in to see a doctor, it's usually for something else". (Carer 4, Wife of Patient 15)

"I don't go unless I have to go, unless like, I'm really, out of breath…and I'm wheezing and I'm coughing. That's when I go. I mean if I'm breathlessness, I don't, I don't bother with them". (Patient 1, Female, 70)

Interviewer: "How do you think they cope, generally on a day-to-day basis, with breathlessness?"

HCP: "Erm…..it's difficult…I would probably say better than they let on (laughs). Yeah. I think, they cope until it becomes a problem. And then it's, the only problem in the world. Which to them it is i'nt it?". (HCP 10, Practice Nurse)

"…when they book in they usually ask what the reason they're booking in for, so a lot of the time it's on there however, do you know now you've said that a lot of it, a lot of the time it doesn't say breathlessness, it's usually a bit of a by-product of something else. So it's usually when you, when you sort of ask, so they might say I don't know 'Oh my cough's got a bit worse' and then when you ask about breathlessness then they'll sort of say 'Actually yeah my breathlessness been getting worse'. So, there isn't that many people if I'm honest who I can actually think I can go back and they would have booked in with that as a main, symptom. Erm it's normally like a symptom, that's, when you ask about they sort of go 'Oh actually yeah'". (HCP 5, ACP)

When patients do seek care from their general practice, they report difficulty in getting appointments, lack of continuity of care (seeing a different practitioner every time), experience of some practitioners not paying attention (not seeming interested, focussing on computer screen), and not having enough time in appointments – restricting to 'one appointment, one problem'.

It seems to be getting busier and busier. It wa'n't that bad at one time you could get an appointment and you got in". (Patient 14, Female, 83)

"I do feel, or it might be the wrong thing to say but, at the moment, it all seems to be going slightly to pot with the doctor's surgery they've, they've m-mixed in with two or three other firms so they're all bigger now. And things seem to have gone awry. Or, you know er, it's always been difficult to try and get through, er where we are, er, but it seems to be even worse to get through now and when you do get through you never know who you're gonna talk to. And none of the doctors that you're used to seeing for years, are either not there anymore, or moved on or, in fact there's only one there now though since I started going there many years ago that's left. The rest have all sort of retired and, and that so it it's a matter of getting used to them again. But I do think it's not as personalised as it used to be. No-whether that's good thing or bad thing I don't know. Providing they read your notes it should be-shouldn't make any difference. Whether they get time to do that, between patients, is another thing" (Patient 6, Male, 73)

"I've been to doctors and got them not even looked at you, he just he's got his head in the computer you know, not even looked at you". (Patient 13, Male, 76)

"Nah I mean I think the doctors now they're that tight for time and, you know you've got to be in and out like, it's like speed dating with the doctor now" (Carer 2, Husband of Patient 9)

Practitioners also expressed frustration at the inadequate length of appointments, particularly for chronic condition management in the context of poor GP staffing levels in the area (fewer GPs per head of population than the national average).

"…if you actually had more GPs and they had more time, they could do much more of the, sort of chronic disease management and I think that's the way it's going you know, my old practice's got a few nurse practitioners now who do a lot of the acute stuff, which has allowed the GPs to go to fifteen minute appointments which is brilliant. It's made a big difference for them, if only from their sanity point of view rather than anything else.

But it means when they do come in with their breathlessness they can also do a medication review they also have time to say, 'And how's things at home?', 'Do you need a stairlift?', you know that type of thing. So yeah I think we're getting a much, we're getting a much more complex…patient who is living longer with multiple morbidity, and at the moment there isn't the funding and facilities within primary care to manage it". (HCP 2, GPwER)

Interviewer: "Does it, are you frustrated by the time, that you don't have?"

HCP: "Yeah. Yeah absolutely. Erm I've more or less, left normal GP for that reason. Yeah. It it feels too much like firefighting at the minute". (HCP 4, GPwER)

"We need to get some more GPs first but…..I think it's a massive factor, certainly in this area erm, I mean a lot of, a lot of…practices have struggled to recruit so a lot of them have emergency care practitioners, which are great they're absolutely excellent for an acute breathlessness but I think some of the chronic disease work is getting missed". (HCP 2, GPwER)

The 'one appointment, one problem' situation was seen as a particular barrier to reporting breathlessness, such that if breathlessness is not their most important symptom at the time, it may not be mentioned at all.

"There's notice up now, you only see for one specific thing you can't ask them three things. You-you've got to ask them one thing. And and and I mean that makes you think well, I can't talk about anything else. Say if I went to with a problem with me knee. I'd have to just see them for that. I couldn't ask them 'Oh and by the way', they don't want to know". (Patient 12, Male, 87)

Despite these barriers, some patients are able to initiate a conversation about breathlessness and are happy to discuss it, although this may be difficult to do.

Practitioners support this and believe other barriers to discussion of breathlessness may include guilt or attending for a different problem.

"I, I was, I'm always happy to bring it, bring it up. Always". (Patient 3, Female, 69)

"*Well, I find it very easy but I don't talk about it very much". (Patient 8, Male, 92)*

"My experience, I find that people who smoke, don't always like to talk about their breathlessness because I think they feel they have this like guilt thing going on don't they?" (HCP 5, ACP)

Some patients do not see their primary care HCP for breathlessness *at all*, because of the perceived time pressures, or even due to previous poor experiences and loss of faith in them for help with this symptom.

"And I I don't, I don't know I mean…I don't have a very great, great faith in my local GPs to be quite er frank". (Patient 10, Male, 82)

"In fact unless I'm dying you know unless I'm really ill and then I'd ring 999. I won't even bother doctor. Er er I've no patience nowadays with them. (Patient 14, Female, 83)

"Well yeah because it, all the doctor tells me is what I'm I'm already doing. 'Calm down, take your pumps [inhalers], and eventually it'll ease off'. You know it's er, so I know all that, yeah so, why, why why why go? You know". (Patient 13, Male, 76)

Some patients preferred their treatment in secondary care to that of primary care due to time and attention from the HCP.

Patient: "…sort of gives me the impression that it isn't her job [GP] to sort your breathlessness out. It's someone else, a specialist. So that's when they refer you to, different doctors".

Interviewer: "And is that why you choose not to, mention your breathlessness?"

Patient: "Yeah er I won't mention that at all".

Interviewer: "Ok, yeah. Er but you're happy to talk about it when you see the specialist?"

Patient: "Oh yeah yeah I'll tell them. 'Cause they they, usually, sit down and ask you things. They ask you about it". (Patient 12, Male, 87)

5.4.2.2.3 Use of 'Chronic Breathlessness Syndrome' Terminology

Consideration was given to chronic breathlessness syndrome terminology to address issues of visibility, legitimacy, and treatment. In general, patients and carers have poor understanding of the terminology used in 'chronic breathlessness syndrome' and were ambivalent about it, referring to 'being breathless' rather than using medical terminology.

Interviewer: "…so, because you have breathlessness every day, erm, if we think about giving that a name on top of, COPD, so you've got COPD but you're treating it with your, inhalers and things like that, but you're still breathless, so your breathlessness still persists, if we called that, chronic breathlessness syndrome, what do you think about that? What are your thoughts about giving it a name?"

Patient: "I never give it a thought er, well-"

CARER: "Why, is they a name for it? Is that the name for it is it?"

Interviewer: "Yeah it would be so erm-"

CARER: "Well what difference does it will that make to COPD then?" (Patient 13, Male, 76 and Carer 3, Wife of Patient 13)

"Well all I can say, I know with the fibrosis, I have chronic, breathing problems so really, on top I don't think I need any more, reference to it that way". (Patient 14, Female, 83)

Interviewer: "Ok. So I'm just wondering whether you think erm, giving something a name makes it easier to discuss, so-"

P017: "No. I'm just breathless (laughs)". (Patient 17, Female, 80)

Most patients did not identify with the term 'chronic' - understanding this from a lay perspective of 'very severe' rather than merely a description of duration – and therefore too strong to use. Therefore, they felt this term does not apply, or is not meaningful, to them. So despite reporting problems consistent with the definition, they do not identify with it as a specific entity, at least in part because of a sense of inevitability and nihilism about anything that might help.

"Chronic to me always sounds as though that I can't get from A to B 'cause I've got to stop in the middle. I haven't got that". (Patient 5, Male, 83)

Patient: "Well…I don't know chronic breathlessness suggests that one's breathless all the time. But I'm not. I'm only breathless, after, some relatively small measure of activity. Erm, and that doesn't seem to, that seems, in a sense rather more acute than than, chronic, what do you agree about that or not?"

Interviewer: "Erm, well I'm I'm just trying to get whether, trying to see whether it makes sense to you and whether you would apply that to your breathlessness?"

Patient: "No I don't I, I don't think I would say it's chronic. Not yet anyway. Erm…it is precipitated every so often by, but increasingly so that's all. But…chronic um, to me says, (demonstrates exhale) I'm breathless all the time and I'm trying to talk to you and I'm breathless now that would be very chronic as well if I was concerned (said with demonstrated breathlessness). (Patient 10, Male, 82)

"Yeah it's no good it's, like you were saying chronic er breathless syndrome, you can call it COPD, you know, you can call it what you like, it doesn't alter the facts of what you've got, does it?" (Patient 13, Male, 76)

Interviewer: So by saying 'I've got COPD, and I've got chronic breathlessness", that would be easier?"

Patient: "Chronic breathlessness. Yes. Emphysema is a better word, even. 'Cause Emphysema, e-everybody knows what Emphysema means. Because it was, in all the pits and all the, you know in the in, West and North Yorkshire, in all the pits. Erm…they were they all had chronic breathlessness at some point, at the end or the middle of their lives. So, you know like, Emphysema is a really good word".

Interviewer: "Yeah. But chronic breathlessness overall, do you think that's-"

Patient: "Describes the same thing". (Patient 3, Female, 69)

In contrast, HCPs have good understanding and are supportive of the terminology but there are mixed views. Some HCPs believe the definition may help increase patient understanding but others disagreed with labels and believe they have the potential to increase anxiety (although another felt it could help reduce anxiety). Some believed the definition to have more clinical, than patient, benefit.

"I think it gives them something to hang their symptom on. I think er, you know and and and sometimes that's, sometimes that's all patients are actually looking for 'cause once you've named something and they, understand that's what it is, to to some extent it removes a lot of the erm, er what's the word I'm looking for, it removes a lot of the anxiety associated with the symptom 'cause they now know what it is". (HCP 1, GPwER)

"But I don't think then, labelling that as a diagnosis in the, problem pages of patients and then they're going around labelling that and then telling them that, is is only, only useful in our anxiety, stimulant for the patient". (HCP 3, GPwER)

"Err, well, ag-again I'm from a, a scientific background, I've done research and then went into medicine, I think we can over medicalise things and make things that, er, it's got useful, er it's got it's useful points for it but I think we can be…chasing names, diagnosing things, labelling things left right and centre and you miss…miss the patient themselves so I I'm never one for, over labelling things despite my, previous training". (HCP 3, GPwER)

Some HCPs report that the definition would be more useful if they were provided with a framework or criteria for diagnosis, and some agree it would be useful to create better access to services, other resources, and improved management for breathlessness; ultimately helping legitimise their symptom.

"I think it would have to have….erm, fairly clear…erm, er diagnostic criteria if you like. If only just to make sure we don't label people with it and then, find we've missed something". (HCP 2, GPwER)

"I think if it was given a name of its own like this as well I think you could get like a little erm, a little bit of a better clearer management plan, in place so people who come in suffering from chronic breathlessness syndrome we should offer this this this and this then if that don't work we should offer this this this and this. So it's a bit more of a, erm so we've got a bit more of a management plan whereas I think at the moment it's very like uhh, depends on this depends on that and it's all a bit wishy washy, and I think, probably the patients pick up on that as well". (HCP 5, ACP)

"But these people have already got a lot of other things going on, so anything that gives it, more visibility is always gonna help". (HCP 6, ACP)

Some HCPs related the definition to other similar syndromes such as chronic pain syndrome or chronic fatigue syndrome and associate this with management of the symptom rather than treatment of the causal condition.

"It's a bit like chronic pain you know. It presents in a similar sort of way and, it is what the patient tells you it is. Yeah and and and you can see it you can measure it, in fact it's perhaps easier to to ascertain than chronic pain 'cause, you can see it it's there". (HCP 9, ACP)

Lack of adequate assessment, inappropriate health-seeking behaviour (leaving till crisis), barriers to managing chronic conditions in primary care (time pressures, lack of continuity), and different views of terminology, are all barriers to effective identification of chronic breathlessness, reinforcing an invisible symptom within this population. However, we can see that HCPs share in the frustrations expressed by patients, with some also trying to attend to symptoms that might be more important than those initially reported in the consultation. Some HCPs also exhibit good practice in their identification of chronic breathlessness by using outcome measurement, holistic assessment, and observational methods.

5.4.2.3 Theme 3 - Variations in the Clinical Management of Chronic Breathlessness

This theme describes variations in treatment and management of chronic breathlessness reported across patients and HCPs. This includes the variation in techniques and tools for breathlessness management, and examples of good practice.

5.4.2.3.1 Variations in Treatment and Management

Varied types of treatment and management of chronic breathlessness were reported by patients and HCPs. Of note, the patients and HCPs I interviewed were not linked. Types of treatment and management were split between pharmacological, non-pharmacological, and self-directed strategies.

Patients reported receiving pharmacological treatment/management directed at the causative medical condition or infective exacerbations, such as the use of inhalers (main method reported), nebulisers, and antibiotics.

"Well I have a, I have erm, [regular use] inhaler. And I have a blue one [reliever inhaler] as well, which I carry about and I, I use it if I need it, but I very rarely use it, really. Yeah, so I've got a blue one the ordinary one I can use anytime, and the other one I use once a day, it's the [regular inhaler] the, er new one they've given me. And I use that first thing in the morning so I, I don't seem too bad after that you know, it's, pretty good that one. And the other one is just, if I'm out doing and I get a bit, I can just take a puff of that you see". (Patient 12, Male, 87)

"No, only only me nebulator [nebuliser] but I I don't use that often, you know try not to anyway, but er, I have-I have me pump [inhaler], I always have me pump, I've had one in every jacket pocket". (Patient 13, Male, 76)

Whilst HCPs also report use of these treatments, many also discussed potential use of opioids. However, there were no reports from patients about receiving opioids for their breathlessness.

"Erm, and then we would sort of, try to explain all avenues around erm, you know things like home oxygen and erm, and that sort of side of things…try improve the experience. I think the only things we had any, er I suppose, useful kind of, help with were probably around the sort of erm, opiate based medications with patients like that, just just to take some of the anxiety, erm away from the breathing difficulties". (HCP 1, GPwER)

"And er in terms of maximal optimal treatment I suppose if they haven't, er if that doesn't include opiates erm I'd use that as well". (HCP 3, GPwER)

HCPs also report non-pharmacological treatment/management options which were very limited in the patient accounts. These included the use of breathing exercises, calming hand, fan, relaxation, rest, and referrals (e.g. physiotherapy, COPD/pulmonary rehabilitation or breathlessness clinics). Most HCPs referred to the management of patients within the context of COPD. Whilst this was the most prevalent condition within this study population, there were a number who also experienced heart or other lung related conditions.

"And the sort of, there's the non-pharmacological stuff basically to pulmonary rehab, breathing exercises, er CBT [cognitive behavioural therapy], you know using a fan on the face that sort er, getting people to pace themselves better erm, I suppose anxiety management's a lot of it too, erm, and and breathing exercises". (HCP 1, GPwER)

"We refer to pulmonary rehab quite often, erm, so they th-that would probably be one of the first things, but I also give 'em some tips as well that I've sort of picked up along the way that might help. So you know like making a, following the door when they're breathing erm with you know to control their breathing a little bit more erm and like the fan, getting the fan to help them erm just to manage their symptoms". (HCP 5, ACP)

"if people can sort of, focus on something it just helps, helps them relax, that's just just, just anecdotal…I've sort of found it helps people so, well especially when people are anxious, and worried about something so, you know be it a jigsaw be, crafting, model making just summit's [something's] gonna help you, focus on, something other than your breathing 'cause if you wake up and you're breathless, all day long, people tell you that, it it, don't it don't go away it's there, it's there. So you need to try and help manage the anxiety, as well as the breathlessness". (HCP 9, ACP)

Although patients did not report HCPs providing them with non-pharmacological interventions for their breathlessness, patients often worked out their own self-directed management strategies which included sit down/rest, to take things slow, and some

breathing exercises. Other techniques included the use of mobility aids (electric scooters, walkers), exercise (walking, swimming), staying calm, not thinking about it or thinking positive thoughts, or inhalers/nebulisers.

Patient: "There's nothing you can do. Just sit you sit, and eventually it all, sort of calms down".

Interviewer: "And there's no other techniques or anything that you do…"

Patient: "Nooo, no. Maybes take a deep few deep breaths just to, you know". (Patient 5, Male, 83)

"Well as I say I go out on my scooter I'm able to do my own shopping. But its, you know 'cause I don't have to get off the scooter. Most shops today…you know, I go up to [Superstore], from here. Which is about a twenty-minute er, ride. So yeah, 'cause as I say when I first got the scooters the boys said 'Oh Mam you're giving up'. But I said 'No on the contrary it's what's gonna keep me going'". (Patient 4, Female, 70)

"And as I say, when I go to baths, I swim up and down, and if, I start getting out of breath I just…stand in the water till I get me breath back". (Patient 20, Male, 75)

"Try and stay calm, try and think good thoughts, happy thoughts, simple daft things really. You know, what you when you say it out loud it sounds stupid but, what else can you do?". (Patient 4, Female, 70)

An exception was one patient relied heavily on breathing techniques they had been taught by physiotherapists.

"I said, 'Fix a picture, get your television'…I said I go from one corner, and breathe (inhales), then I let it out in the other corner then I breathe into that, in like a picture

frame, and go round…I said that's what me, me, that's what the physios have taught me". (Patient 18, Female, 81)

Religious beliefs and their faith/spirituality were also described by some as a coping strategy when dealing with their breathlessness.

"You've gotta have, beliefs. I said it's no good having my illnesses, and not believing that…I've got longer. I said I aren't give up on life yet". (Patient 18, Female, 81)

"Erm, so no the actual mechanics of my breathlessness…are not really altered by my faith. God's not gonna take that away. Much as I would like him to but (laughs), erm I'm not a special person as such so, he's not gonna work that for me because he's he's, for a very good reasons, he's not doing that at this time. Erm so I I know the mechanics of my breathlessness won't, improve really but it does help me just to, not be fearful, not to panic, as much (laughs). Breathlessness is a terrible a thing and and no matter how strong your faith is, God knows that you're gonna feel, a bit upset about it yeah. So it's not that I don't have the faith it's just, mechanics of it is, bad. Yeah". (Patient 4, Female, 70)

The role of the carer could also be understood as a tool for management. A number of carers reported providing medical or social support to help the patient with their breathlessness. This includes cooking, driving, shopping, attending and keeping records of medical appointments, and understanding the patients' needs for care.

Carer: "And what I've tried to do is I've tried to write things down now. In fact there's a file there that's [patient's] file. Yeah".

Interviewer: "But you keep a, a record basically of, all the different things that have gone on?"

Carer: "Yes. Well I am doing now. More or less. And I've got a file with all the letters and everything". (Carer 4, Wife of Patient 15).

5.4.2.3.2 Examples of Good Practice

There were a number of examples of good practice from HCPs who went 'over and above' for their patients.

One HCP reported an advanced heart failure patient who has attended his clinic for twice weekly appointments for the previous two years (and continues to do so). Due to the patient being optimally managed, the HCP is able to offer nothing more than a comforting holistic chat, which the patient responds well to. However, whilst this is good practice it does not seem to be something which could be offered at scale. Other HCPs also report treating their patients holistically in their appointments, focusing on managing the person as a whole.

"…it's holistic he comes to see me I don't effectively do anything, it's just that chat that gets him through. It's quite frustrating 'cause I can't manage him with anything 'cause he's intolerant of everything. Er, and he's been through the lot so the only support I can give him is just to, have a chat so it goes from, one extreme, to the other". (HCP 3, GPwER)

"I tend to focus on a bit bit of a holistic care so, you know what, you know what is the problem that they're coming to see me for and generally it's either breathlessness, or pain, or they'll mention their breathing 'I can't breathe', so then you're trying to look at trying to manage that and it and, you know COPD brings with it anxiety and depression, you know, more or less guaranteed unfortunately especially longer term, erm, so you're trying and look at the patient holistically and…..try and manage you as as a whole, you know rather than just look at, concentrate on one thing at a time". (HCP 9, ACP)

Another HCP reported using a number of different outcome measures to help provide an accurate picture on the individuals mental health and wellbeing, alongside using

observation skills to assess the patients walking and breathing when getting to the treatment room.

Interviewer: "Erm, and when a patient comes into an appointment to see you and they want to talk about their breathlessness, is it normally the patient that says that that's why they're here or do you have to, figure that out and ask them…about their breathlessness?"

HCP: "Yeah I mean erm…..sometimes they they bring it up but, I always do the MRC score, and I'm also looking at their oxygen and the colour [sputum], and, how they, manage with just walking from the waiting room. So I'm looking sort of you know are they are they breathing fast are they, do they sound wheezy do they so, you're doing like a, like a physical, assessment, of of how they look, erm, and, I think sometimes, you know, erm, they're so used to being like that, possibly sometimes they don't notice it as much as, er like the nurse would really. Sometimes I think they toler-can quite often tolerate, things erm, more". (HCP 8, Respiratory Practice Nurse)

Some HCPs try to provide more follow ups if they think their patient could benefit from further contact. One HCP provides group consultations to help support those with COPD, where patients can learn from each other about their condition. Others spoke about using educational tools, such as providing information, to enable patients and carers to fully understand their symptom, condition, and medications.

"So I, might get criticised by colleagues for doing it but I do follow my patients up quite a lot and I bring 'em back erm, because I think you know if you're you're gonna be thorough and, you know look after 'em properly, I don't think you can do it in a short space of time". (HCP 8, Respiratory Practice Nurse)

"Erm, I've recently set up like group consultations erm, here for COPD. Erm, because I think again, these are a group that, benefit hugely by others, erm and support because quite often, isolation and depression is part of, COPD, because they can't get out maybe

as much or, they're erm breathless and they don't want to, you know erm, exert their selves or, they they can get quite depressed and things so I think erm, I think that sort of support". (HCP 8, Respiratory Practice Nurse)

HCP: "I think education is just massive. It's education all the time".

Interviewer: "Yeah, and that is that the biggest thing that you're dealing with?"

HCP: "I think so, definitely. Yeah even, to technique to the asthma plans, to the COPD plans to, why they're taking their medication and what for and just just basic things like that. Do you know why you're doing something?, do you know what it does to you?...not everybody's like that but me personally if I'm putting summit [something] in my body I wanna know what it's doing and why I'm taking it. Some people'll just walk out this door and, take anything you say as gospel [truth] and, not really know why they're doing it or taking it and, and I don't think that should be the case I think everybody should wanna know, what they're taking and what they're doing and so yeah education all the time" (HCP 10, Practice Nurse)

Some HCPs also report using peer support and discussions with colleagues to provide advice and guidance to improve their own understanding, in order to offer better care to their patients.

"Sometimes they go off and I think is there something else that I could have offered in which case I might speak to one of my colleagues and just say 'I've got this this person's come in, da da da da' and see what they might suggest because, I, we're quite lucky in the situation we've got a lot of clinical practice nurse with different backgrounds and they know about other resources. They might even say 'Oh you can phone this number and maybe get some respite care for them, for their daughter or their son or, whoever's looking after them'. So they know about a lot of other things that are out there in the community that I might not know as a doctor. Erm, so yeah, I would, so sometimes they do leave and I think oh dear I don't know if I've really contributed much but, I would probably discuss that person with someone else". (HCP 7, GP)

Patients believe that having HCPs who are nice, kind, attentive, and take notice, feeling listened to and understood by their practitioner, and getting the right treatment, are all important aspects of the health care encounter.

"Yeah she's a nice kind person. She's got empathy (laughs). A massive thing that you need when you're a doctor". (Patient 3, Female, 69)

"And that's why I love her because it's been easy all the way through. Erm…plus she understands…she understood then and she understands now. And she understands the difference between then and now to it too". (Patient 3, Female, 69)

5.4.2.4 Theme 4 - The Need for Education and Information about Chronic Breathlessness

This theme describes the varied knowledge, management, and expectations of care regarding chronic breathlessness, from the patient, carer, and HCP perspective.

5.4.2.4.1 Practitioner's Knowledge and Expectations of Care Regarding Chronic Breathlessness

Some practitioners demonstrate good knowledge, awareness, and understanding of breathlessness and its impact on both patient and carers.

"Yeah I think I've understood a little bit more about, about the symptom rather than just the sort of, the pathology behind it" (HCP 1, GPwER, after attending a palliative care course about breathlessness)

"I think for most of them, it's, related to mobility. So, they're not, able to get out, they're not able to do as much they become much more, reliant on other people be it their carers, be it their family. Erm, and I think also they, they can get very frightened, erm because

most of them if they're chronically breathless 'cause of failure or of COPD or asthma or something like that, they've generally nearly always had, an exacerbation that's put them in hospital. And I think, that in itself you know, to have to go in as an emergency when you're acutely breathless, and sit in AAU [Acute Assessment Unit] for, goodness knows how long, you know can be quite a terrifying experience, and added to that you know if you can't breathe you think you're gonna die. Erm, so I I think for a lot of patients I think there is an element of fear, erm I can certainly think of a couple of patients who, a percentage of their breathing problem, was anxiety". (HCP 2, GPwER)

"Erm well, it has a huge impact in terms of erm, you know mental wellbeing 'cause often these people cannot do, carry out their hobbies that they're used to, erm you know even activities of daily living are reduced so depending on how bad the breathlessness is people might even struggle with simple things such as erm, you know dressing, washing, and so, I think it impacts not only the physical but the mental health as well. It's harder for, carers to manage them as well…you know it can increase social isolation and all those things that, are important". (HCP 4, GPwER)

However, some HCPs also report feeling as though they do not have enough knowledge about the symptom or techniques for treatment and management. Some report feeling helpless, powerless, and useless, even when exhibiting good general knowledge or confidence about the symptom of breathlessness.

Interviewer: "How well do you think that you understand someone's breathlessness?"

HCP: "…Hmm, probably not very well at all. Erm, I have absolutely no appreciation of what it must be like to be living like that. I can only imagine, and that's probably not even close. Erm, so er er probably not at all. But you try and listen to what they say, you try and, understand the, where where they're coming from. It's not easy though". (HCP 6, ACP)

"…understanding as a symptom and and, is different to our understanding of the pathology behind it. Erm I think, as doctors we're all, quite smug about understanding the pathology but, but that doesn't always mean we can treat the symptom, and and in fact we're often quite useless at treating the symptom, even though we understand what's going on (laughs)" (HCP 1, GPwER)

"…for me as a clinician, sometimes it does feel a bit overwhelming when they come in there and you have to just try and, help them and, they you can see sometimes they're very desperate and frustrated about it, and it's that horrible feeling, when someone comes to you, and you, just sometimes you just feel powerless especially when they're on all the optimal, therapy and they've, been and done that and they've been there and, similar like we get with a lot of chronic diseases the pain management that kind of thing. Just feel, well your heart goes to them". (HCP 7, GP)

Practitioners may experience a lack of understanding about when a disease is optimally managed as they often report wanting to try and find the cause of breathlessness, even when presented with a patient's diagnosis – potentially treating the condition and not the symptom.

"…half of it's just making sure you know what the cause of the chronic breathlessness is so they they mostly come in with a diagnosis but, a a lot of it is is, you know so you spend a bit of time in the consultation trying to find out whether it is that or whether there's something else that's causing the problem" (HCP 1, GPwER)

"Er, it well it depends on the patient I mean it's all very, dependent upon what they present with, and what their history is is this a flare up of their chronic breathlessness erm, that, we're pretty sure it's the same thing just getting worse, exacerbation. If it is then you, you, take a good history it's, revolved around that had it happened before, do they have an infection, are they wheezy, and your typical COPD ones. If it's a new patient, who's never really had breathlessness erm, you've gotta figure out what is causing the

breathlessness, even with the chronic ones you need to make sure it's no new cause of breathlessness that's, summit [something] else flaring up". (HCP 6, ACP)

5.4.2.4.2 Patient's Knowledge and Expectations of Care Regarding Chronic Breathlessness

Patients and carers exhibit a lack of knowledge and low expectations about treatments for their chronic breathlessness. The most reported method of self-management (theme two) was to sit and rest and take some deep breaths (aside from inhaler use). It is possible that patients and carers are not aware of other treatment options, or that they can ask their HCP about them, exemplifying the need for education about breathlessness and its treatment.

Interviewer: "What more would you like them to have done…you don't think they really took it that seriously what more would you like from them?"

Patient: "I don't know really because I don't know really what they could have done. I don't know if they could have give you maybe some, medication to help you breathe, you know" (Patient 9, Female, 71)

Carer: "Well yeah you take you're taking your inhalers".

Patient: "That's all. Yes".

Carer: "Well that's all there is isn't it". (Patient 15, Male, 78 and Carer 4, Wife of Patient 15)

"Erm and also I think educating the family because, you know it must be very frightening if your, you know your mum or dad or whatever can't breathe and you're there witnessing that and then you panic as well and, and you're gonna be ringing 999 and, erm, it maybe educating them about warning signs". (HCP 7, GP)

Most patients show a general lack of understanding about breathlessness, often conflating breathlessness with their condition. They also under-report their breathlessness, perhaps due to normalisation and misattribution of the problem to ageing. Patients lack understanding of this symptom as a reporting priority, as something that can be helped, partly due to the disease focused and time constrained approach of primary care.

"Well it's got a name hasn't it, it got COPD, that's, that is the condition isn't it, breathlessness". (Patient 1, Female, 70)

"I never spoke about it when I first had it. I never bothered. I just thought it was old age". (Patient 8, Male, 92)

"So, well I mean it's probably jut old age really but I I I, that that's my, experience at the moment". (Patient 10, Male, 82)

"So if they've come about their foot, erm and they're come in…out of breath I would probably see it, as essential really that you discuss their breathing, erm, but then they might want to, they've, that's not what they've come about, they've come about something else so it's trying to negotiate with them and say to them, 'Actually I'm more concerned about your chest today, shall we have a talk about that?' or, just trying to cram it, in to the time or, rebook them to come back and discuss something. But it can be it can be difficult 'cause their agenda's not always the same as, our (laughs), what you want to discuss with them". (HCP 7, GP)

One patient felt that education was greatly needed in order to inform others (affected by breathlessness or not) about the impact of this symptom and related conditions.

"So I don't see why, there isn't some kind of fundraising being seen for COPD and and the, all over the place because, there are a lot of people of my age, with this disease, loads of people. And all the smokers in the world have all, are all going to come across this in later life, at some point. And I really do think it's important. Because it's self-inflicted nobody wants to know, but it's not always self-inflicted. My [sister-in-law] never smoked in her whole life has it. You know and she's quite debilitated at times with it. And erm…but people…they'll only conceive what they think won't they, and that's it, you can't help that. But it needs more help I think. I really do. And I hope for the you know like for the future that…it gets that, help". (Patient 3, Female, 69)

Carers show some general understanding of breathlessness, mostly relating to the impact it has on the patient or help with medical management.

"Erm…I think it, it affects, everything in your life I think, breathlessness. Only you don't realise it, till you've got it". (Carer 4, Wife of Patient 15)

"I think it's one of the more debilitating [symptoms], to him. 'Cause he can't do what, he would like to do. Because of the breathing". (Carer 5, Wife of Patient 16)

Overall, patients often still report being happy with the treatment they have received for breathlessness (usually inhalers), demonstrating low expectations and the need for an immediate fix for the problem.

Interviewer: "Do you feel happy with the treatment and help that they've given you?"

Patient: "Yes. In fact I don't think I'd still be here if I had not had it". (Patient 3, Female, 69)

"They're still, despite their reviews and despite telling 'em and despite them coming constantly and, they still want the steroids and they still want the antibiotics and they

still push for it, even though we explain to 'em that it's not gonna happen you need to maintain it you need the, they they want their breathlessness they still want that magic cure for it". (HCP 10, Practice Nurse)

This theme demonstrates the need for further education, information, and promotion about chronic breathlessness and its treatment, to patients, HCPs, and public.

5.5 DISCUSSION

Chronic breathlessness has a wide and burdensome impact on the older, frail adult, and their carer. This population reported adverse effects across psychological, physical, and social domains, often giving up activities to avoid breathlessness. Often they do not wish to share their feelings about breathlessness to avoid upsetting others, and perhaps because they are trying to get on with their lives the best they can without focusing too much on this symptom. Carers often share in the feelings of stress or fear exhibited by those they support.

Various forms of identification and assessment of chronic breathlessness were reported by patients and HCPs, from patient reports of 'nothing' to varying HCP reports of either focussing solely on the disease, with some good practice examples of asking about the impact of chronic breathlessness in detailed holistic discussions. Adequate identification and assessment are restricted by the many challenges of managing this problem in the primary care environment. Despite these challenges, there are some positive examples of care, and patients report being happy to discuss their breathlessness with their practitioner. Chronic breathlessness syndrome terminology was met with mixed views by both patients and practitioners. For the most part, patients were far away from recognising their breathlessness as an entity in its own right as something for which there were specific treatments and understood the term 'chronic' as 'very severe' rather than as 'persistent'. Their breathlessness was something to be stoically managed and part of ageing or an inevitable part of their disease – a concept learned from, or at least reinforced by, a lack of systematic enquiry from their HCPs. Overall, patients had a lack of understanding of the causes of breathlessness, often conflating breathlessness with their condition, and were not aware of the availability of symptom specific treatments.

HCPs had mixed views about a named syndrome, with some being reluctant to 'label', but others believing it would help legitimise the symptom and provide a structure for recognition, assessment and management.

There were variations in the treatment and management of chronic breathlessness, which were split into pharmacological and non-pharmacological interventions. Patients also had various self-management techniques discovered often through their own resources. Most HCPs referred to management of breathlessness within the context of COPD, and there were a number of examples of good practice exhibited.

Practitioners demonstrated good general knowledge about breathlessness and its impact but still feel helpless or useless about its management, even if they portrayed a degree of confidence about the symptom.

5.5.1 Theme 1 - The Widespread Impact of Chronic Breathlessness on Patients and Carers

This theme reports that chronic breathlessness impacts the older, frail adult in a number of ways, primarily psychologically, physically, and socially. This relates to the Total Dsypnea conceptual framework (137) which is discussed in section 5.5.1.3.

5.5.1.1 Psychological Impact

My findings show that psychological impact can include anxiety and depression, and this is consistent with the results from my quantitative survey (see Chapter 4) and previous research that shows these factors to be more prevalent in both the chronic breathlessness (19, 26), and the older populations (20) than the general population.

A cross-sectional online survey conducted in the adult population shows there was an association between depression, anxiety, and co-existing anxiety/depression and clinically important breathlessness (mMRC ≥2) (19). Results from the 2015 South Australian Health Omnibus Survey showed that increasing severity of chronic breathlessness was associated with worsening of both physical and mental health related quality of life (HRQoL) (26). And previous research conducted in older adults (≥70) during the last year of life found that there was a relationship between increasing

breathlessness and anxiety and depression over time (20). My findings add to this research, extending our understanding of the impact of chronic breathlessness in the older, frail population.

My findings support previous literature which discusses the psychological impact of chronic breathlessness on the carer. A study interviewing patients and carers about their experience of COPD associated chronic breathlessness found that carers are often worried and scared when the patient has an exacerbation (52), and a review reports that carers of individuals with COPD also feel fearful of breathlessness itself (53). An earlier study about the experiences of caregivers of breathless patients with lung cancer or heart failure reported a number of factors associated with caregiver burden such as depression, anxiety, and worse quality of life (49). This is similar to a recent review which highlighted the widespread effects of chronic breathlessness on physical and mental health in the carer (27).

5.5.1.2 Physical and Social Impact

As well as psychological impact, my findings show that chronic breathlessness often has a physical and social impact on older, frail individuals as they restrict their movement, eventually choosing to give up activities to prevent further breathlessness. They are no longer able to look after family members (e.g. grandchildren) and are less likely to get out of the house much or on their own.

My results show that older, frail adults are often giving up activities *because* of their breathlessness. Similarly, a general population survey showed the progressive limitations on activities caused by worsening chronic breathlessness (31). This paper reported on the activities people gave up due to their breathlessness, and most were hobbies or recreational activities; similarly reported here in my findings, and in my previous chapter (See Chapter 4: Quantitative Component).

The long-term effects of physical and social impact of chronic breathlessness could be detrimental to the older, frail population. Ultimately, a lack of activities and restricted movement can decrease functional performance resulting in deconditioning (4). A reduction in activities can lead to social withdrawal and a downward spiral of frustration, loneliness, and depression (4). These factors all reinforce each other, as demonstrated

in the Breathing, Thinking, Functioning model (193). This downward vicious spiral is demonstrated in my findings in reports from HCPs about the impact of chronic breathlessness. Previous research using a longitudinal data set found that social isolation is associated with increased risk of hospital admission for older adults with respiratory diseases (35).

5.5.1.3 Consequences for the Older, Frail Adult

The impact of chronic breathlessness on the older, frail adult and their carer is extremely important. My findings can be contextualised within the conceptual framework of Total Dyspnoea (137) (see section 2.3: Conceptual Frameworks for more details) which is categorised by four domains (psychological, physical, social, and existential/spiritual) showing an increased and substantial impact on the individual. We can see that the widespread impact of this debilitating symptom leads to increased psychological factors (anxiety, depression, fear, stress) and physical factors such as restricted movement, and a decrease in quality of life (giving up/restricting activities). This in turn could lead to a loss of independence (impacting social factors such as being unable to contribute to family/social activities and not getting out on their own) and a restricted life space for the patient (263) and potentially the carer. Not sharing thoughts or feelings about breathlessness with family, friends, or practitioners, means that breathlessness becomes a solitary burden. Loneliness is a consequence of social isolation and is also common amongst older adults; this may be detrimental to overall health (264) and result in high utilisation of health care resources (265). This could be considered a downward vicious spiral, where domains (physical, social, psychological) are interlinked and impact each other with added factors such as social isolation and loneliness contributing. However, we can also see that this downward vicious spiral can help some patients figure out how to self-manage their symptom and condition - by engaging with coping strategies such as rest, breathing exercises or religious beliefs - and relates to the engaged coping domain of the Breathing Space conceptual framework (27).

Increased attention through systematic assessment and routine enquiry (about chronic breathlessness and related factors) should be placed on the older, frail adult with chronic breathlessness, especially when suffering with additional symptoms such as anxiety or depression.

5.5.2 Theme 2 - Barriers to Optimal Health-Seeking Behaviour and the Identification of Chronic Breathlessness

5.5.2.1 Identification and Assessment of Chronic Breathlessness

Results in my study show that there are various forms of identification and assessment reported from both patients and HCPs. The most common form of identification/assessment was disease-focussed investigatory tests such as lung function tests (spirometry), and very few patients reported receiving 'nothing'. Some HCPs reported not actively using outcome measurements like the mMRC (although some did), despite its ease of use (116). In contrast, some HCPs did use the mMRC regularly, but this was done so by practice/respiratory nurses or advanced clinical practitioners when conducting COPD reviews, this is part of the Quality and Outcomes Framework (QOF) (a financial incentive payment in English primary care). Some HCPs may feel recording an outcome measurement to be more beneficial when patients return regularly.

Chronic disease management reviews - such as those used for COPD – could provide a 'ready-made' infrastructure or model to provide the basis for good breathlessness identification and assessment *in all patients with conditions which cause breathlessness*. However, any connection to breathlessness interventions in COPD has only recently been added (previously measurement alone was sufficient to receive the QOF payment) where payments are now attached to identification (breathlessness assessment of mMRC breathlessness scale ≥3) and additional offer of pulmonary rehabilitation (199). Identification *with* follow up intervention is important. However, this scenario is still far away from a holistic assessment and other diseases such as heart failure do not receive anything similar.

Within the primary care clinical setting, some HCPs reported asking about impact of breathlessness in open, holistic discussion. However, many HCPs relied on the assumption that important or relevant factors related to breathlessness will be raised by the patient without specific prompts, whereas patients may expect to be asked and therefore do not readily volunteer. There is a mismatch between the HCP belief in what will be raised in clinical practice, compared to evidence which suggests that breathlessness is largely invisible due to assumptions that it is an inevitable part of

ageing or disease progression with no therapeutic options in its own right, possible feelings of guilt (e.g., smoking), and potential non-response from HCPs (often as a result of health care system barriers) (106). In addition, other evidence suggests that patients tend to present only a small proportion of even serious concerns in response to open questions, compared with much greater disclosure on systematic questioning (108).

5.5.2.2 Barriers and Challenges to Accessing Primary Care

I identified a number of challenges to the appropriate management of chronic breathlessness in primary care. Ultimately, for the older, frail adult, breathlessness may be one of many symptoms and not always prioritised given the perceived pressures, potentially only reporting in moments of crisis. Difficulty getting appointments, lack of continuity of care, practitioners not seeming interested or not having enough time only add to the barriers to health-seeking behaviour. Practitioners reflect the frustrations of patients about length of appointments, reporting lack of time (particularly for chronic condition management) as a perceived barrier to care.

These challenges are reflected in an exploratory qualitative study which interviewed older adults (mean age of 70) with COPD about their experiences accessing primary care services (266). Barriers such as difficulties accessing the practice, poor response to telephone calls, delay in prescribing medications, lack of continuity of care, feeling as though there was little the doctor could do and not wanting to bother them, all impact help-seeking behaviour (266). Guilt and stigma due to lifestyle factors and the inevitability of breathlessness also play a role in its identification and treatment (106, 267).

Further, a number of recent studies have shown evidence that good continuity of care is associated with lower use of out of hours services, fewer hospital admissions, (268) and lower mortality (268-271). A longitudinal cohort study of 1712 older adults (≥60 years of age) in the Netherlands also found that low continuity of care was associated with a higher risk of mortality (272).

A paper reporting insight from respiratory trainees (273) about difficulties discussing breathlessness explains that one reason (perhaps not reported extensively in the literature) for not discussing this symptom with patients is simply that clinicians find it

difficult to do so. The feeling of being overwhelmed by patient accounts and concern to find a solution - whilst also attending to other symptoms and treatment – leads to avoidance of the topic. Time restraints and lack of knowledge/awareness of resources external to the outpatient setting added to these already demanding barriers (273). This is not a UK only issue. Practitioners in India interviewed about the recognition, assessment and management of chronic breathlessness syndrome also actively avoided the topic due to feelings of distress and uselessness (109). This was reflected in my study where HCPs reported feeling hopeless, useless, or overwhelmed when presented with chronic breathlessness.

Breathlessness is not often the most prioritised symptom and may only be reported in times of crisis. Some patients do not actively seek help from their HCP about breathlessness at all, having little faith in them to adequately attend to the symptom. A number of patients in my study expressed that they should just 'get on with it', and whilst this may be interpreted as stoicism, perhaps it relates to a fatalistic attitude towards their symptom, believing in the therapeutic nihilism that nothing can be done. Patients may believe that if something could be done about their breathlessness, then their doctor would ask directly - as they report this does not happen, then they have to manage the best they can. My data demonstrating that patients predominantly seek medical advice for their breathlessness in times of crisis (both patients and HCPs support this notion), with some patients not seeing their practitioner *at all*, reflects the help-seeking behaviour domain of the Breathing Space conceptual framework (which demonstrates actively seeking help for breathlessness or only doing so in times of crisis) (27).

These barriers are a challenge for both patient and HCP who wish to experience/provide holistic, person-centred care. The current model of primary health care, incorporating the 10-15 minute appointment with a potential 'one appointment, one problem' model, based heavily on treatment related to the reactive, biomedical model of care, demonstrates how it is difficult to manage chronic symptoms and potentially associated multiple long-term conditions in this setting. However, findings from my study support that some HCPs try to attend to more urgent symptoms than those initially reported, for instance one HCP commented on how they addressed a patient's breathlessness when they had attended for another reason.

Within my study, for these older, frail adults, chronic breathlessness was just one of several symptoms and medical conditions. Recent research has identified that, for those individuals with multiple long-term conditions, not all require the same type of care within the primary care setting, and that different elements of person-centred care may be more important to some patients than to others (274). This allows HCPs to tailor their care for each individual, attending to symptom as well as disease; this reflects the clinicians' responsiveness domain of the Breathing Space conceptual framework (27) where clinicians are responsive to breathlessness and underlying disease. Furthermore, person-centred care for those with respiratory disease has been found to be the most effective way of increasing QoL, clinical outcomes and diminishing ineffective care (32). In those with advanced disease and chronic breathlessness, holistic services demonstrate an overall positive effect on breathlessness related distress and psychological health (253). A recent study targeting exertional breathlessness in order to improve physical activity in those with COPD (275) concluded that an holistic approach to management (including smoking cessation, pulmonary rehabilitation, and psychological therapies, alongside pharmacological treatments) would be most beneficial.

5.5.2.3 Chronic Breathlessness Syndrome Terminology

The term 'chronic breathlessness syndrome' was poorly understood, not meaningful or welcomed by many patients and carers; the word 'chronic' in particular was strongly disliked by patients. A term more understandable to patients, such as 'persistent' may be more relevant. In addition, the lack of welcome may be because patients don't understand that breathlessness is something that can be helped, or that the symptom is distinct (including as a therapeutic target) to the disease: patients conflated the two. This feeds into the concept of therapeutic nihilism that nothing can be done. People with serious illness try hard to carry on and manage the best they can in spite of it, not focussing on, or burdening their families or GPs with it. Therefore, what is the point of labelling it? However, if breathlessness was understood as something that could be helped, then they may have a different outlook – that it is something that can be recognised, assessed, and managed, supported by health services as necessary. Patients thought that terminology and definitions had no benefit and did not matter to them, as

this would not change the fact that they were going to breathless anyway. This demonstrates the gap between patient experience of chronic breathlessness and accessing clinical care. A lack of belief that something can be done leaves chronic breathlessness un-named and un-seen.

While practitioners had mixed or differing views about this term - and some did not agree with labels due to their potential to increase patient anxiety - some felt the definition would be useful in order to increase patient understanding, and to create access to better services and therefore management; naming the symptom would help legitimise it. Some practitioners expressed thoughts about the parallels between chronic breathlessness syndrome and chronic pain syndrome, appreciating that management of the symptom is paramount. The initial concept of 'chronic breathlessness syndrome' shared this consensus about the need and benefits for naming and defining this syndrome (7). A study using hypothetical scenarios to treat chronic breathlessness or chronic pain found that fewer physicians recognised the need for, or offered, treatment in the chronic breathlessness group compared to the chronic pain group (110). Other research has shown that a significant proportion of individuals with COPD have persistent breathlessness despite optimal treatment of the underlying pathophysiology (chronic breathlessness syndrome), but that little was being done - or seen as needing to be done – about it (111, 112). This raises awareness of the significant problem of chronic breathlessness, bringing it more into view.

My findings relating to HCP's views about this syndrome support a recent study which interviewed practitioners in India about the recognition, assessment and management of chronic breathlessness syndrome (109). All physicians interviewed believed that the delineation of chronic breathlessness as a syndrome would allow practitioners to increase their skills in the management of breathlessness and would allow for more research into its cause and management. The physicians also agreed with the similarities with chronic pain syndrome, appreciating that symptom management, service development, and research could advance if chronic breathlessness syndrome had a similar approach (109).

To my knowledge, my study is the first to investigate patients and carers thoughts about the definition 'chronic breathlessness syndrome', and broader challenges in chronic disease management, after the terminology was established in 2017 (7). As most

patients did not agree with the term ‘chronic’, we need to understand that this word is not understood in the lay public as well as in the medical community (chronic as ‘very severe’ rather than ‘ongoing’). Therefore, further work in this area should use more easily understood terminology, such as ‘persistent breathlessness syndrome’, which may be more patient appropriate.

5.5.2.4 Overcoming Barriers to Care

Invisibility of chronic breathlessness is a key issue. The active reduction in health-seeking behaviour, a lack of adequate assessment, barriers to managing chronic symptoms in primary care, and understanding of chronic breathlessness as a syndrome, all create difficulties in the effective identification and assessment of chronic breathlessness, ultimately reinforcing an invisible population – as evidenced by the response from patients and carers in my interviews. In order to move forward, reduce and overcome these barriers, and better identify chronic breathlessness, a symptom focused integrated (holistic) approach to symptom management should be promoted amongst HCPs (32) for use in primary care with older, frail adults. This approach to person-centred care would ensure the best individualised care possible, allowing for better recognition and management of chronic breathlessness, particularly for an already vulnerable population. Some examples of good practice related to this were demonstrated in my results, where HCPs used observational skills to monitor patients as they were coming from the waiting room, or where they identified someone with breathlessness and brought this symptom up the priority list.

Use of a named and defined syndrome as part of a framework for recognition, assessment and management for primary care practitioners would be helpful, such as the Breathing, Thinking, Functioning clinical framework already developed to support breathlessness management (193). Further, the model of chronic disease management reviews used as part of the QOF framework (described above in Theme 2, section 5.5.2.1) could be adapted for use in patients with breathlessness as a result of other conditions, where identification of breathlessness could trigger review and application of interventions.

5.5.3 Theme 3 - Variations in the Clinical Management of Chronic Breathlessness

The results from my study show the disparity between patient and HCP accounts of treatment and management of chronic breathlessness in the primary care environment. Ultimately, there is a gap between provision reported by the HCP and that received from the patients. The mismatch illustrated here raises the question as to whether this group of older, frail adults with multiple long-term conditions are particularly 'invisible'? Additionally, this may also be in part due to potential bias in my sample of HCPs who were all either working at the ICC as a GPwER (alongside a regular practice) or belonged to a related primary care practice. Those working at the ICC were interested in treatment of older, frail patients (belonging to practices that supported their interest and expertise in frailty), and all HCPs were interested in holistic treatment. Therefore this may partly explain the difference in the accounts of treatment/management given by HCPs compared to patients.

5.5.3.1 Pharmacological Treatments

Pharmacological methods discussed refer mostly to the use of inhalers; no patients refer to the use of opioids for breathlessness, but half of the HCPs do describe this as a potential treatment.

The recent definition of chronic breathlessness as a syndrome (disabling breathlessness that persists despite optimal treatment of the underlying pathophysiology) (7) has emphasised the importance of optimised disease treatments alongside breathlessness targeted interventions (276). There is evidence that additional pharmacological interventions, such as opioids, are beneficial for breathlessness, with the aim of reducing the subjective sensations of this symptom (276). The Australian Therapeutic Goods Administration has (February 2019) approved use of sustained-release morphine (Kapanol) for the treatment of chronic breathlessness (276). However, this should only be used when the underlying conditions have received optimal treatment and when non-pharmacological treatments are not effective (277). In contrast to the increasing evidence base for the use of opioids for breathlessness, my findings showed no patient reported accounts of their use, despite some practitioners stating it was a viable treatment. This is reflected in a previous study of COPD patients (n=120) in a tertiary

care centre (112) where 52% of pulmonologists who responded to a survey about breathlessness management stated they were willing to prescribe opioids for chronic breathlessness, however, none of the study patients received such treatments (112).

Similarly, a recent systematic review reported the variation in opioid use in clinical practice (278). This showed that clinicians were hesitant to prescribe opioids for breathlessness due to fear of adverse effects such as respiratory depression, lack of knowledge and experience. In patients, reluctance often resulted from a lack of knowledge and poor information or communication about opioids (278). In contrast, previous research shows that some patients with advanced COPD (and their carers) felt opioids provided a sense of calm and relief, improved anxiety or depression, and improved overall QoL (279).

5.5.3.2 Non-pharmacological Treatments and Coping Strategies

HCPs refer to non-pharmacological treatments such as pulmonary rehabilitation, handheld fan, breathing exercises, referrals to other services, and relaxation techniques; but again there is little reference to this from patients from their own experience, again indicating variation in practice and experience. Most patients relied more on their own self-management techniques, predominantly to sit and rest, but some did use breathing exercises including one who relied heavily on their daily use. This participant was taught by a physiotherapist, but it was not evident whether the physiotherapist was referred from primary care services or elsewhere, although use of these exercises is still important. Further, others used their faith/religious beliefs as a management strategy to help cope with their breathlessness. The self-management reported here is evidence of patients coping strategies and reflects the spiritual/existential domain of the Total Dyspnoea conceptual framework (137) through the use of religious beliefs, and the patients' coping domain of the Breathing Space conceptual framework (27) through the use of self-management techniques such as sitting and resting, and use of breathing exercises (see section 2.3 for more details on conceptual frameworks).

Despite an increasing evidence base for their use, no patients in my study reported routine use of a handheld fan for their breathlessness. This may be because patients or HCPs do not fully understand their importance. The HCPs in my study, although

expressing knowledge of these methods, did not express detailed knowledge of how they may be used. A recent qualitative study with specialist respiratory clinicians (280) has shown poor implementation of the handheld fan due to a number of barriers, such as lack of clarity regarding whose role it is to implement, what advice should be provided to patients, and limited access to fans in hospitals (280). A recent systematic review (281) about implementation of the fan and mobility aids also identified barriers to fan use by patients which included appearance and credibility of the fan, stigma, and technical specifications (281). Previous research has also shown that the way an intervention is delivered by the clinician will influence the outcome; for example if a fan is handed to patients without detailed instruction, then it may not be effective (282). A secondary analysis using pooled data from two RCTs in people with chronic breathlessness aged 65-76 found the fan to be helpful for most and was also perceived to increase physical activity (283). Handheld fans are beneficial in the symptomatic management of breathlessness, easy to use, and have no adverse effects (284).

5.5.3.3 Examples of Good Practice

A number of examples of good practice were reported by the HCPs involved in my study. However, the HCPs were mostly from one primary care practice where there was a focus on holistic care (and affiliated with the ICC). Whilst this is an example of good practice exhibited on an individual level, the question is whether this type of care can be transferred to other general practices? This may not be feasible as is illustrated in previous research showing that patients often receive little support in terms of breathlessness management from their primary care practitioner; this shapes patient future help-seeking behaviour often resulting in the decision to present to the emergency department (285). As evidenced in theme two, for individuals with multiple long-term conditions, person-centred care may be more beneficial (274). The primary care practice and HCPs involved in my study seem to be demonstrating an approach to holistic, patient-centred, individualised care, for those with chronic breathlessness. In the case of the individual who attends his GP twice a week, this may contribute to his overall wellbeing by decreasing loneliness and social isolation, albeit over-utilising his primary health care needs (265).

In the main, the treatment and management of breathlessness discussed between patients and practitioners in this study was within the context of COPD. This is consistent with the results of my systematic review (192) (See Chapter 3) and my quantitative study (See Chapter 4) where COPD was the most common condition reported. It is evident that other conditions with similar symptoms may be able to learn from the already developed treatment pathways and resources applicable to COPD.

The examples of good practice and the holistic nature of treatment portrayed by some practitioners provides evidence for the clinician responsiveness domain of the Breathing Space conceptual framework (27), demonstrating that HCPs were responsive to both the underlying disease *and* the symptom of breathlessness.

5.5.3.4 Bridging the Gap

We can see that my findings report on the disparate accounts between patients and HCPs in the treatment and management of chronic breathlessness. Here we need to consider the epistemic injustice that is exhibited by this gap in information sharing and communication. Epistemic injustice (286) can be divided into testimonial injustice which occurs "when prejudice causes a hearer to give a deflated level of credibility to a speaker's word" (286), so an individuals' testimony may not be considered when the decision has to be made by another; and hermeneutical injustice which occurs "when a gap in collective interpretative resources puts a speaker at a disadvantage when trying to make sense of their social experiences" (286), whereby there may not be a shared understanding of a particular phenomenon to interpret that experience fully. If we consider this in terms of chronic breathlessness, we can see that there is a divide in the information and communication between patient and practitioner regarding this symptom, and this lack of understanding is where epistemic injustice is evident. The patient does not mention it because they think nothing can be done, and if there was something to be done then the practitioner would ask. In addition, the practitioner does not ask because they feel helpless that nothing can be done, and because if it were a problem then the patient would ultimately bring it up. Hence, the invisibility of the chronic breathlessness population is reinforced. As mentioned in theme two, use of terminology such as persistent (rather than chronic) breathlessness syndrome may be beneficial to help engage patients with bringing this symptom into light.

Chronic breathlessness is often a challenging symptom for management by HCPs, and this can lead to communication difficulties and ultimately the invisibility of this symptom (106), creating a bigger gap between patient and practitioner. In order to bridge this gap in communication, increased information sharing is needed between these two groups, and should apply to all aspects of primary health care. The following would help facilitate this: naming and defining the problem itself (chronic/persistent breathlessness syndrome); educating and training practitioners about chronic breathlessness; and teaching practitioners to systematically enquire, assess, and manage this symptom.

5.5.4 Theme 4 - The Need for Education and Information about Chronic Breathlessness

5.5.4.1 Practitioners' Knowledge

My results show that despite HCPs demonstrating good, general knowledge about breathlessness in the main, they reported not having enough knowledge about its treatment or management, often feeling helpless or powerless in the face of this symptom (and patients do not often present with it as the main reason for consultation). Perhaps this is related to the HCPs confidence and belief in the efficacy of the treatment, or lack of knowledge of how to implement these treatments or associated management. For example, few HCPs explained how they would instruct someone to use the handheld fan or breathing exercises and some discussed further use of diagnostic testing to make sure there was no new cause of breathlessness. Furthermore, they may lack skill/knowledge of when the disease is optimally managed (often relying on diagnostic tests to rule out new causes of breathlessness), although some HCPs in this study referred to optimal management of their patients.

A recent qualitative systematic review of barriers and facilitators to self-management of COPD found that practitioners (respiratory specialists, GP's, non-respiratory nurses, allied health professionals, pharmacists, and other health professionals) lacked knowledge, skills, or education to be able to support patient self-management, often focussing on smoking cessation or medication management instead (287). Other research investigating Australian General Practitioners' management of severe chronic breathlessness in COPD found there was low awareness of non-pharmacological management strategies amongst practitioners (288). Whereas a study on use of opioids

in chronic breathlessness (278) showed that improvements in clinicians knowledge increased their confidence in prescribing. These studies support my results and the perceived lack of knowledge and awareness regarding treatment and management options for chronic breathlessness, particularly in primary care. Practitioners who struggle to adequately treat or manage this symptom may find it difficult to refer patients on to the necessary secondary services, consequently leaving patients' breathlessness under recognised and under treated, again adding to the invisibility of this symptom. Improvement in primary care HCPs knowledge of breathlessness, alongside greater understanding of associated treatment and management is needed.

Here, we can see that the clinician responsiveness domain of the Breathing Space conceptual framework (27) is demonstrated, whereby HCPs are responsive to the underlying disease *only* – considering new causes or not attending to the symptom of breathlessness itself. This is in contrast to the examples of good practice demonstrated in theme 3 (5.5.3.3: Examples of Good Practice) where some HCPs responded to both the underlying disease *and* the symptom of breathlessness itself.

5.5.4.2 Patients and Carers' Knowledge

Patients have very poor knowledge and awareness of treatments and management, and a general lack of understanding about breathlessness itself, often conflating the symptom with their condition. Their under-reporting and normalisation of breathlessness to ageing exemplifies their lack of understanding and is reflected by their non-engagement with the concept of a named syndrome.

In order for patients to better understand the concept of, and management of breathlessness, education is necessary. Research in the area of chronic pain has shown that educational interventions such as Pain Neurophysiology Education (PNE) (289) is beneficial to the patient in the management and reduction of their pain. PNE is a cognitive behavioural educational intervention which aims to help patients reconceptualise their pain beliefs away from the biomedical to a biopsychosocial understanding. This is accomplished by explaining the biology of pain mechanisms, in order to reduce negative beliefs or behaviours regarding chronic pain (289). This type of educational intervention could be applied to chronic breathlessness in much the same

way; educating the patient about the biological mechanisms behind their breathlessness, while creating an understanding that other cognitive and behavioural factors contribute to their breathlessness (193). Breathlessness intervention services aim to deliver similar interventions by focusing on breathing (targeting breathing control), thinking (distraction and psychological support), and functioning (exercise and activity plans) elements (125), and have been found to be more clinically effective than standard care for patients with advanced cancer and their carers (127). However, the specific biological factors may need more focus. Holistic services also demonstrate positive effects on breathlessness related distress and psychological health in those with chronic breathlessness and advanced disease (253).

By understanding the various mechanisms and contributors to breathlessness, individuals may be able to reduce their breathlessness and its impact. This is further supported in research using a 'Bayesian brain' model, which explains that the generation of sensations from the brain are based on previous experiences (priors) which may then amplify incoming afferent signals if priors are distressing (24). By educating and explaining about breathlessness, it could be possible to reduce the impact of previous bad experiences which lead to the perception of breathlessness.

Furthermore, education of carers about breathlessness is also warranted, and could be beneficial for both patient and carer (50). Results from an online survey considering clinicians' views of educational interventions for carers of patients with breathlessness, found that carers' education was often neglected, yet very important (51). Carers often have a pivotal role in the management of breathlessness and educational interventions tailored towards this group would help their confidence, patient self-management, and may also reduce hospital admissions (which may be more prevalent when carers feel less able to cope) (51). A narrative review about needs of the carer in those supporting individuals with COPD (53), stated that assessment of carers which gives consideration to their support needs, caring capacity, and clinical requirements, would enable unmet needs of the carer to be addressed.

5.6 STRENGTHS AND LIMITATIONS

The main strength of this study was the use of in-depth interviews which allowed for the collection of rich, varied, in-depth and detailed data from a wide selection of participants (a population who had already provided quantitative data). Here, participants were purposively selected for interview based on their involvement in the prior 249-patient strong PACE survey (See Chapter 4: Quantitative Component), and their agreement to interview (of which 76 patients indicated willingness to participate). The use of clinical data, collected as part of the PACE project, allowed me to contextualise my findings by linking patients with their demographic and clinical characteristics.

HCP recruitment took place across two locations (ICC and an associated surgery) with a wide variety of practitioners involved, e.g. General Practitioners with Extended Roles, General Practitioners, Advanced Clinical Practitioners, and Nurses, allowing for breadth of knowledge across the medical discipline.

However, there were limitations to this study. The use of telephone interviews (which were only used for HCPs) limits the potential for non-verbal communication and can be prone to technical errors (any technical errors experienced were minimal and quickly resolved).

The interviews with patients and HCPs were not linked interviews, i.e. the HCPs were not the patients' practitioners. If linked interviews were possible, data collected may have been different to that obtained within this study.

This study has the potential for HCP bias, as those involved were either working at the ICC as a GPwER (alongside a regular practice), or at one primary care practice to which one of the GPwER belonged. All practitioners expressed interest in holistic treatment of the individual. These HCPs may have had more skills and better standards of care/practice, therefore not a representative sample of the HCP population. This may also explain the examples of good practice portrayed by the HCPs compared to the experiences described by patients.

Finally, all patients involved in this study were resident in Hull, Yorkshire, which is a deprived area and therefore results may not be generalisable nationwide.

5.7 RECOMMENDATIONS FOR CLINICAL PRACTICE AND RESEARCH

There are several recommendations for clinical practice and further research as a result of my study.

First, routine identification and assessment of chronic breathlessness with systematic enquiry by health care practitioners should be conducted, in order for patients to report their symptoms in the clinical environment.

Second, a move to integrated, person-centred (holistic) care within the context of the primary care setting should be promoted for those older, frail adults with chronic breathlessness. This includes pharmacological and non-pharmacological treatments and management delivered by both GPs and practice nurses, with onward referrals where needed. This should include attention to social isolation where social prescribing initiatives should be considered for those older, frail adults with chronic breathlessness who may exhibit symptoms such as anxiety or depression. Community activities such as social engagement may contribute to overall wellbeing and minimise social isolation and loneliness (which can contribute to increased health care usage as a consequence of worsening chronic breathlessness).

Third, further education should be provided for patients, carers, and primary health care practitioners about chronic breathlessness. For HCPs this would enable better understanding of treatment, management, and interventions for this symptom and should include training on better methods of information sharing between HCP and patients/carers. For patients/carers, this could be done through educational interventions about the biology of or mechanisms behind breathlessness, or through similar educational training programmes provided as part of breathlessness services or clinics. This could include strategies or models such as The Breathing, Thinking, Functioning clinical framework (193) which was developed to support breathlessness management, alongside teaching around breathing techniques, use of the handheld fan, and other breathlessness symptom specific interventions. This would help individuals and carers with better management of this symptom.

Fourth, ‘the one appointment, one problem’ model is not fit for purpose in older, frail adults with multiple long-term conditions, where chronic breathlessness could be even more invisible.

Finally, further research conducted in the area of chronic breathlessness syndrome should use the more patient appropriate terminology 'persistent breathlessness syndrome' to account for patients' disagreement with the word 'chronic'. Patient/carer understanding of this terminology may be helpful to stop conflation between breathlessness and underlying disease.

Additionally, future research should be conducted to help understand whether interventions not only reduce breathlessness severity but can also help individuals return to activities of daily living/hobbies forgone. More consideration should be given to measuring the outcomes that are most meaningful to individuals; this could be explored in qualitative research with patients and carers.

5.8 SUMMARY CONCLUSIONS

The widespread impact of chronic breathlessness is well-reported within existing literature. However, my study adds new evidence, specifically regarding the burden and impact on the *older, frail adult* (and their carer) where there is limited evidence about chronic breathlessness in this population alone.

Chronic breathlessness plays a large and distressing role to the *older, frail adult*, and their carer, negatively impacting their psychological wellbeing and overall QoL. A number of barriers are evident in the adequate identification and assessment of chronic breathlessness in the primary care setting. Mixed views of chronic breathlessness syndrome terminology showed that patients lacked understanding or recognition of breathlessness as an entity in its own right. Disparities between patient/carer and HCP opinions on the treatment and management of this symptom (despite some examples of good practice), along with poor knowledge and understanding on part of *both* the patient and practitioner, support the notion of the invisibility of breathlessness. Chronic breathlessness as one of many symptoms makes this population particularly invisible in an already invisible scenario. Consequentially breathlessness goes *unidentified and untreated*, adversely impacting the older, frail adult.

The next chapter will synthesise and discuss the findings from my mixed-methods study (quantitative survey [see Chapter 4: Quantitative Component], and in-depth interviews [this chapter]), and systematic review (see Chapter 3: Systematic Review).

CHAPTER 6 - SYNTHESIS OF THESIS FINDINGS: FINAL DISCUSSION AND CONCLUSION

6.1 INTRODUCTION

6.1.1 Chapter Rationale

The aim of my thesis was to explore the impact of chronic breathlessness on older, frail adults (patients) and their carer's psychological wellbeing and quality of life (QoL). I also investigated how chronic breathlessness is identified and assessed in primary care, and explored patient experiences in the primary care setting, considering the impact these experiences have on patients, carers, and health care practitioners (HCPs).

In this chapter I will first synthesise the findings from my mixed methods study (which included a quantitative survey and in-depth qualitative interviews) using a modified Critical Interpretive Synthesis (163, 164) (described in section 2.4.2: Critical Interpretive Synthesis) by tabulating the findings (Table 6.1). Then I will integrate this with the findings from my systematic review to provide overall findings from my thesis, in context of my overarching research questions (see below and section 1.7 for research questions). This demonstrates how I have addressed the thesis' aims and objectives. Using an integrative table to draw together the findings of all aspects where they inform my overarching research questions, will offer new, overall insights. This is demonstrated in two stages (see Table 6.1): firstly, the findings from my mixed-method quantitative and qualitative studies are presented along with a column for synthesised findings; this is followed by a column providing additional integrated insights from my systematic review.

I will then discuss the strengths and limitations, and present recommendations for clinical practice and research before concluding my PhD thesis.

6.1.2 Aims

1. To explore the impact of chronic breathlessness on patients and carer's psychological wellbeing and quality of life.

2. To explore how chronic breathlessness is identified and assessed in primary care, considering the patient, carer, and health care practitioner experiences.

6.1.3 Research Questions

1. What impact does chronic breathlessness have on patients and carer's psychological wellbeing and quality of life?
2. What experiences do patient and carers have in relation to the identification and assessment of chronic breathlessness in primary care, and what impact do these experiences of care have on patients, carers, and health care practitioners?

6.1.4 Objectives

1. To understand the impact that chronic breathlessness has on patients and carer's psychological wellbeing and quality of life.
2. To understand the experiences of patients, carers, and health care practitioners in relation to the identification and assessment of chronic breathlessness in primary care.

6.2 SYNTHESIS OF FINDINGS

My thesis highlights the prevalence and severity of chronic breathlessness; a symptom that is common and neglected but potentially remediable if HCPs identify and assess it systematically and manage it effectively. Chronic breathlessness has a detrimental impact on both patients' and carers' psychological concerns and QoL. Clinicians have mixed views of "chronic breathlessness" being considered as a specific syndrome, although benefits with regard to recognition, management, research and education are noted. However, patients are far from being able to recognise chronic breathlessness as a therapeutic target in its own right; terminology relating to this requires modification, along with clear signalling from practitioners that this is a legitimate concern with its own treatment options, for better patient and carer understanding. Overall, improved identification, assessment, and management may improve psychological health, QoL,

promote wellbeing, and create a better understanding that chronic breathlessness can be addressed in addition to management of the underlying disease.

Key findings from each component (mixed-methods study and systematic review) of my thesis are summarised in Table 6.1. The mixed-methods study (quantitative survey and qualitative interview) findings were synthesised and then further integrated with the systematic review findings (where applicable), in order to answer the overarching research questions (see section 2.4.2 for more information on synthesis). I present a brief summary of the synthesised findings, first by research question, followed by a summary discussion.

Table 6.1 Summary of Key Findings from Overarching Research Questions Across Components of the PhD

Overarching Thesis Research Questions	**Mixed-methods Study**		**Mixed-methods (Quantitative and Qualitative) Summary Synthesis**	**With integrated insights from Systematic Review**
	Quantitative Survey	**Qualitative Interviews**		
Research Question 1: What impact does chronic breathlessness have on patients' and carers' psychological wellbeing and QoL?	• There is a high prevalence (99/249 [39.8%]) of older, frail adults self-reporting chronic breathlessness in the primary care setting • Those with chronic breathlessness have overall poorer health, a greater negative impact of shortness of breath, increased negative impact of psychological symptoms, and poorer QoL than those without chronic breathlessness • As breathlessness worsens, daily function and activities are reduced to avoid breathlessness and its effects • Psychological factors impact both the individual and carer	• Individuals with chronic breathlessness reported widespread and negative impact on psychological wellbeing (anxiety, depression) and QoL (impact on daily lives, reducing or giving up physical and social activities because of their breathlessness) • Psychological factors impact both the individual and carer • Chronic breathlessness symptoms and impact become a solitary burden	• There is a high prevalence of older, frail adults self-reporting chronic breathlessness in the primary care setting, higher than the general population of older adults • Chronic breathlessness impacts the overall health of the older, frail adult (and their carer) and plays a large and distressing role in relation to psychological health and QoL • Within this context, the older, frail adult requires symptom specific and holistic support, including consideration of psychological impact • For the older, frail adult, chronic breathlessness is associated with psychological distress, reductions in activities and daily function, and a poor QoL leading to deconditioning, a shrinking life world, social isolation and loneliness, and a dependence on health care services	• There are outcome measures/tools available which measure the impact of breathlessness; however, these tools were largely missing in the primary care setting where assessment of impact (other than in relation to physical exertion, e.g. mMRC scales) was largely absent (only 3/9 studies in the primary care setting referred to measures which assessed impact, and were in studies of COPD)

Research Question 2: What experiences do patients and carers have in relation to the identification of chronic breathlessness in primary care and what impact do these experiences of care have on patients, carers, and health care practitioners?	• Only one fifth of patients reported that their practitioners ask about the impact of breathlessness on daily life • GPs were the most common HCP that patients discussed their breathlessness with, however some talked to no-one at all • Lack of attendance at primary care for breathlessness and some did not attend at all unless breathlessness was very bad • Few HCPs asked about chronic breathlessness or its impact • Few treatments in addition to usual care were initiated in the primary care setting	• There is a wide range of tools available to identify/assess chronic breathlessness but there is little systematic use in primary care • There is reduced breathlessness help-seeking behaviour from patients in response to negative primary care experiences (barriers to care, not feeling like they are asked about breathlessness, 'one appointment, one problem' scenario) • On the part of the practitioner there is lack of adequate assessment and low knowledge, awareness, and confidence in the difficult to manage symptom of breathlessness (despite some examples of good practice) • There were disparities in patient and HCP accounts of treatment and management (pharmacological, non-pharmacological, and self-	• Despite the wide range of tools for identification and assessment of chronic breathlessness, there is a lack of routine use in primary care, particularly for the older, frail adult • There is a lack of systematic assessment and routine enquiry regarding *impact* of this symptom and its effects in primary care – implementation of systematic assessment could promote better symptom management • HCPs don't ask about breathlessness (partly due to poor knowledge about treatment) and patients don't volunteer the symptom (they think it's inevitable and untreatable) • A 'one appointment, one problem' situation means patients have to prioritise symptoms where breathlessness may not be top priority • In the older, frail adult in primary care, breathlessness sits as one of many symptoms – Clinicians express some knowledge of breathlessness and its impact but low knowledge and confidence in treatment and management, so patients do not experience benefit of symptom specific interventions – this highlights a need for increased education	• There is little evidence of identification/assessment of breathlessness in the primary care setting; only 9/97 identified studies were in the primary care setting, most of which were in relation to people with COPD; the COPD model could transfer to other conditions • There was no evidence for identification/assessment of breathlessness specifically in the *older, frail population*, in any setting

		management) of chronic breathlessness in the primary care setting • Some patients did not see HCP at all for breathlessness • Patients did not understand that chronic breathlessness was a distinct entity with effective treatments, therefore the chronic breathlessness syndrome terminology was not considered relevant by patients, however, HCPs could see the benefits of naming and identifying this currently invisible symptom. • Various and discrepant forms of identification and assessment are reported between patients and practitioners (e.g. nothing at all, general observation, detailed assessment) • Adequate identification and assessment are restricted by challenges of managing chronic breathlessness in primary care (e.g. not enough time, particularly for	• There is a gap in communication between patient and practitioner, in relation to a 'don't ask, don't tell' situation where breathlessness is not discussed, and in relation to terminology to help identify chronic breathlessness as a symptom with targeted interventions • Poor knowledge and understanding of chronic breathlessness in both patient and practitioner support the notion of the invisibility of breathlessness in primary care • Chronic breathlessness remains unidentified, unassessed (despite its serious and negative impact), and untreated; older, frail adults therefore experience limited support for their breathlessness in the primary care setting • Despite some examples of good practice, education for patients, carers, and HCPs about chronic breathlessness, its treatment, and management would be beneficial to utilise symptom targeted interventions • Within the context of missed opportunities for identification and assessment, this population is overlooked for adequate symptom specific intervention, limiting management opportunities	

		chronic condition management) • There is varied knowledge, understanding and expectations of care regarding breathlessness from both patient and practitioner	• Identification and assessment, along with adequate symptom specific treatments are paramount to the management of chronic breathlessness, otherwise this debilitating symptom will continue to go unidentified and untreated, remaining an invisible symptom Potential solutions • There is an urgent need to better support those with chronic breathlessness, particularly in relation to active screening of chronic breathlessness and related psychological symptoms; this would aid delivery of targeted interventions, promote symptom management, and could be beneficial to overall health. This could be achieved by: • The systematic implementation of adequate tools to identify/assess breathlessness and its impact within a holistic, person-centred care setting • Provide education/training for patients, carers, and HCPs about chronic breathlessness, its treatment and management	

6.3 BRIEF SUMMARY OF SYNTHESISED FINDINGS

6.3.1 Novel Findings

I found a number of novel findings:

1. There is a high prevalence (40%) of self-reported chronic breathlessness in older, frail adults, in the UK primary care setting; higher than that found in the general population of older adults.
2. There is an association between my screening question ('Have you suffered with breathlessness for most days in the last month?') and the IPOS impact of shortness of breath question suggesting construct validity of both questions. Hence, my single screening question may be helpfully used in the primary care setting, to indicate those who may be restricted as a result of chronic breathlessness. A positive response to this question could trigger further assessment and management of this symptom.
3. For older, frail adults, chronic breathlessness is one of many symptoms. A 'one appointment, one problem' situation is inadequate for this population. Within the contexts of the current model of primary care and increasing prevalence of multiple long-term conditions, this forces the individual patient to prioritise their symptoms for presentation to the clinician in the consultation. Breathlessness may not be the most pressing, or the problem the patient believes to be most remediable. Coupled with a choice to also not 'burden' family members with the problem, this means that chronic breathlessness remains unidentified, untreated, and invisible.
4. Patients are not currently in the mindset of seeing chronic breathlessness as a symptom that can be improved with interventions. Lack of recognition from patients and lack of identification and assessment from HCPs means this symptom is not understood as an entity in its own right. For 'chronic breathlessness syndrome' to be meaningful, firstly, patients need to understand that chronic breathlessness is a legitimate concern that can be treated, and secondly, the word 'chronic' should be changed to a more easily understood lay term, for example, 'persistent'.

6.3.2 What Impact Does Chronic Breathlessness Have on Patients and Carers Psychological Wellbeing and Quality of Life?

Forty percent of older, frail adults self-reported chronic breathlessness in the primary care setting. People with chronic breathlessness are approximately twice as likely to experience psychological problems (such as severe impact of depression, anxiety, and family anxiety), and are more likely to experience reductions in activities and daily functions, and a poor QoL, compared to those without, playing a large and distressing role to the individual and their carer(s). These individuals are actively reducing or giving up their activities *because* of breathlessness.

The impact of chronic breathlessness becomes a solitary burden where individuals choose not to share their thoughts/feelings about breathlessness with others. This reduces their ability to cope with this symptom with help from others, instead – with varying degrees of success - relying on solitary coping techniques.

6.3.3 What Experiences do Patients and Carers Have in Relation to the Identification and Assessment of Chronic Breathlessness in Primary Care, and What Impact do These Experiences of Care have on Patients, Carers, and Health Care Practitioners?

My data indicate that despite its serious and negative impact, older, frail adults experience limited support for their breathlessness in the primary care setting. Clinicians lack knowledge and confidence in adequate treatments (highlighting a need for education), and patients do not experience the benefit of symptom specific interventions - such as self-management techniques like the handheld fan (283, 290, 291) - due to reduced health-seeking behaviour and barriers to primary care. As patients adapt and give up their activities *because* of breathlessness, they learn to live with it, lacking knowledge of treatments and confidence in their clinician to attend to the symptom or to receive continuity of care.

There are gaps in communication between patient and practitioner, particularly regarding a ‘don’t ask, don’t tell’ situation where breathlessness is not discussed and remains invisible, and also regarding terminology to identify chronic breathlessness as a symptom with targeted interventions (which is poorly understood, and not heard of, by

patients). Poor understanding of chronic breathlessness as a modifiable problem amongst both patients and practitioners, along with lack of adequate assessment, awareness and HCP confidence in the management of this symptom, reinforces the concept of breathlessness as an invisible symptom receiving little attention as a therapeutic target. The older, frail adult in primary care may experience breathlessness as one of many symptoms/conditions, where, as one problem amongst a number in the context of 'one appointment, one problem', it may not always be the top priority to present to the HCP. The impact therefore remains invisible and unmanaged. Despite these factors, a number of examples of good practice, exhibited during qualitative interviews, showed good quality holistic care, including the use of observation skills, outcome measurements, and person-centred care.

There is an urgent need to better support those with this symptom, particularly in relation to symptom specific evidence-based care, considering active screening of chronic breathlessness (such as my breathlessness screening question – see section 6.4.2.1 and 4.5.4) and related psychological symptoms. Asking about and understanding the impact of this symptom is the first step to symptom management and application of breathlessness interventions and could improve overall health.

The systematic implementation of adequate clinician-led tools to identify and assess chronic breathlessness, along with adequate symptom specific treatments within a holistic, person-centred care setting, would be beneficial for the older, frail adult with chronic breathlessness. This is paramount for the management of chronic breathlessness, otherwise this debilitating symptom can go unidentified and untreated, remaining invisible and adversely impacting the older, frail adult.

6.4 DISCUSSION

6.4.1 What Impact Does Chronic Breathlessness Have on Patients and Carers Psychological Wellbeing and Quality of Life?

My thesis findings highlight chronic breathlessness as a highly prevalent symptom (almost 40%) in older, frail adults within primary care; and is more common than in previous reports in older adults in general (13). It is associated with widespread impact on the older, frail adult (and carer), contributing to psychological concerns such as

depression and anxiety, and towards a poor QoL (impact on mobility, self-care, and usual activities). This population are restricting/giving up their activities and hobbies *because of their breathlessness*. To the best of my knowledge, this is the first study of chronic breathlessness in the older, frail population.

My findings support previous research in adults in general which shows that chronic breathlessness has a significant and detrimental impact on the individual, where consequences are multidimensional and impact varying aspects of daily life for both patients and carers (9). A cross-sectional study of the adult population evaluated associations between chronic breathlessness and anxiety, depression, and functional status (19). It was found that age, breathlessness and function had significant associations with psychological morbidity. Further, breathlessness was strongly associated with depression, anxiety, and coexisting depression/anxiety (19). A recent study investigating activities forgone due to chronic breathlessness in the adult population found that individuals progressively reduced or stopped their varied activities *because* of breathlessness (31). My study replicated this finding in that older, frail adults also gave up or reduced their activities due to breathlessness (reported in both quantitative survey responses and qualitative interviews), often viewing this decline as a natural part of ageing or an inevitable part of their condition. As a result of the impact of breathlessness, patients are giving up activities which leads to deconditioning (1, 4), social isolation and an increase in psychological symptoms such as anxiety and depression; ultimately affecting all aspects of their lives and leading to a diminished QoL (1). Here we can see a cycle of deconditioning and worsening breathlessness.

The widespread impact of chronic breathlessness on the older, frail adult can be understood within the context of the Total Dyspnoea (137) conceptual framework, which considers the impact of chronic breathlessness on psychological, physical, social, and existential factors and underpins this research, providing explanatory understanding for my findings (see section 2.3: Conceptual Frameworks). This framework has particular relevance to this research question (research question one), considering the widespread – including psycho-social - *impact* of chronic breathlessness.

In my quantitative survey (Chapter 4), patients reported high levels of impact of anxiety, family anxiety, depression, and QoL, with only one fifth stating that their practitioner

asked about the impact of breathlessness on their daily lives. These results were corroborated in the qualitative interviews (Chapter 5) where patients talked in depth about the psychological, physical, and social ramifications of this debilitating symptom, again stating that HCPs in the primary care setting did not ask about the impact of their breathlessness; patients lacked faith in their practitioner for treatment of this symptom and some did not visit them at all. This could increase psychological symptoms in patients (and carers) as they do not feel they are being attended to. Findings from my systematic review support these findings showing a lack of impact assessment in the primary care setting. My systematic review highlighted outcome measures/tools which are available to measure the impact of breathlessness, but showed they were largely absent within primary care publications; when they were used in this setting (in only 3/9 papers), they were done so in the context of COPD.

Further, 12% of participants in my quantitative survey stated that they did not talk to anyone at all about their breathlessness and my qualitative interviews showed individuals often *chose* not to share their feelings about breathlessness with their family or friends, in order to avoid upsetting others. By not seeing their practitioner when needed and forgoing activities, the patient diminishes their capacity to cope with this symptom with help from others. Here, we can see that chronic breathlessness and its impact becomes a solitary burden for the patient, reducing the help and support they choose to seek from others, unless it was very bad (e.g., in 'crisis'). In order to cope with the impact of chronic breathlessness, patients reported (during qualitative interviews) utilising different methods in order to manage their breathlessness, many of which are solitary or personal techniques such as sitting and resting, or religious beliefs. When coping mechanisms have the potential to be group activities - such as attendance at a religious venue - but attendance is restricted by breathlessness, then individuals may be excluded from the full benefits of this particular coping mechanism, adding to the solitary burden of this symptom.

The impact and solitary burden of chronic breathlessness could result in many long-term negative health effects, particularly social isolation and loneliness. We can see this within the context of the Breathing Space conceptual framework (27) which, alongside the widespread impact of breathlessness for the patient and carer, considers coping, help-seeking, and clinician responsiveness to breathlessness and underpins this

research (see section 2.3: Conceptual Frameworks). This is exemplified in my research where patients reported only seeing their practitioner on rare occasions and usually in crisis; some reported not talking to *anyone at all* about their breathlessness (reflected throughout both quantitative and qualitative components). By only seeking help in these moments, and not having faith in clinicians to be responsive to their symptom, the patient stops trying to get support as the belief in the therapeutic nihilism that 'nothing can be done' becomes apparent. If the patient doesn't seek or ask for help and the HCP doesn't ask about the presence of breathlessness or its impact (or have the opportunity to enquire further due to lack of patient attendance) then we see a communication *impasse* between patients and HCPs (see section 6.4.2.3: Communication Difficulties). Help-seeking in crisis only, non-responsiveness of clinician, lack of faith in HCP to provide suitable help, and not confiding in others about their symptom (disengaged coping) means the patient is less likely to seek help overall and becomes more isolated from sources of help and more socially isolated as a result of worsening impact on their lives.

A previous study on loneliness and QoL in chronically ill community dwelling rural older adults in the US showed that loneliness was associated with chronic illness, functional decline, and a greater risk of mortality (292). This convenience sample found that the highest mean loneliness scores belonged to those with depression or anxiety, followed closely by those with lung or heart disease (292). This research supports my findings as a number of participants (of similar age and comorbidities) reported their lack of attendance at a primary care practice for their breathlessness, along with an unwillingness to discuss chronic breathlessness with others and withdrawal from social activity. It is therefore likely that those older, frail adults in my study would have also experienced loneliness. Other research using data from the English Longitudinal Study of Ageing (ELSA) (34) showed that older adults were at greater risk of experiencing social isolation and loneliness and these factors were associated with a greater risk of inactivity, smoking, and other risk behaviours (34). My results reported inactivity (giving up activities) due to breathlessness. Another study using the same longitudinal data (ELSA) found that social isolation is associated with an increased risk of hospital admission in older adults with respiratory disease (35).

The overall impact of chronic breathlessness on the older, frail adult reported in my thesis (levels of depression and anxiety, along with poor QoL) is substantial. Within the

context of high prevalence and high impact, we can see that chronic breathlessness is multi-faceted, with a large and burdensome influence on the individual. With many potential negative long-term outcomes, there is an urgent need to better support those older, frail adults with chronic breathlessness.

6.4.2 What Experiences do Patients and Carers Have in Relation to the Identification and Assessment of Chronic Breathlessness in Primary Care, and What Impact do These Experiences of Care have on Patients, Carers, and Health Care Practitioners?

6.4.2.1 Experiences of the Identification and Assessment of Chronic Breathlessness in Primary Care

My thesis has highlighted the lack of routine implementation of tools to identify and/or assess chronic breathlessness in the adult population within the primary care setting. Findings from my systematic review (192) (Chapter 3) indicated that identification of breathlessness across clinical practice is poor, with a wide range of tools available (such as the mMRC [modified Medical Research Council breathlessness scale] or ESAS [Edmonton Symptom Assessment Scale]) but with little systematic use except in COPD; only nine of 97 included papers were from the primary care setting. Most included papers were within the context of COPD and any associated treatment/management that may occur as a result of that condition, where treatment pathways could provide access to - and benefits from - treatment such as pulmonary rehabilitation. This is good practice but also raises a concern for the assessment and management of those with breathlessness due to other causes; models of care used in COPD treatment/management could be transferred to other conditions, such as heart failure where the Quality and Outcomes Framework (QOF) does not refer to symptoms at all, only diagnostic criteria and medications (293). My systematic review also found no evidence for identification or assessment of breathlessness in the *older, frail population*, in any setting. Results from my qualitative interviews (Chapter 5) support findings from my systematic review and show there are various forms of identification and assessment for application within clinical practice, interestingly, mostly reported by HCPs. Use of

these tools appears *ad hoc* and does not amount to systematic assessment. It is only recently that mMRC breathlessness scale ≥3 in annual COPD reviews is counted for QOF incentive payments if that patient has also been offered pulmonary rehabilitation (199). Because patients often recognise the disease and not the symptom, they may not understand treatments offered as being primarily for their breathlessness. Identification and follow up intervention are important. Whilst COPD management within primary care may be well placed to triage to other targeted services, this does not necessarily benefit those with different diagnoses causing chronic breathlessness. Patients and carers report poor experiences of identification and assessment (such as very few methods of assessment used - sometimes none at all - with little enquiry from HCPs), along with reports in my quantitative survey (Chapter 4) of inconsistent chronic breathlessness management (such as very few breathlessness related assessments made, or treatments given). Whilst HCPs report varying methods of assessment used, they have little confidence in the use or application of these tools or treatments.

Previous evidence (114) shows that outcome measures such as the mMRC are quick and simple for the assessment of breathlessness. The screening question from my quantitative survey ('Have you suffered with breathlessness for most days in the last month?') showed construct validity with the IPOS impact of shortness of breath question. This novel finding shows that my screening question might be a useful and simple single question to ask in a routine consultation, without the need to remember the mMRC categories, which are longer and could take more time. This would identify those with chronic breathlessness and could trigger a more in-depth assessment.

Overall, this represents a lack of consistent, reliable support within primary care for the older, frail adult in whom chronic breathlessness is common and has a large impact. One way of improving support would be to provide education on chronic breathlessness, its treatment, and management, to both patient/carer and HCPs. Clinicians show general understanding about chronic breathlessness and its impact but lack knowledge or confidence of how to deal with it effectively and are constrained by the restrictions of primary care. Interestingly, even in very different cultures and health service delivery models, such as India, there are similar findings; for example a recent study of practitioners in South India who took part in focus groups about the recognition and assessment of chronic breathlessness syndrome (109) - breathlessness that persists

despite optimum treatment of the underlying condition (7). The authors found that practitioners perceived a lack of assessment tools and had poor awareness of therapeutic interventions (109). Similarly, my findings show that patients display a degree of stoicism to their suffering and learn to live with it. However, a 'therapeutic nihilism' that nothing can be done, and the need to prioritise problems, may prevent patients from mentioning chronic breathlessness to their HCP. Providing education would help patients, carers, and practitioners understand that there *are* evidence-based interventions, and clinical frameworks available, which means that breathlessness itself *can* be treated and managed. Approaches to care such as the Breathing, Thinking, Functioning (BTF) clinical model – an educational tool used to support the management of breathlessness – could be used in clinical training to educate HCPs on effective symptom control (193). The BTF is useful in improving both patient and HCP understanding, and helping to promote self-management approaches (193). Some approaches include the handheld-fan, of which there is substantial evidence confirming its use as an effective self-management tool for chronic breathlessness (290, 291). Further, the BTF model has been used effectively elsewhere; it is central to the Breathlessness Intervention Services provided in the UK and in Germany, which provide symptom specific support alongside self-management strategies (294), reducing impact of breathlessness and improving QoL for patients and their carers (130).

Poor support in healthcare can exacerbate the problem of breathlessness (this relates to the importance of continuity of care which is discussed in more detail in section 6.4.2.2). Poor identification and assessment can lead to a lack of support for the patient and carer, which in turn diminishes patient/carers confidence in the HCP to provide meaningful symptom targeted treatments; ultimately, health-seeking behaviour is impacted, and appointments are not made for attention to this symptom (unless in crisis). The disengagement of both patients and practitioners can be understand in the context of the Breathing Space (27) conceptual framework (Chapter 2) which underpins this research and describes in part the help-seeking behaviour of the patient (for breathlessness *or* in crisis only), and the responsiveness of the HCP (responsive to breathlessness and underlying disease *or* responsive to underlying disease only). This framework is most applicable to this research question (research question two), considering the role of primary care in identifying, assessing, and supporting older, frail

adults with chronic breathlessness. My findings show that patients do not seek help for attention to their breathlessness unless it is very bad. In my quantitative survey, approximately seven percent of individuals stated they *only* went to their primary care HCP for breathlessness when it was bad/as needed. Qualitative interviews confirmed this, where some patients reported not seeing their primary care HCP at all and expressed a lack of faith in them for help with this symptom. This may be due to the HCPs response to breathlessness, which is critical (285). Delays in help-seeking behaviour can have negative impact and poor outcomes (295) and often help is delayed until there is significant impairment in general, everyday activities (296), making continuity of care very difficult. Providing education about breathlessness and its management (described above) would be beneficial to help the patient understand about available treatments and interventions, promoting more appropriate help-seeking behaviour and helping patients move from disengaged to engaged coping.

The levels of depression and anxiety exhibited within my research are high and troubling and do not seem to be addressed. We can see this in my quantitative survey (and confirmed in my qualitative interviews) where only one fifth of patients reported that their HCPs asked about the impact of breathlessness. Asking about breathlessness and understanding the impact of this symptom on the individual's psychological wellbeing and QoL (with consideration for social isolation and loneliness), within the primary care setting, would aid in the delivery of targeted interventions. This would help to promote symptom management through the application of, for example, handheld fans, breathing techniques, anxiety management, or pulmonary rehabilitation (193), and could be beneficial to overall health. Treatment and management for chronic breathlessness primarily, could be an essential way in which symptoms such as anxiety and depression are reduced.

This population requires symptom specific, holistic support, particularly in relation to screening of the symptom itself, and of psychological symptoms such as anxiety and depression. For instance, there were some examples of good practice, and attention to the symptom, reported in my qualitative interviews (Chapter 5) where some practitioners used observation skills to assess the patient as they were walking to the treatment room, along with a number of different outcome measures – such as the mMRC (modified Medical Research Council breathlessness scale) and the CAT (COPD

Assessment Test) - to provide an accurate picture on the individuals overall mental health and wellbeing. Holistic support was further exemplified where one practitioner reflected on an optimally managed frequent attender who he provided with a comforting chat as means of treatment, which the patient sought comfort in and responded well to. Good practice such as this could be employed within the primary care setting.

6.4.2.2 Chronic Breathlessness in the Context of Multiple Long-term Conditions

Multiple long-term conditions are prevalent in older adults (297) and are associated with frailty (298). A novel finding in my study showed that older, frail adults experienced a number of symptoms and conditions, often where breathlessness was of high impact, but where it sat as 'one of many' symptoms. Alongside this, some patients reported a 'one appointment, one problem' situation, where they discussed (during qualitative interviews) how their primary care practice encouraged them to book one appointment per complaint only. Within this model, the patient must prioritise the worst of their concerns to discuss with the HCP and does not mention breathlessness as they do not identify it as a therapeutic target, or it may not be their worst problem, despite its potential impact. A published letter (299) from one GP discussed the current model of primary care – one in which the ten-minute appointment is the norm – and how it contributes to further issues. Consequences included, the patient's problem not being dealt with effectively, the appointment running late whilst the problem *is* dealt with effectively, or the patient needs to return (299), recognising that some settings may be testing different, more appropriate models of care. However, in the case of the older, frail adult with chronic breathlessness and multiple long-term conditions, and within the context of 'one appointment, one problem', the whole person is not 'seen'; only the most prioritised symptom will be discussed in the short appointment time.

Findings throughout my study highlighted barriers which impacted health-seeking behaviour for the older, frail adult. My quantitative survey demonstrated how little some patients saw their HCP for breathlessness - some not seeing them at all - with very few HCPs asking about the impact of breathlessness on daily life. My qualitative findings confirmed and expanded on these results where patients cited barriers to access as one of the reasons for non-attendance at primary care. This is in contrast to recent research

showing that health service utilisation was higher for those individuals who were older, and those with breathlessness (3). Other research has shown severe physical ill health to be a main reason for frequent attendance at primary care for older adults (300) and where breathlessness was the fifth most common nonprocedural reason for primary care attendance (96). Lack of continuity of care was also a concern, where patients were disappointed at not being able to see the same practitioner over time. This supports previous research using the 2009/2010 English General Practitioner Patient Survey (GPPS) (301) which found that approximately two thirds of English patients valued continuity of care and had preference for seeing a particular doctor, however approximately one quarter struggled to see their preferred HCP most of the time (301). Continuity of care is important and evidence has shown this to improve patient experience (302), increase quality of care (by decreasing emergency department/hospital use) (303), reduce secondary care costs (302), and is associated with lower mortality rates (268-270). Further, a longitudinal cohort study of older adults in the Netherlands (272) demonstrated that low continuity of care within the general practice setting was associated with higher risks of mortality (272).

My findings also found that patients, carers, and practitioners expressed time restrictions as a considerable barrier to care. Previous research has identified time as a barrier for practitioners to care for older patients with multiple long-term conditions (304). Other research looking at access to care for socio-economically disadvantaged older adults in rural areas, found similar barriers to care, such as difficulty obtaining appointments and restrictions due to service developments (305). Research has shown that continuity of care contributes to improved health outcomes (306), and that older adults with multiple long-term conditions desire continuity of care which is individualised and patient centred (307).

A number of poor health outcomes are associated with multiple long-term conditions in older patients including: polypharmacy, depression, frailty, and overall, reduced QoL (308). Research using data obtained from a UK biobank has shown that multiple long-term conditions were common in frail participants, with odds of experiencing frailty increasing with higher number of comorbidities (88). Individuals with chronic breathlessness can attribute their symptom to a number of different causes (77), including of respiratory and cardiac origin (309), many of which – such as COPD and

cardiovascular disease – often occur together with worse combined outcomes than for each individual condition (64). Therefore, individuals with multiple long-term conditions are likely to have different clinical needs than those with one chronic condition (307, 310). The predominant UK model of primary care does not appear to be capable of providing holistic care to the older, frail adult with chronic breathlessness, multiple long-term conditions, and associated psychological symptoms. We know that current recommendations for care based on disease-specific guidelines may not be applicable to patients with multiple long-term conditions (307, 311). Considering each condition in isolation can create excessive treatment/illness burden (312, 313) and therefore, division of care across conditions may not be beneficial (311). Current National Institute for Health and Clinical Excellence (NICE) guidelines recommend the optimisation of care for adults with multiple long-term conditions by reducing treatment burden and unplanned care, with an overall aim of improving QoL and shared decisions, with a focus on what is important to the individual (314). A recent pragmatic cluster-randomised trial evaluated the effectiveness of a holistic assessment for people with multiple long-term conditions in primary care with regard to QoL (311). Whilst this study did not find any improvements in QoL or perceived treatment/illness burden, it did find improvements in measures of patient-centred care (311). Here, a shift in focus from the single condition to the complex patient is warranted (88).

Accumulating evidence supports the use of holistic breathlessness services (253) with a growing consensus about service components (315). Holistic services for chronic breathlessness have shown a decrease in patient breathlessness-related distress and psychological symptoms in those with advanced disease (253).

Providing best care within the primary care setting could have benefits to the broader health care system, such as reducing unplanned admissions to hospital. Previous research has reported that one in five conveyances *via* ambulance to the emergency department (ED) are for those experiencing acute-on-chronic breathlessness (2), and that one third of ED presentations could be discharged home rather than admitted to hospital (2). Improved primary care (and self-management) could prevent unnecessary health care utilisation. The International Primary Care Respiratory Group (IPCRG) have recently employed an e-Delphi process to identify and prioritise respiratory research needs of HCPs across worldwide primary care (316). Results included themes related to

training of primary care clinicians, primary care guidelines, patient self-management, and multidisciplinary health care, showing the importance of primary care as a pivotal healthcare initiative relating to the prevention, diagnosis, and management of respiratory diseases (316).

Research within primary care is currently considering the redesign and implications of person-centred generalist care, and it is here where individuals with complex needs will be managed (317). The Health and Care Act 2022 outlines the new Integrated Health Care Services which aim to deliver better joined-up care from different health and care organisations, making it easier for those individuals who rely on multiple services (318). This is a step in the right direction for holistic care. Holistic, person-centred care and support for the older, frail adult with chronic breathlessness (and multiple long-term conditions) therefore must be considered a priority within primary care.

6.4.2.3 Communication Difficulties

When considering the experiences within primary care, we can see that there is a significant problem related to communication between patients/carers and HCPs, creating a cycle of distress where support is lacking, and psychological symptoms are evident.

Evidence from my qualitative interviews shows that, if the topic is raised in a clinical consultation at all, it is usually the patients that initiate the discussion. Data from my quantitative survey, confirmed in qualitative interviews, suggests that very few HCPs ask about the impact of this symptom. Whilst there are tools available for the identification or assessment of breathlessness, there is no gold standard (114) and several practitioners stated in my qualitative interviews that they do not use them other than for COPD reviews or similar appointments. This could add to their lack of confidence in systematic assessment about the symptom itself. As mentioned above (section 6.4.2.1), the screening question used in my quantitative survey (showing construct validity with the IPOS impact of shortness of breath question) might be a useful simple, single question to identify chronic breathlessness within the clinical setting.

We can see that the communication problem spirals by patients not asking for help whilst simultaneously HCPs are not offering it: a ‘don’t ask, don’t tell’ situation. This

could be because patient lack of knowledge of treatments and low HCP confidence in their use or applicability seems to create a mutual ignoring between patient and practitioner. Even if the patient brings up the *topic* of breathlessness, they do not ask for treatment/tests because they do not know what is available to them, and HCPs may not offer because of their lack of confidence in treating the symptom. If no intervention is forthcoming, the patient may then not mention it again, and the clinician assumes the problem is resolved. A novel finding in this study shows that the definition of chronic breathlessness syndrome - breathlessness that persists despite optimum treatment of the underlying condition (7) - is not meaningful to patients to help them understand their breathlessness as a symptom with therapeutic target either (partly because the word 'chronic' was seen to determine 'severity' rather than 'persistence over time'). However, some HCPs saw the utility in the definition, reporting that it may increase patient understanding and provide access to services, resources, or management for breathlessness. Some practitioners also saw the similarities between chronic breathlessness and chronic pain, appreciating symptom management as a fundamental benefit of delineating the syndrome. In a study using hypothetical scenarios for the treatment of severe chronic pain or severe chronic breathlessness in people with optimally treated COPD (110), it was found that fewer physicians recognised the need for – or indeed offered – treatment to those individuals with chronic breathlessness (10%) compared to those with chronic pain (31%) (110). This illustrates the substantial problem of chronic breathlessness and how naming a syndrome may facilitate recognition and management. Previous research with physicians in South India found that chronic breathlessness was not only complex and difficult to measure, but physicians themselves experienced discomfort and helplessness in relation to this symptom, often avoiding the topic itself due to feelings of distress. However, they agreed a definition of chronic breathlessness would aid identification of this symptom (109). Insight from respiratory trainees in the UK (273) also highlights the difficulties discussing breathlessness, such as being overwhelmed by patient accounts of the symptom, concern over dealing with it, and trying to attend to other related needs, leading to avoidance of the topic of breathlessness altogether (273). These papers support my HCP findings in relation to helplessness and lack of knowledge regarding management of chronic breathlessness; factors which may feed in to the 'don't ask, don't tell' situation.

My findings support previous research discussing the notion of breathlessness as an invisible symptom. By not discussing breathlessness, the problem is perceived not to exist. The 'don't ask, don't tell' situation creates inadequate communication between patient and practitioner contributing to diminished help-seeking from patients. The invisibility of breathlessness is further reinforced by the concept of the 'one appointment, one problem' situation which pushes breathlessness further from view as it is not always top priority, particularly in the older, frail patient with multiple long-term conditions. The lived experience of chronic breathlessness is therefore often hidden or invisible (107). This may also be why some patients only attend primary care for their chronic breathlessness 'in crisis', reflecting the help-seeking domain of the Breathing Space (27) conceptual framework. Breathlessness is a subjective experience and the clinical approach is to consider the underlying condition first (105). In the context of the patient's breathlessness, some of the practitioners in my qualitative interviews discussed how they would often carry out diagnostic testing even if a diagnosis had been made, to rule out new causes of breathlessness. Until recently there was little research regarding interventions for breathlessness as a therapeutic target, therefore once the underlying condition had been treated, the symptom of chronic breathlessness remained invisible (107). Data from my quantitative survey highlights this where very few breathlessness related treatments were offered, and further during my qualitative interviews where HCPs referred to possible treatment options, but which were very limited in the patient's accounts. A qualitative interview study with COPD patients also highlighted the invisibility of breathlessness due to the nature of breathlessness, stigma, and potential non-response from health care services (106).

It is within these many 'layers' of the patient-practitioner interaction, that chronic breathlessness is hidden – it remains invisible and therefore not treated or managed, proving detrimental to the older, frail adult. This contributes to the overall poor experience of the management of chronic breathlessness in primary care for the older, frail patient.

6.5 STRENGTHS AND LIMITATIONS

There were a number of strengths to my thesis. The use of different methods allowed two elements of research (systematic review, and mixed-methods study [quantitative survey and qualitative interviews]) to be conducted, analysed separately, and then synthesised together to provide overall findings, offering increased insight and understanding about the overarching research questions. Confirmatory and explanatory findings were found. The study was conducted within the PACE service evaluation and therefore allowed efficient recruitment of and access to a pool of participants already involved within a research project. Consecutive referrals to the ICC were invited and a high percentage agreed to participate which increased representativeness of the sample. Participants were involved at both quantitative survey (249-participant strong population) and qualitative interview stage, allowing for rich and varied data to be collected from a wide selection of participants very quickly. Lastly, although data collection took place in a single centre in Yorkshire, findings across this study supported previous research with similar findings in different populations; this fitted with the Breathing Space conceptual framework (27) which was derived from approximately 100 studies from around the world, and resonates with work on primary care models in multiple long-term conditions. Therefore, findings from my thesis are likely to be applicable to other older, frail populations.

Some limitations of my research were also evident. My systematic review was only able to identify clinical practice which had been published – there may be other examples of good practice which have not been identified if they are not published. My systematic review added a large amount of information about tools and measurements, however there was little other evidence from this component about the impact of chronic breathlessness, or about the older, frail population. The sample size of the quantitative study was relatively small (n=249) however this work was exploratory and confidence intervals reported in research question four were still quite narrow, showing that results were likely to fall within this range. Whilst the association between my chronic breathlessness screening question and IPOS shortness of breath question supported construct validity, my study was not designed to test this and there would need to be formal evaluation to confirm these preliminary findings. Further, my chronic breathlessness survey was developed for use within this PhD, and as such is not a

validated instrument. Therefore, further evaluation of this survey (and, in particular, the chronic breathlessness screening question), in relation to its psychometric properties, would be beneficial for its future use.

Most of the information about impact was gathered from my quantitative survey and qualitative interview components. Patients and clinicians interviewed in the qualitative component were not linked, and therefore their views and opinions were not necessarily related. A small number of interviews were conducted as dyads; consideration must be given to the interaction between participants in these types of interviews and whether this changes the nature of the conversation (e.g. do individual responses change due to the presence of another). In dyad interviews, there is a risk that either participant may have felt restricted in free expression of their opinions due to presence of the other. However this was not observed and was considered a minor risk due to the low number of dyad interviews (which were between family members with both providing informed consent). However, dyad interviews may also have benefits, whereby the presence of another person may promote deeper discussion and understanding. Interviewing patient and carer together allowed me to observe their dynamic interaction, which was useful when considering chronic breathlessness which also impacts the family carers significantly. My own possible unconscious biases and preconceptions may also influence the gathering and interpretation of data at all stages. I am a young, white, healthy individual potentially different from that of my study population. However, reflexivity and bias were considered throughout the PhD, and I have taken steps to make a justifiable analysis and interpretation. I used a second reviewer during elements of the systematic review to minimise bias and also discussed qualitative interviews and analysis with my supervisors for different points of view. Finally, this study was conducted in a single centre in Hull, Yorkshire, which is one of the most deprived authorities in England and with one of the highest prevalence of respiratory disease (319). Therefore, results may not be representative/generalisable to other areas of the country.

6.6 RECOMMENDATIONS FOR CLINICAL PRACTICE AND RESEARCH

The principal clinical recommendations of my PhD thesis are summarised here, followed by research recommendations.

6.6.1 Clinical Recommendations

1. Identify. Given the prevalent, but hidden, impactful, and potentially modifiable nature of chronic breathlessness in older, frail adults, this should be identified and assessed routinely through systematic enquiry by HCPs within primary care clinical practice. This could be implemented through a simple, single question such as my breathlessness survey screening question 'Have you suffered with breathlessness for most days in the last month?' within the patient consultation, and during annual health condition (e.g., COPD/heart failure) reviews. Identification of chronic breathlessness could promote adequate interventions, treatment, and management.
2. Assess the impact. The *impact* of chronic breathlessness must also be assessed. Asking directly about how chronic breathlessness affects daily life, or specifically asking "what have you given up because of your breathlessness?" would be particularly beneficial and would allow an understanding of the degree of restriction. This could also take place in the patient consultation (and again during the annual condition review), enquired by any HCP.
3. Screen. Screen for anxiety and depression in older, frail adults with chronic breathlessness. This could also take place in the primary care setting by the HCP and could initially be a simple question of 'Have you felt anxious or depressed lately?'. Older, frail adults with chronic breathlessness are at an increased risk of psychological symptoms such as anxiety and depression. Therefore, routine screening for anxiety and depression in this population is paramount in order to understand the impact of chronic breathlessness and related symptoms and to implement any treatment/management solutions.
4. Educate. Education for patients, carers, and HCPs about chronic breathlessness, its treatment, and management would be beneficial to utilise symptom targeted interventions; this could include self-management approaches such as the handheld-fan (193, 203) or breathing exercises (32, 129, 193). Educational tools such as the BTF clinical model (193), which focus on breathing control (breathing), psychological support (thinking), and exercise/activity (functioning) have been shown to increase HCP and patient understanding of chronic breathlessness, and provide self-management approaches (254).

6.6.2 Research Recommendations

1. Further research on chronic breathlessness terminology could explore if and how a modification from the term 'chronic breathlessness syndrome' to 'persistent breathlessness syndrome' might be better understood by patients and their carers/families. This could take place within qualitative interviews with patients and carers, gathering views about the most appropriate terms applicable to and understood by the patient/carer.
2. Other research (such as a quasi-experimental study or randomised controlled trial) could:
    a. confirm the construct validity of my screening question with specifically designed psychometric studies.
    b. investigate the effect of routine screening (using my single question - 'Have you suffered with breathlessness for most days in the last month?') and assessment as necessary of older adults screening positively for chronic breathlessness, on implementation of assessment and management of breathlessness and benefit with regard to their physical and mental QoL and physical and social function.
    c. investigate whether interventions to reduce breathlessness severity can also facilitate individuals return to activities forgone.
    d. explore whether routine identification of breathlessness in primary care leads to improved management and reduction in acute-on-chronic breathlessness episodes.
    e. determine whether education of HCPs has any impact on systematic identification of breathlessness in older adults with frailty in primary care.

6.7 SUMMARY CONCLUSIONS

There is a high prevalence (almost 40%) of older, frail adults self-reporting chronic breathlessness in the primary care setting in Hull. Breathlessness is associated with worse psychological symptoms and poor QoL; this has a distressing, and lasting negative

impact and could lead to social isolation, loneliness, and an increase in hospital admissions and health care utilisation.

A lack of systematic assessment of chronic breathlessness alongside limited support in the primary care setting means that older, frail adults with chronic breathlessness risk not benefitting from symptom specific targeted interventions, such as the handheld fan, and other evidence-based interventions targeting breathlessness. Lack of adequate communication between patient and practitioner, use of inappropriate and misunderstood terminology, and barriers to care are also evident within this setting. This notwithstanding, we must consider the examples of good practice portrayed by HCPs within my study, such as using different outcome measures to gather a detailed understanding of the individuals' mental and physical wellbeing, detailed observation, and trying to provide holistic care.

Chronic breathlessness in the older, frail adult (likely to experience multiple long-term conditions) is *still being missed*, along with opportunities for its management, leading to detrimental effects on the patient. The implementation of holistic, person-centred care for the older, frail adult within primary care would be beneficial to identify/assess breathlessness, its impact, and associated psychological symptoms. This would lead to use of effective interventions (such as self-management using the handheld-fan and/or breathing exercises) and improved management, with a potential to decrease symptom impact and increase quality of life.

Without improvements, those living with chronic breathlessness will continue to suffer significant problems which may be avoidable with appropriate identification, assessment, and management.

Research priorities for the future need to consider the systematic identification and widespread impact of chronic breathlessness in older, frail individuals; this could also be extended to *all* individuals.

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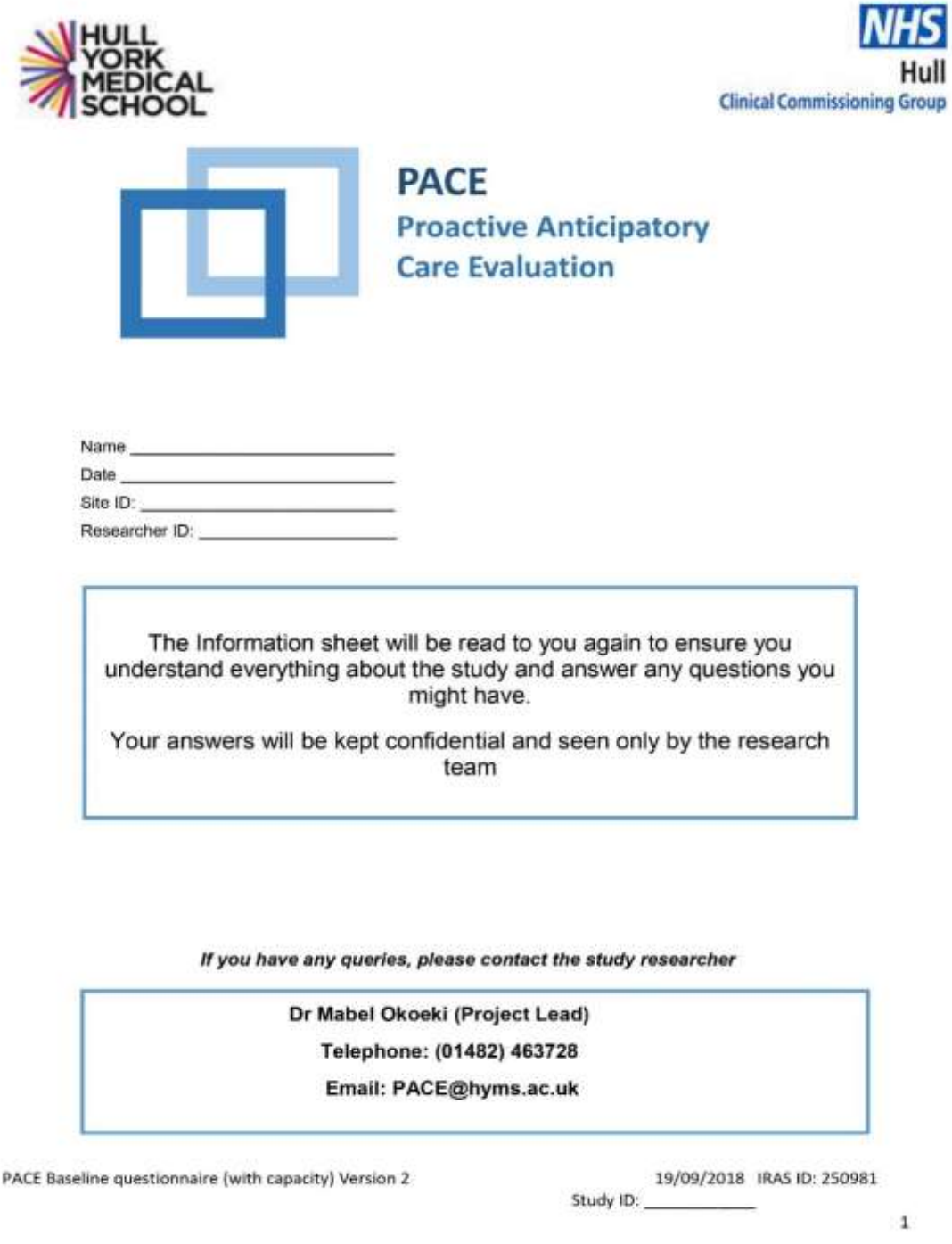
APPENDICES

APPENDIX A – PACE SURVEY



HULL YORK MEDICAL SCHOOL

NHS Hull Clinical Commissioning Group

PACE
Proactive Anticipatory Care Evaluation

Name _____
Date _____
Site ID: _____
Researcher ID: _____

The Information sheet will be read to you again to ensure you understand everything about the study and answer any questions you might have.

Your answers will be kept confidential and seen only by the research team

If you have any queries, please contact the study researcher

Dr Mabel Okoeki (Project Lead)
Telephone: (01482) 463728
Email: PACE@hyms.ac.uk

PACE Baseline questionnaire (with capacity) Version 2 19/09/2018 IRAS ID: 250981
Study ID: _____
1

SECTION ONE

ABOUT YOUR WELLBEING (IPOS)

Q1. What have been your main health problems or concerns over the past week?

.....

.....

.....

Q2. Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick one box that best describes how it has affected you over the past week.

	Not at all	Slightly	Moderately	Severely	Over-whelmingly
Pain	0☐	1☐	2☐	3☐	4☐
Shortness of breath	0☐	1☐	2☐	3☐	4☐
Weakness or lack of energy	0☐	1☐	2☐	3☐	4☐
Nausea (feeling like you are going to be sick)	0☐	1☐	2☐	3☐	4☐
Vomiting (being sick)	0☐	1☐	2☐	3☐	4☐
Poor appetite	0☐	1☐	2☐	3☐	4☐
Constipation	0☐	1☐	2☐	3☐	4☐
Sore or dry mouth	0☐	1☐	2☐	3☐	4☐
Drowsiness	0☐	1☐	2☐	3☐	4☐
Poor mobility	0☐	1☐	2☐	3☐	4☐
Please list any other symptoms not mentioned above, and tick one box to show how they have affected you over the past week.					
_____	0☐	1☐	2☐	3☐	4☐
_____	0☐	1☐	2☐	3☐	4☐
_____	0☐	1☐	2☐	3☐	4☐

Over the past week:

	Not at all	*Occasionally*	*Sometimes*	*Most of the time*	*Always*
Q3. Have you been feeling anxious or worried about your illness or treatment?	0☐	1☐	2☐	3☐	4☐
Q4. Have any of your family or friends been anxious or worried about you?	0☐	1☐	2☐	3☐	4☐
Q5. Have you been feeling depressed?	0☐	1☐	2☐	3☐	4☐
	Always	*Most of the time*	*Sometimes*	*Ocassionally*	*Not at all*
Q6. Have you felt settled or comfortable?	0☐	1☐	2☐	3☐	4☐
Q7. Have you been able to share how you are feeling with your family or friends as much as you wanted?	0☐	1☐	2☐	3☐	4☐
Q8. Have you been given as much information as you needed?	0☐	1☐	2☐	3☐	4☐
	Problems addressed/ No problems	*Problems mostly addressed*	*Problems partly addressed*	*Problems hardly addressed*	*Problems not addressed*
Q9. Have any practical problems resulting from your illness been addressed? (such as financial or personal)	0☐	1☐	2☐	3☐	4☐
	On my own	*With help from a friend or relative*			*With help from a member of staff/researcher*
Q10. How did you complete this questionnaire?	☐		☐		☐

SECTION TWO HEALTH QUESTIONNAIRE (EQ-5D-5L)	
Under each heading, please tick the ONE box that best describe your health TODAY	
MOBILITY	
I have no problems in walking about	☐
I have slight problems in walking about	☐
I have moderate problems in walking about	☐
I have severe problems in walking about	☐
I am unable to walk about	☐
SELF-CARE	
I have no problems washing or dressing myself	☐
I have slight problems washing or dressing myself	☐
I have moderate problems washing or dressing myself	☐
I have severe problems washing or dressing myself	☐
I am unable to wash or dress myself	☐
USUAL ACTIVITIES *(e.g. work, study, housework, family or leisure activities)*	
I have no problems doing my usual activities	☐
I have slight problems doing my usual activities	☐
I have moderate problems doing my usual activities	☐
I have severe problems doing my usual activities	☐
I am unable to do my usual activities	☐

PAIN / DISCOMFORT	
I have no pain or discomfort	☐
I have slight pain or discomfort	☐
I have moderate pain or discomfort	☐
I have severe pain or discomfort	☐
I have extreme pain or discomfort	☐
ANXIETY / DEPRESSION	
I am not anxious or depressed	☐
I am slightly anxious or depressed	☐
I am moderately anxious or depressed	☐
I am severely anxious or depressed	☐
I am extremely anxious or depressed	☐

We would like to know how good or bad your health is TODAY.

This scale is numbered from 0 to 100.

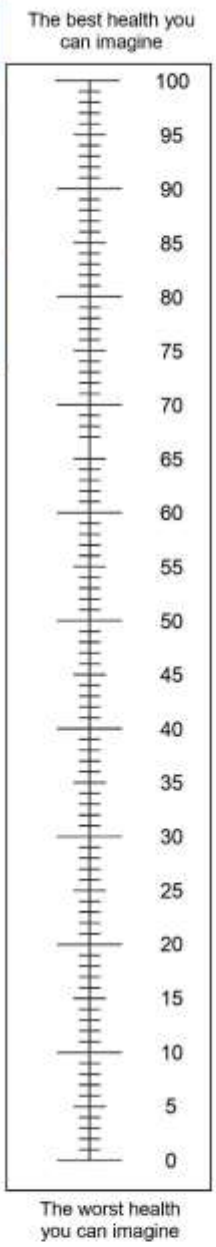
100 means the best health you can imagine.

0 means the worst health you can imagine.

Mark an X on the scale to indicate how your health is TODAY

Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY = ☐



SECTION THREE

SYMPTOMS SURVEY

We will like to ask you some health questions that will help us to better understand chronic breathlessness, unintentional weight loss or use of medicines for pain management, whichever is relevant.

Please tick the boxes and provide answers where appropriate to questions that are applicable to you.

Now some questions about your health:

Over the past 12 months, have you been prescribed any medications to manage pain?	Yes	☐	No	☐	Not sure	☐
Have you suffered with breathlessness for most days in the last month?	Yes	☐		No		☐
Have you lost some weight, without trying, in the last 12 months	Yes	☐	No	☐	Not sure	☐

If you have experience of using medicines to manage pain, please turn to page 9.

If you have experience of chronic breathlessness please turn to page 11

If you have experience of unintentional weight loss, please turn to page 13.

If you answered No to all the answers above, please go to page 14.

SECTION A

USING MEDICINES TO MANAGE PAIN

Please answer only if you have been prescribed medicines to manage pain in the last twelve months.

If you have not, please go to page 11 Section B

1) Over the last 12 months, how has your pain been?

No pain at all	A little pain	Moderate pain	Severe pain	Overwhelming pain
☐	☐	☐	☐	☐

2) How long have you been affected by pain?

_____

3) What medications are you currently taking to manage your pain?

_____

_____

_____

4) Have you talked to your GP or another health professional about your pain?

Yes	No
☐	☐

5) Please could you tell me a bit more about your answer above? (e.g., who did you talk to? What happened from this discussion? If you answered no, please go to question 6)

_____

_____

6) Do you feel that you had the opportunity to talk about using pain medications with your general practitioner or another health professional?

Yes	No
☐	☐

7) Did you have any initial concerns about taking the pain medications you were prescribed?

Yes	No
☐	☐

8) If yes, what concerns did you have?

_____

_____

_____

9) Have your pain medicines caused you any problems (i.e. side effects)?

Yes	No
☐	☐

10) If so, what problems have they caused?

_____

_____

_____

11) Have your painkillers caused you any problems with the following? *Please tick all that apply*

	Yes	No		Yes	No
Nausea (feeling sick)	☐	☐	Drowsiness/sleepiness	☐	☐
Vomiting (being sick)	☐	☐	Constipation	☐	☐
Memory	☐	☐	Fitting	☐	☐
Confusion	☐	☐	Falls	☐	☐
Attention/concentration	☐	☐	Headaches	☐	☐
Seeing or hearing things that are not	☐	☐	Other	☐	☐

If other, please state: _____

12) Do you take/use pain medicines in the way the health professional suggested? [If answered 'Yes' skip to question 14]

Yes	No
☐	☐

13) If no, please explain more.

_____

_____

_____

_____

14) If you have made changes to taking your pain medications, did you discuss this with your GP or health professional?

Yes	No
☐	☐

15) How often are your pain and pain medications reviewed?

_____

x

SECTION B

BREATHLESSNESS

Please answer only if you have suffered with breathlessness for most days in the last month

(if you have none, go to page 13 section C)

1) On average over the **past month**, how would you describe his/her breathlessness? (Please tick **one** that best describes your breathlessness).

- I am not troubled by breathlessness except on strenuous exercise ☐
- I am breathless when hurrying on the level, or walking up a slight hill ☐
- I walk slower than most people on the level, or stop after a mile or so, or stop after 15 minutes at my own pace, ☐
- I stop for breath after walking about 100 yards or after a few minutes on level ground ☐
- I am too breathless to leave the house, or I am breathless undressing ☐

2) How long have you experienced breathlessness?

less than 6 months ☐ between 6 months and 1 year ☐ Over 1 year ☐

3) Does your breathlessness affect your normal day-to-day activities?

Never	Rarely	Sometimes	Often	Very Often	Always
☐	☐	☐	☐	☐	☐

4) Do you feel anxious or depressed **because of your breathlessness**?

Never	Rarely	Sometimes	Often	Very Often	Always
☐	☐	☐	☐	☐	☐

5) Have you had to give up or change any of the following **because of your breathlessness**?

Please specify where appropriate.

- ☐ Hobbies _____
- ☐ Exercise _____
- ☐ Family Roles e.g. looking after family members _____
- ☐ Social Roles e.g. meeting friends _____
- ☐ Work/Volunteer Roles _____
- ☐ Sexual Activity _____
- ☐ I have not had to give up or change anything

6) Who do you normally talk to **about your breathlessness**?

General practitioner (GP)	☐	Heart Failure nurse	☐
Practice Nurse	☐	Macmillan nurse	☐
Healthcare Assistant	☐	Long term conditions nurse	☐
Respiratory specialist doctor	☐	Family/friends	☐
Respiratory nurse	☐	No-one	☐
Heart Failure specialist doctor	☐	Other (please specify)	_____

7) Roughly, how often do you see a GP, nurse, or other health professional from your GP surgery **about your breathlessness?**

Every week	Every month	Every three months	Every six months	Yearly	Other (please specify)
☐	☐	☐	☐	☐	_____

8) Does your GP, nurse, or other health professional from your GP surgery ask you about how breathlessness **affects your daily life?**

Yes ☐ No ☐ Not sure ☐

9) What treatments **for your breathlessness** have been organized by your GP, nurse, or other health professional from your GP surgery **in addition to your usual treatment (e.g. inhalers or heart tablets)?** (tick all that apply)

Pulmonary Rehabilitation	☐	Psychological Treatments	☐
Breathing Exercise Techniques	☐	Morphine-like medicines	☐
Handheld Fan	☐	Oxygen	☐
Anxiety Treatment	☐	Other (please specify)	_____

10) **Do you have any of the following conditions?**

COPD (also called emphysema or chronic bronchitis)	☐	Other cancer	☐
Heart disease	☐	Asthma	☐
Lung Cancer	☐	Other (please specify)	_____

SECTION C

UNINTENTIONAL WEIGHT LOSS

Please answer if you have lost weight, without trying in the last 12 months

Appetite

1) Has how much you eat changed in the last 12 months?

Yes, I eat more ☐ No, it's the same ☐ Yes, I eat less ☐

2) My appetite is currently:

Very good ☐ Good ☐ Average ☐ Poor ☐ Very poor ☐

3) Currently, how does food taste to you?

Very good ☐ Good ☐ Average ☐ Bad ☐ Very bad ☐

Weight loss:

4) In the last 12 months, roughly how much weight do you think you have lost?

A few pounds ☐ Half a stone ☐ A stone ☐ Over a stone ☐ Not sure ☐

5) Are you worried about your weight loss?

Yes ☐ No ☐ Not sure ☐

6) Have you mentioned your weight loss to anyone?

A hospital Doctor	☐	Your spouse	☐
Your GP	☐	Family member or friend	☐
Practice nurse	☐	Other person	☐
Another nurse	☐	If other people, please specify	
Carer	☐	_____	

7) Did any of the above weigh you?

Yes ☐ No ☐ Can't remember ☐

8) Have any of the following offered you advice on how to gain weight?

A hospital Doctor	☐	Your spouse	☐
Your GP	☐	Family member or friend	☐
Practice nurse	☐	Other person?	☐

Another nurse	☐	Can't remember	☐
Carer	☐	If other person, please specify_____	

9) What advice/help were you given?

A change in your diet	☐	Can't remember	☐
A referral to your dietitian	☐	Other help?	☐
A new medicine prescribed for you	☐	If other help, please specify:_____	

Are you happy for us to contact you for a more detailed follow-up interview on your experience of any of the symptoms above?

Yes ☐ No ☐

Preferred Contact Detail

Telephone_____ **Mobile** _____

Date of Birth _____

Signature _____

Thank you for completing the questionnaire

APPENDIX B – PATIENT/CARER TOPIC GUIDE

Introduction

At the beginning, the researcher will introduce self, thank the participant(s) for their involvement, explain what will happen (mention breaks if needed), confirm consent to interview and to be recorded.

Questions

PSYCHOLOGICAL IMPACT OF BREATHLESSNESS

1. Can you tell me a bit about your <<or name's>> breathlessness?
    - How long?
    - *Start from beginning*
    - *when did it occur, when did you first start feeling breathless, what problems did you have in the first place*
    - *what happened over time, what is it like to have breathlessness*
    - *what does it mean to have breathlessness (at the beginning and now), has there been a change in your breathlessness*
    - *is breathlessness your biggest problem/symptom, where does breathlessness sit in your other health problems*
    - Impact on daily life?
    - *what impact does it have on you/daily life*
    - *what might you be able to do that you can't do now because of it*
    - *how do you manage it, strategies that you put in place*
    - How does it make you feel in yourself?
    - *how do you feel with it, what does it do to you, what does it feel like, how does it make you feel in yourself, consequences of this, what do you do when you get breathless*

ENCOUNTER WITH DOCTOR/NURSE ETC

2. Let's think about if you <<they>> visit or contact your GP surgery about your breathlessness. Can you tell me about this?
    - *When first had breathlessness*
    - *did you go to your GP when it first occurred, when did you first see a GP/how long before going to GP*

- *did/why did you wait, how bad was breathlessness before taken seriously, was breathlessness taken seriously*
- Who? (who brings up topic of breathlessness) *who brought it up (you or them), was breathlessness taken seriously*
- What was it like getting an appointment? (Did you say why you needed an appointment?)
- What (was discussed about your <<their>> breathlessness)? (symptom vs disease/cause, tests, treatments, management), *what was discussed about your breathlessness (symptom/disease, tests, treatments, management), how do they respond to you about breathlessness, treatments for breathlessness OR condition*
- *how long before they did anything (tests at the time, treatments, management since then)*
- How well do you think they see or understand your breathlessness? *how well do they see/understand it, what/how would you like them to be able to understand about your breathlessness?, how/did you get diagnosis*
- Do you feel happy with the treatment/help they give you (how they deal with the problem)? *are you happy with the treatment you've been given*
- How does this make you feel?
- *what was it like going through this (interaction with HCP)*
- *Did you feel as though your breathlessness had really been considered/taken seriously in the appointment?*

3. How easy or otherwise do you find it to talk about your <<their>> breathlessness with your GP, nurse, or other health professional and why? (How do you feel in the appointment?)

- How easy was it to talk about when it first appeared/or if it persists despite treatment (do you stop telling your doctor about it once you have treatment for whatever disease is diagnosed)? *How easy is it to talk to them about it, what about over time*
- *how do you feel if you see GP about breathlessness now – do you still mention breathlessness*
- *does the GP discuss the impact breathlessness has on you/what you can't do because of breathlessness, if not would you like them to, do you think they know how scary it is for you*
- Disease/cause vs symptom
- Interested, not interested in symptom

    - Practitioner still interested in your breathlessness even after you have been diagnosed and treated? Or do you not bring it up?
- Legitimacy of taking symptom to GP practice (justifiable, valid, reasonable, understandable) *What do you think is legitimate/justifiable to bring to the GP about your breathlessness, what do you feel you can say, what do you want to say, if not why do you not feel you can say anything*
- Barriers (difficulties) and facilitators (help) in mentioning/discussing breathlessness
- How does that make you feel? (e.g. empowered, listened to, frustrated, resigned, helpless etc)

4. What is important/helpful to you in the way your <<their>> GP, nurse, or other health professional listens to you about your breathlessness and the things they might do to help?

- *What is important in the way they listen to you or how they help*
- How does GP/HCP respond?
- Is the GP/HCP responsive/engaged/disengaged? (what about in the long term?)
- Barriers (difficulties) and facilitators (help) in mentioning/discussing breathlessness

CHRONIC BREATHLESSNESS DEFINITION

5. Do you think having a name for your daily breathlessness, such as chronic breathlessness, would help make it easier to understand? What are your thoughts about that?

- Would it be helpful to say you have chronic breathlessness, in addition to COPD, Heart Failure etc?
- How might a name make it more real/legitimate/visible (e.g. help you to talk to your GP team, help them to ask you about it)?
  How would you feel about this?
- *Attitudes of family/friends, do they understand already about your breathlessness, what do they think when you're breathless, how well/do your family/friends understand/support this term*
- *understanding, experience/attitudes towards breathlessness*
- *general visibility*
- *how might a definition help, would it be more helpful/understandable to say COPD etc and chronic breathlessness*
- *easier to have a name in the early stages or now*

6. Is there anything else (patient and/or carer) that you would like to say or discuss?

Those not seeing Primary Care Health Care Practitioner

- Why do you choose not to see a primary care health care practitioner?
    - What stops you?
    - How do you feel about that?
- What would make you go to a primary care health care practitioner?
    - What would help you make the decision to go?
    - Do you want to see a primary care health practitioner?
- Who do you speak to instead?
    - What kind of things do you talk about?

<u>Reminder</u>

Chronic breathlessness syndrome (lay definition) - When breathlessness persists (and leads to disability), despite the underlying condition (e.g. COPD, lung diseases etc) being treated effectively.

Chronic breathlessness syndrome (medical definition) – breathlessness that persists despite optimal treatment of the underlying pathophysiology and that results in disability. A stated duration is not needed for "chronic".

APPENDIX C – HEALTH CARE PRACTITIONER TOPIC GUIDE

Introduction

At the beginning, the researcher will introduce self, thank the participant for their involvement, explain what will happen, confirm consent to interview and to be recorded.

Questions

1. Can you tell me about your experiences when presented with someone suffering with chronic breathlessness? *Perhaps think of someone you have treated for chronic/breathlessness?*

- What happens/what was discussed? (look at disease vs symptom, tests, treatments, management)
- Who raises the topic of breathlessness/how do you determine they are breathless? e.g. patient tells you, you can see it
    - Bring up the topic of breathlessness once treatment has been given for whatever disease is diagnosed?
    - How do you respond to their breathlessness?
- How do you proceed? e.g. management, strategies, referrals, guidance
    - Referred to specialist clinics, first line of treatment?
        - Who goes to which clinics/which conditions referred where?
    - If breathlessness is used as a signpost to diagnosis, do breathlessness management strategies also get offered?
    - If meds and referrals are optimised, is this the beginning of diagnosis and the end of symptom management?
- How easy do you think it is for them (or you) to raise the topic of breathlessness?
    - What about if their breathlessness is persistent (once an individual has been given treatment for whatever disease is diagnosed)?
- How do you think chronic breathlessness affects those that you see (patients and carers?)
- Do you bring patients back to review their breathlessness?
- Do you use any outcome measurements for breathlessness, e.g. mMRC, VAS, NRS
    - If no, do you think they would useful (changes over time etc)?

2. How do you feel when presented with someone with chronic breathlessness and any associated side effects (physical or psychological)?

- adequately prepared, comfortable, well equipped, not prepared
    - training?
        - How did you access training, why did you go?
        - If not been on any courses
            - How well known are any self-management strategies?
            - Any other training out there to help you? Anything else you would like/any training needs within general practice?
                - How to access them?
    - How well do you think you understand their breathlessness?
- Do you ask about how their breathlessness impacts their life?
- How do you think people 'cope' with it?
- Do you feel you've done everything you can in order to attend to someone's breathlessness?

3. What are your thoughts about recognising chronic breathlessness as a syndrome in its own right? *Helpful to say COPD and chronic breathlessness? Give definition again*

- How might a name make it more real/legitimate/visible (e.g. increase awareness)?
- Why might it be important to give something a name?
- How do you think patients feel about receiving a diagnosis of chronic breathlessness?
- What does it mean to you as a practitioner?
    - Would it help with the general visibility of breathlessness?
    - Would it help when discussing it with patients and their family/carers?
- How do you feel about it/this term?
- Designation of syndrome raise awareness amongst colleagues?

4. How do you feel about telling someone they have chronic breathlessness syndrome?

- Further breathlessness support in secondary care?
- Is breathlessness as a symptom something which may fall between the gap?

5. Is there anything else that you would like to say or discuss about chronic breathlessness (about practitioners, patients, carers, or the primary care encounter)?

Reminder

Chronic breathlessness syndrome (medical definition) – breathlessness that persists despite optimal treatment of the underlying pathophysiology and that results in disability. A stated duration is not needed for "chronic".

Chronic breathlessness syndrome (lay definition) - When breathlessness persists (and leads to disability), despite the underlying condition (e.g. COPD, lung diseases etc) being treated effectively.

APPENDIX D – ETHICAL APPROVALS

HYMS Approval

Hull York Medical School
Hull
University of Hull
Hull, HU6 7RX, UK
York
University of York
York, YO10 5DD, UK
T 0870 1245500
info@hyms.ac.uk
www.hyms.ac.uk

3 October 2018

Dr Mabel Okoeki
Research Associate
Wolfson Palliative Care Research Centre
Hull York Medical School

Dear Mabel

18 25 – Proactive Anticipatory Care Evaluation (PACE) study

I have reviewed this study on behalf of HYMS Ethical Committee with respect to the documents received on 28 September 2018. I am pleased to inform you that I do not have any HYMS-specific or ethical concerns, or additional requirements. On receipt of HRA approval please forward a copy of this letter for our files.

On behalf of the Ethics Committee, we wish you success with this study.

Please let me know if I can be of further assistance.

Kind regards

Yours sincerely

Professor Thozhukat Sathyapalan
Chair
HYMS Ethics Committee

Cc: Prof F Murtagh

Research Ethics Committee Approval

NHS
Health Research Authority
Yorkshire & The Humber - Bradford Leeds Research Ethics Committee
NHSBT Newcastle Blood Donor Centre
Holland Drive
Newcastle upon Tyne
NE2 4NQ

Telephone: 0207 1048 088

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

24 January 2019

Professor Fliss Murtagh
Allam Medical Building
University of Hull
Cottingham Road
Hull
HU6 7RX

Dear Professor Murtagh

Study title:	**Proactive Anticipatory Care Evaluation (PACE) study**
REC reference:	**18/YH/0470**
Protocol number:	**N/A**
IRAS project ID:	**250981**

Thank you for your submission of 17 January 2019, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a **favourable** ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Mental Capacity Act 2005

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non-registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

The Committee has not yet completed any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. We will write to you again as soon as an SSA application(s) has been reviewed. In the meantime no study procedures should be initiated at non-NHS sites.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Introduction leaflet]	2	19 September 2018
Copies of advertisement materials for research participants [Introduction leaflet]	3	09 January 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [evidence of sponsorship insurance or indemnity]		18 October 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [evidence of sponsorship insurance or indemnity]		24 September 2018
Interview schedules or topic guides for participants [patient topic guide (breathlessness)]	2	19 September 2018
Interview schedules or topic guides for participants [health professional topic guide (Breathlessness)]	2	19 September 2018
Interview schedules or topic guides for participants [patient topic guide (pain medicine)]	2	19 September 2018
Interview schedules or topic guides for participants [Carers topic guide-pain medicine]	2	19 September 2018
Interview schedules or topic guides for participants [health professionals topic guide (pain medicine)]	2	19 September 2018
Interview schedules or topic guides for participants [patient/care topic guide (unintentional weight loss)]	2	19 September 2018
Interview schedules or topic guides for participants [health professional topic guide (unintentional weight loss)]	2	19 September 2018
IRAS Application Form [IRAS_Form_23112018]		23 November 2018
Letter from funder [confirmation of scholarship]		03 January 2017
Letter from sponsor [letter of sponsorship]		16 October 2018
Letter from sponsor [letter of sponsorship]		16 October 2018
Letters of invitation to participant [Letter of invitation]	3	09 January 2019
Letters of invitation to participant [Letter of invitation with track changes]	3	09 January 2019

Non-validated questionnaire [Baseline questionnaire (those with capacity)]	2	19 September 2018
Non-validated questionnaire [baseline questionnaires (without capacity)]	2	19 September 2018
Non-validated questionnaire [Baseline questionnaire (control group)]	2	19 September 2018
Non-validated questionnaire [Follow up questionnaire (with capacity)]	2	19 September 2018
Non-validated questionnaire [follow up questionnaire (without capacity)]	2	19 September 2018
Non-validated questionnaire [Questionnaire for patients information (records)]	3	09 January 2019
Non-validated questionnaire [Questionnaires for patient information (records) with track changes]	3	09 January 2019
Other [Response to REC amendment]		14 January 2019
Other [University of Hull lone worker policy]		15 December 2016
Participant consent form [Patient consent form]	3	08 January 2019
Participant consent form [patient informed consent form (interview)]	3	08 January 2019
Participant consent form [informed consent form (interview) with track changes]	3	08 January 2019
Participant consent form [Informed consent form with track changes]	3	08 January 2019
Participant consent form [consultee declaration form]	3	08 January 2019
Participant consent form [consultee declaration form with track changes]	3	08 January 2019
Participant information sheet (PIS) [participants information sheet (cases)]	3	08 January 2019
Participant information sheet (PIS) [participant information sheet (cases) with track changes]	3	08 January 2019
Participant information sheet (PIS) [participants information sheet (control group)]	3	08 January 2019
Participant information sheet (PIS) [participant information sheet (control group) with track changes]	3	08 January 2019
Participant information sheet (PIS) [patient/family information sheet (interviews)]	3	08 January 2019
Participant information sheet (PIS) [Patient/carer information sheet with (interview) with track changes]	3	08 January 2019
Participant information sheet (PIS) [Health professional information sheets (interviews)]	3	08 January 2019
Participant information sheet (PIS) [health professionals information sheet (interview) with track changes]	3	08 January 2019
Participant information sheet (PIS) [Consultee Information sheet]	1	08 January 2019
Research protocol or project proposal [Project protocol]	10	09 January 2019
Summary CV for Chief Investigator (CI) [Fliss CV]	1	18 September 2018
Summary CV for student [Helene CV]	1	19 September 2018
Summary CV for student [Gochi CV]	1	19 September 2018
Summary CV for student [Sophie's CV]	1	19 September 2018
Summary CV for supervisor (student research) [Fliss CV]	1	19 September 2018
Summary CV for supervisor (student research) [Jason CV]	1	19 September 2018
Summary CV for supervisor (student research) [Joseph CV]	1	19 September 2018
Summary CV for supervisor (student research) [Miriam's CV]	2	19 September 2018
Summary, synopsis or diagram (flowchart) of protocol in non-technical language [Summary of project]	2	17 August 2018

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

18/YH/0470	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely
pp

Sarah Pothero

Dr Janet Holt
Chair

Email: nrescommittee.yorkandhumber-bradfordleeds@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Dr Andrew Taylor, University of Hull*

Dr Marie Girdham, NHS East Riding of Yorkshire Clinical Commissioning Group

A Research Ethics Committee established by the Health Research Authority

APPENDIX E – PUBLISHED SYSTEMATIC REVIEW ARTICLE

Elliott-Button HL, Johnson MJ, Nwulu U, Clark J. Identification and assessment of breathlessness in clinical practice: a systematic review and narrative synthesis. Journal of pain and symptom management. 2020 Mar 1;59(3):724-33.

https://www.sciencedirect.com/science/article/abs/pii/S0885392419306050

APPENDIX F – SEARCH STRATEGY EXAMPLE

1	EXPOSURE	Dyspnea exp
2		Dyspnea
3		Dyspnoea
4		Breathlessness
5		“shortness of breath”
6		“difficult* breathing”
7		“breathing difficult*”
8		1 or 2 or 3 or 4 or 5 or 6 or 7
9	OUTCOME	“symptom assessment” exp
10		assess*
11		“patient reported outcome measures” exp
12		“patient reported outcome”
13		9 or 10 or 11 or 12
14	POPULATION	8 and 13 (Limited to English Language; Human; Adult; 2000 - Feb 2018)

APPENDIX G – REFERENCE LIST OF INCLUDED STUDIES

1. Haughney J, Gruffydd-Jones K, Roberts J, et al. The distribution of COPD in UK general practice using the new GOLD classification. Eur Respir J. 2014;43(4):993-1002.

2. Merinopoulou E, Raluy-Callado M, Ramagopalan S, Maclachlan S, Khalid JM. COPD exacerbations by disease severity in England. International Journal of COPD. 2016;11(1):697-709.

3. Nibber A, Chisholm A, Soler-Cataluna J, et al. Validating the Concept of COPD Control: A Real-world Cohort Study from the United Kingdom. COPD: Journal of Chronic Obstructive Pulmonary Disease. 2017;14(5):504-12.

4. van den Bemt L, Smeele I, Kolkman M, et al. Low body mass index, airflow obstruction, and dyspnoea in a primary care COPD patient population. Primary Care Respiratory Journal. 2010;19(2):118-23.

5. Mullerova H, Lu C, Li H, Tabberer M. Prevalence and burden of breathlessness in patients with chronic obstructive pulmonary disease managed in primary care. PLoS ONE. 2014;9(1):e85540.

6. Jones R, Dickson-Spillmann M, Mather M, Marks D, Shackell B. Accuracy of diagnostic registers and management of chronic obstructive pulmonary disease: the Devon primary care audit. Respiratory Research. 2008;9:62-.

7. Lee L, Patel T, Hillier L, Milligan J. Office-Based Case Finding for Chronic Obstructive Pulmonary Disease in Older Adults in Primary Care. Canadian Respiratory Journal. 2016;2016:1083270.

8. Singh MP. Indacaterol therapy in moderate-to-severe chronic obstructive pulmonary disease: Findings from a single-center primary care cohort. International Journal of Chronic Obstructive Pulmonary Disease. 2013;8:613-9.

9. Steer J, Norman E, Afolabi O, Gibson G, Bourke S. Dyspnoea severity and pneumonia as predictors of in-hospital mortality and early readmission in acute exacerbations of COPD. Thorax. 2012;67(2):117-21.

10. Morris D, Galicia-Castillo M. Dying With Dyspnea in the Hospital. American Journal of Hospice & Palliative Medicine. 2017;34(2):132-4.

11. Webb M, Moody L, Mason L. Dyspnea assessment and management in hospice patients with pulmonary disorders. American Journal of Hospice & Palliative Medicine. 2000;17(4):259-64.

12. Manali E, Stathopoulos G, Kollintza A, et al. The Medical Research Council chronic dyspnea score predicts the survival of patients with idiopathic pulmonary fibrosis. Respir Med. 2008;102(4):586-92.

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APPENDIX H – GENERAL CHARACTERISTICS OF INCLUDED STUDIES – PRIMARY CARE

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Hall P et al (2002)	Canada, Primary Care/Long Term Care	Observational, chart review, retrospective	185; 86.2 (Range 55 - 107); Different conditions: Cognitive impairment, Cardiac, Other, Respiratory, Neurologic, Musculoskeletal, Cancer	Documented - no further information on identification	
Haughney J et al 2013	UK, Primary Care	Observational, retrospective cohort	9219; 69.5 ± 11.1; COPD		Lung function measurements (FEV1)
				mrc - mMRC	mrc - mMRC
				CAT	CAT
Jones RC et al (2008)	UK, Primary Care	Audit, prospective	422; 69.2 (8.7); COPD		Lung function measurements (FEV1)
				mrc - MRC	mrc - MRC
				Clinical COPD Questionnaire (CCQ)	Clinical COPD Questionnaire (CCQ)
					Lung Information Needs Questionnaire (LINQ)

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Lee L et al (2016)	Canada, Primary Care	Observational, medical records review, retrospective	516; 80.8 ± 4.5 (Range 74-96); COPD		Lung function measurements (FEV1/FVC)
				CTS	CTS
Merinopoulou E et al 2016	UK, Primary Care	Observational, retrospective cohort	44201; 71.5 (10.7); COPD		Lung function measurements (FEV1)
				mrc - mMRC	mrc - mMRC
Mullerova H (2014)	UK, Primary Care	Observational, retrospective cohort	49438; 69.2 (10.3); COPD		Lung function measurements (FEV1)
				mrc - MRC	mrc - MRC
Nibber A et al (2017)	UK, Primary Care	Observational, retrospective cohort	2788; Mild/moderate COPD - 71.1 (9.5) Severe/very severe COPD - 72 (8.8); COPD		Lung function measurements (FEV1)
				CAT	CAT
				mrc - mMRC	mrc - mMRC
Singh MP (2013)	UK, Primary Care	Audit, retrospective	15; 64 (7.7) (Range 52–74); COPD	Patient reported (volunteered)	Lung function measurements (FEV1)

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
van den Bemt L et al (2010)	Netherlands, Primary Care	Observational, cross-sectional, prospective	2023; 62.8 (10.8); COPD		Lung function measurements (FEV1)
				mrc - mMRC	mrc - mMRC

CAT: COPD Assessment Test; CCQ: Clinical COPD Questionnaire; CTS: Canadian Thoracic Screening Questionnaire; mMRC: modified Medical Research Council Dyspnea Scale; LINQ: Lung Information Needs Questionnaire

APPENDIX I – GENERAL CHARACTERISTICS OF INCLUDED STUDIES – SECONDARY CARE

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Bagheri R et al (2015)	Iran, Secondary/Tertiary Care	Observational, retrospective study	38; Mean - 47.73 (Range 22 - 79); ILD - Interstitial Lung Disease		VATS (Video assisted thoracic surgery)
				Clinician assessment (asked)	
Bailey SP et al (2008)	USA, Secondary/Tertiary Care	Observational, chart review, retrospective	159 (Completers 139, Non-Completers 20); Completers - 68+1, Non-Completers - 68+2; COPD		Walk tests - 6MWT
				UCSD (University of California San Diego Shortness of Breath Questionnaire)	UCSD (University of California San Diego Shortness of Breath Questionnaire)
					Lung function measurements (FEV1% pred, FVC% pred)
Bajwah S et al (2012)	UK, Secondary/Tertiary Care	Case note assessment, retrospective	45; RBH: 61 ± 11, KCH: 83 ± 8; ILD - Progressive idiopathic fibrotic interstitial lung disease (PIF-ILD)	Clinician assessment (asked)	

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Banerjee D et al (2017)	USA, Secondary/Tertiary Care	Observational, retrospective study	50; 62 (Range 49–71); Pulmonary Arterial Hypertension	Borg - MBS (Modified Borg Scale)	Borg - MBS (Modified Borg Scale)
Burton AW et al (2011)	USA, Secondary/Tertiary Care	Observational, medical records review, retrospective	407; 62.9; Cancer	esas – ESAS	esas - ESAS
Calle Rubio M et al (2017)	Spain, Secondary/Tertiary Care	Clinical audit, retrospective	4508; Median (IQR) - 69.7 (63–77.7); COPD	mrc - mMRC	mrc - mMRC
				CAT	CAT
					Lung function measurements (FEV1)
Cameron P et al (2012)	Canada, Secondary/Tertiary Care	Observational, chart review, retrospective	202; 67.0 (9.9) (Range 35–89); Cancer	esas - ESAS	esas - ESAS

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Cheng Y et al (2017)	China, Secondary/Tertiary Care	Observational, retrospective study	142; FE - 72.1±8.24, iFE - 66.72±10.97; COPD		Imaging - HRCT (Thoracic high-resolution computed tomography)
				CAT	CAT
				mrc - mMRC	mrc - mMRC
					Lung function measurements (FEV1% pred, FEV1/FVC, PaO2, PaCO2)
Clini EM et al (2009)	Italy, Secondary/Tertiary Care	Observational, retrospective cohort	1826; 70.8 (8.4); COPD		Walk tests - 6MWD
				Borg - BORG	Borg - BORG
				SGRQ	SGRQ
				mrc - MRC Score	mrc - MRC Score
					Lung function measurements (FEV1% pred, PaO2, PaCO2)

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Connor MC et al (2001)	Ireland, Secondary/Tertiary Care	Observational, prospective study	170; 68.5 ± 8.3; COPD		Walk tests - Shuttle Walk Test
					Walk tests - Treadmill Walk Test
				Borg - BORG	Borg - BORG
					BPQ (Breathing Problems Questionnaire)
					CRDQ - CRDQ (Chronic Respiratory Disease Questionnaire)
				SGRQ	SGRQ
Eades M et al (2013)	Canada, Secondary/Tertiary Care	Observational, retrospective study	27; 54.9 (9.2); Cancer	esas - ESAS (Modified)	esas - ESAS (Modified)
				MD Anderson Symptom Inventory (MDASI)	MD Anderson Symptom Inventory (MDASI)–Impact on Function Subscale
					Walk tests - 6MWT

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Ernst A et al (2009)	USA, Secondary/Tertiary Care	Observational, chart review, retrospective	31 (30 >18 DATA); Median (Range) - 42.5 (19 - 61); Relapsing Polychondritis (RP)		Imaging - CT Scan
					Bronchoscopy
				Clinician assessment (asked)	
Evangelista LS et al (2000)	USA, Secondary/Tertiary Care	Observational, medical records review, retrospective	753l 69 (±11.7) (Range 35 - 99); Heart Failure		NYHA
				Patient reported (volunteered)	
Ferreira A et al (2009)	USA, Secondary/Tertiary Care	Observational, retrospective study	99; 66 (13); ILD		Lung function measurements (FEV, FEV% pred, DLco, DLco %)
				Borg - BORG	Borg - BORG
				UCSD (University of California San Diego Shortness of Breath Questionnaire)	UCSD (University of California San Diego Shortness of Breath Questionnaire)
					Walk tests - 6MWT

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Franssen FM et al (2011)	Netherlands, Secondary/Tertiary Care	Observational, medical records review, retrospective	1859; 64.3 ± 9.7; COPD		Lung function measurements (FEV1, FEV1% pred, FEV1/FVC, Dlco, PaO2, PaCO2)
				mrc - MRC	mrc - MRC
				SGRQ	SGRQ
					Walk tests - 6MWD
Greulich T et al (2015)	Germany, Secondary/Tertiary Care	Observational, retrospective study	544; 57.23 ± 6.82; COPD		Lung function measurements (FEV1, RV, So2)
				CAT	CAT
				mrc - mMRC	mrc - mMRC
				Borg - BORG	Borg - BORG
					Walk tests - 6MWT

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Hunter CL et al (2015)	USA, Secondary/Tertiary Care	Observational, retrospective cohort	106 (31 - CHF Data); 69 (16); CHF (Congestive Heart Failure)		Waveform capnography (ETCO2 [End tidal carbon dioxide])
					Lung function measurements (SPO2)
Johnson-Warrington V et al (2015)	UK, Secondary/Tertiary Care	Service evaluation (prospective?)	43; 72.17 (10.54); ILD (interstitial lung disease)	Borg - BORG	Borg - BORG
					Walk tests - ISWT
					Walk tests - ESWT
				mrc - MRC	mrc - MRC
					Lung function measurements (FEV1, FEV1% pred, FVC, FVC% pred, FEV1/FVC, TLCO, TLCO% pred, SaO2)
Kaymaz D et al (2013)	Turkey, Secondary/Tertiary Care	Observational, retrospective study	10; 51.3 ± 16.5; ILD - Interstitial Lung Diseases	mrc - mMRC	mrc - mMRC
					Walk tests - ISWT
					Walk tests - ESWT
				SGRQ	SGRQ
					Lung function measurements (FEV1%, FVC%, FEV/FVC, DLCO)

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Kelly JL et al (2012)	UK, Secondary/Tertiary Care	Observational, prospective study	224; 63.5±10.3; COPD	mrc - MRC	mrc - MRC
				CAT	CAT
					Lung function measurements (FEV1, FEV1% pred, FVC, FEV1/FVC%, TLC%, RV/TLC%, FRC % pred, TLCO% pred, KCO% pred, PaO2 kPa, PaCO2 kPa, SaO2 %)
Kendrick KR et al (2000)	USA, Secondary/Tertiary Care	Observational, chart review, retrospective	102; 59 (24 - 87); COPD		Lung function measurements (PEFR, SaO2)
				Borg - MBS (Modified Borg Scale)	Borg - MBS (Modified Borg Scale)

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Kontogianni K et al (2014)	Germany, Secondary/Tertiary Care	Observational, retrospective study	26; 66±8; COPD		Walk tests - 6MWT
				SGRQ	SGRQ
				mrc - mMRC	mrc – mMRC
					Lung function measurements (FEV1, FEV1% pred, VC, VC% pred, RV, RV% pred, TLC, TLC% pred, RV/TLC, PaO2 mm Hg)
Lange P et al (2009)	Denmark, Secondary/Tertiary Care	Audit, retrospective	Audit 1 - 941; 69.2 (10.7); COPD; Audit 2 - 927; 68.5 (10.3); COPD		Lung function measurements (FEV1% pred, FVC% pred)
				mrc - MRC	mrc - MRC
Lecleire S et al (2007)	France, Secondary/Tertiary Care	Observational, retrospective study	15; 58 (Range 39–68); Cancer	Van Den Bongard's Score (none (0), slight (1), severe (2) and high-grade stenosis with cyanosis or stridor (3))	Van Den Bongard's Score (none (0), slight (1), severe (2) and high-grade stenosis with cyanosis or stridor (3))

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Majewski M et al (2010)	UK, Secondary/Tertiary Care	Observational, retrospective study	7; 69.13 ± 9.76; COPD	SGRQ	SGRQ
					CRDQ - CRQ
				Borg - BORG	Borg - BORG
					Lung function measurements (SaO2)
					Walk tests - ISWT
					Walk tests - ESWT
Major S et al (2014)	USA, Secondary/Tertiary Care	Observational, medical records review, retrospective	78; 65.4 ± 9.0; COPD		Lung function measurements (FEV1)
				SGRQ	SGRQ
				mrc - mMRC	mrc - mMRC
				UCSD (University of California San Diego Shortness of Breath Questionnaire)	UCSD (University of California San Diego Shortness of Breath Questionnaire)
					Walk tests - 6MWT

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Malin JL et al (2011)	USA, Secondary/Tertiary Care	Observational, medical records review, retrospective	118; 65.9 (9.9); Cancer	Documented - no further information on identification	
Manali ED et al (2008)	Greece, Secondary/Tertiary Care	Observational, medical records review, retrospective	25; 64±2; ILD (Interstitial Lung Disease) - Usual interstitial pneumonia/idiopathic pulmonary fibrosis (UIP/IPF)		Lung function measurements (FEV1, FVC, FEV1/FVC, TLC, DLCO, PaO2, PaCO2)
				mrc - MRC	mrc - MRC
Mapel DW et al (2005)	USA, Secondary/Tertiary Care	Observational, medical records review, retrospective	2116; 71.1 (Range 32–99); COPD		Lung function measurements (FEV1% pred)
				Patient reported (volunteered)	
Miyahara S et al (2015)	Japan, Secondary/Tertiary Care	Observational, retrospective study	269; 71.2 ± 10.6; COPD		Lung function measurements (FEV1/FVC)
				mrc - mMRC	mrc – mMRC

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Morris D et al (2017)	USA, Secondary/Tertiary Care	Observational, chart review, retrospective	106; 60 (17); Different conditions: Cancer, Cardiac, Pulmonary, Neurologic, Renal, Other	Clinician assessment (observation)	
Morris GS et al (2009)	USA, Secondary/Tertiary Care	Observational, chart review, retrospective	30; 64.9±4.21; Cancer		Walk tests - 6MWT
				Borg - Borg RPE (Rating of Perceived Exertion)	Borg - Borg RPE (Rating of Perceived Exertion)
				Borg - BORG	Borg - BORG
					Lung function measurements (SaO2)
Nishiyama O et al (2010)	Japan, Secondary/Tertiary Care	Observational, retrospective study	93; 66.3±8.1; ILD - IPF (Idiopathic Pulmonary Fibrosis)		Lung function measurements (FVC L, FVC% pred, FEV1 L, FEV% pred, DLCO, PaO2, PaCO2, pH)
				mrc - mMRC	mrc - mMRC
					Walk tests - 6MWT
				Borg - BORG	Borg - BORG
Nishizaki Y et al (2013)	Japan, Secondary/Tertiary Care	Observational, chart review, retrospective	170; 69.7 ± 10.8; Aortic Valve Stenosis		Doppler echocardiography (2D)
					NYHA

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Pierie JP et al (2002)	USA, Secondary/Tertiary Care	Observational, retrospective study	67; Median 73 (Range 40-92); Cancer	Patient reported (volunteered)	
Revill SM et al (2009)	UK, Secondary/Tertiary Care	Observational, retrospective study	44; 67.6 (9.0); COPD		Walk tests - ESWT
					Walk tests - ISWT
					Lung function measurements (SaO2)
				Borg - MBS (Modified Borg Scale)	Borg - MBS (Modified Borg Scale)
Roche N et al (2001)	France, Secondary/Tertiary Care	Observational, prospective study	1510 (631 - COPD); 64.3±0.5; COPD	VAS (Dyspnea)	VAS (Dyspnea)
				mrc – MRC	mrc – MRC
					Lung function measurements (PEFR [Peak Expiratory Flow Rate], FEV1, FEV1/VC, TLC, PaO2, PaCO2)

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Rozenberg D et al (2015)	Canada, Secondary/Tertiary Care	Observational, retrospective study	790; Median (IQR) - 53 (41-65); Hereditary hemorrhagic telangiectasia		Lung function measurements (FEV1/FVC, TLC, DLCO, PaO2, PaCO2)
					Echocardiogram
					Imaging - Radiology (CT, Chest X-Ray)
				mrc – mMRC	mrc – mMRC
Seow H et al (2012)	Canada, Secondary/Tertiary Care	Observational, chart review, retrospective	912; 64.3 (12.2); Cancer	esas – ESAS	esas - ESAS
Steer J et al (2012)	UK, Secondary/Tertiary Care	Observational, prospective study	920; 73.1 (10.0); COPD		Lung function measurements (FEV1)
				mrc – MRC	mrc – MRC
				mrc – eMRC	mrc – eMRC

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Stevens JP et al (2018)	USA, Secondary/Tertiary Care	Observational, prospective study	67362; 58.0±18.8; Different conditions: Disease of the circulatory system, Diseases of the digestive system	NRS	NRS
Thaiss W et al (2016)	Germany, Secondary/Tertiary Care	Observational, retrospective study	18; Median±SD - 57±17.3, Range - 30–82; Relapsing Polychondritis		Imaging - CT/MRI
				Clinician assessment (asked)	
Tottenborg SS et al (2013)	Denmark, Secondary/Tertiary Care	Observational, prospective cohort	32018; Median: 2008 - 70.1, 2009 - 70.4, 2010 - 70.6, 2011 - 70.6; COPD	mrc – MRC	mrc – MRC
					Lung function measurements (FEV1% pred)
Tramacere A et al (2004)	Italy, Secondary/Tertiary Care	Observational, chart review, retrospective (case-control)	146; Cases - 71 ± 7, Controls - 72 ± 7; COPD		Lung function measurements (FEV1, FEV1/FVC, FVC, PaO2, PaCO2, MIP [Maximal Inspiratory Pressure]/MEP [Maximal Expiratory Pressure])
				mrc – MRC	mrc – MRC
					Walk tests - 6MWD
				Borg – BORG	Borg – BORG

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Twaddle ML et al (2007)	USA, Secondary/Tertiary Care	Observational, cross-sectional, chart review, retrospective	1596; 58.4 (Range 18–99); Different conditions: Heart Failure, Cancer, HIV, Respiratory		Quantitative scale - Dyspnea (no further information)
				Documented - no further information on identification	
Vanfleteren LEGW et al (2011)	Netherlands, Secondary/Tertiary Care	Observational, retrospective study	536; 63.7 ± 9.4; COPD	mrc – mMRC	mrc – mMRC
					Walk tests - 6MWD
					Lung function measurements (FEV1, FVC, Diffusion lung capacity for carbon monoxide % pred, partial pressure of carbon dioxide/arterial carbon dioxide tension [kPa], partial pressure of oxygen/arterial oxygen tension (kPa))
					ECG (Electrocardiogram)
					High-sensitive C-reactive protein

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Walling AM et al (2010)	USA, Secondary/Tertiary Care	Observational, medical records review, retrospective	496; 62.3 (18) (Range 18-104); Different conditions: Advanced cancer, End-stage pulmonary disease, End-stage heart failure, End-stage liver disease, End-stage renal disease, AIDS, Severe dementia	Documented - no further information on identification	
Walling AM et al (2012)	USA, Secondary/Tertiary Care	Observational, medical records review, retrospective	118; 60.3 (18) (Range 20–92); Cancer		Unknown - Dyspnea assessed after treatment
				Documented - no further information on identification	
Walling AM et al (2013)	USA, Secondary/Tertiary Care	Observational, retrospective cohort	719; 66.2 (10.3); Cancer	Documented - no further information on identification	
Wu JR et al (2016)	USA, Secondary/Tertiary Care	Observational, chart review, retrospective	482; 62 (15); Heart Failure	Documented - no further information on identification	

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Wysham NG et al (2016)	USA, Secondary/Tertiary Care	Observational, database review, retrospective	254; 67.5 (17.3); Different conditions: Neurologic disease, Cardiovascular disease, Cancer, Pulmonary disease, Infectious disease, Gastrointestinal disease, Other diagnosis	Documented - no further information on identification	
Zanini A et al (2015)	Italy, Secondary/Tertiary Care	Observational, retrospective study	108; 71 ± 13; Non-Cystic Fibrosis Bronchiectasis		Lung function measurements (FEV1 % pred, VC % pred, FEV1/VC %, RV % pred, TLC % pred, RV/TLC %, TLCO % pred, PaO2 mm Hg, PaCO2 mm Hg)
				BDI/TDI (Baseline and Transition Dyspnea Index)	BDI/TDI (Baseline and Transition Dyspnea Index)
				Borg - BORG	Borg - BORG
					Walk tests - 6MWD

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Zhang J et al (2014)	China, Secondary/Tertiary Care	Observational, medical records review, retrospective	605; 64.8±8.5; COPD		Lung function measurements (FEV1% pred, FVC, FVC% pred, FEV1/FVC, MVV% pred, RV% pred, TLC% pred, RV/TLC% pred, IC% pred, IC/TLC%, DLCO% pred, DLCO/VA%, VC% pred, PaO2, PaCO2)
					Imaging - CT Scan
				mrc - mMRC	mrc - mMRC

6MWD: Six minute walk distance; 6MWT: Six minute walk test; Borg RPE: Rate of Perceived Exertion; Borg MBS: Modified Borg Scale; BPQ: Breathing Problems Questionnaire; CAT: COPD Assessment Test; CRQ: Chronic Respiratory Disease Questionnaire; ESAS: Edmonton Symptom Assessment Scale; ESWT: Endurance Shuttle Walk Test; HRCT: Thoracic high-resolution computed tomography; ISWT: Incremental Shuttle Walk Test; Lung Function Measurements (DLCO: Diffusing capacity for carbon monoxide; DLCO%: Diffuse capacity for carbon monoxide % predicted; FEV1: Forced Expiratory Volume in one second; FEV: Forced Expiratory Volume; FEV% predicted: Forced Expiratory Volume % predicted; FEV1% predicted: Forced Expiratory Volume in one second % predicted; FRC% predicted: Functional residual capacity % predicted; FVC: Forced Vital Capacity; FVC% predicted: Forced Vital Capacity % predicted; FEV1/FVC: Forced Expiratory Volume in one second/Forced Vital Capacity; KCO% predicted; Carbon monoxide transfer coefficient % predicted; MIP: Maximal Inspiratory Pressure; MEP: Maximal Expiratory Pressure: MVV% predicted: Maximum voluntary ventilation %; Pa02: Partial pressure of oxygen; PaCo2: Partial pressure of carbon dioxide; PEFR: Peak Expiratory Flow Rate; RV: Residual Volume; RV% predicted: Residual volume % predicted; RV/TLC: Residual volume/Total lung capacity; RV/TLC%: Residual volume/Total lung capacity%; SaO2: Oxygen Saturation; SO2: Oxygen saturation; SPO2: Peripheral capillary oxygen saturation; TLC%: Total lung capacity%; TLC% predicted: Total lung capacity% predicted; TLCO: Transfer factor of the lung for carbon monoxide; TLCO% predicted; Transfer factor of the lung for carbon monoxide % predicted; VC: Vital Capacity; VC% predicted: Vital capacity % predicted); MDASI: MD Anderson Symptom Inventory; MRC: Medical Research Council Dyspnea Scale; mMRC: modified Medical Research Council Dyspnea Scale; NRS: Numerical Rating Scale; NYHA: New York Heart Association Functional Classification; SGRQ: St. George's Respiratory Questionnaire; UCSD: University of California San Diego Shortness of Breath Questionnaire; VAS: Visual Analogue Scale; VATS: Video Assisted Thoracic Surgery

APPENDIX J – GENERAL CHARACTERISTICS OF INCLUDED STUDIES – SPECIALIST PALLIATIVE CARE

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Abela J (2009)	Malta, Palliative Care	Evaluation (prospective?)	56; 69.2; Different conditions: Cancer, Motor Neurone Disease		STAS - Support Team Assessment Schedule
Bostwick D et al (2017)	USA, Palliative Care	Observational, cross-sectional, retrospective	879; 66.9 (15.0); Different conditions: Cancer, End-Stage Renal Disease, Heart Failure, COPD		PPS - Palliative Performance Scale
				esas - ESAS	esas – ESAS
Bourke SJ et al (2016)	UK, Palliative Care	Service evaluation (prospective case-series)	28; 31 (Range 18 - 47); Cystic Fibrosis	Palliative Care Assessment Tool	Palliative Care Assessment Tool
Bruera E et al (2000)	USA, Palliative Care	Observational, prospective study	135; 60±13; Cancer	VAS (Dyspnea)	VAS (Dyspnea)
					Lung function measurements (VC% pred, peak flow% pred, MIP, SAO2)

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Caraceni A et al (2012)	Italy, Palliative Care	Observational, retrospective study	129; Median - 58 (25th–75th percentile 48–69); Cancer		Palliative Prognostic Score (PaP)
				Documented - no further information on identification	
Cheung WY et al (2009a)	Canada, Palliative Care	Observational, medical records review, retrospective	198; 63.8 (12.9) (Range 24.9-89.3); Cancer	esas - ESAS	esas – ESAS
Cheung WY et al (2009b)	Canada, Palliative Care	Observational, medical records review, retrospective	1366; 64.4 (Range 18.7–74.1); Cancer	esas - ESAS	esas – ESAS
Covarrubias-Gómez A et al (2014)	Mexico, Palliative Care	Observational, medical records review, retrospective	38; 60.7 (15.6) (Range 30 - 90); Cancer	esas - ESAS	esas – ESAS

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Cowan JD et al (2002)	USA, Palliative Care	Observational, prospective study	210; Median 70 (Range 28 – 102); Different conditions: Cancer; Noncancer - 35 (17%):	Clinician assessment (asked)	
de la Cruz M et al (2015)	USA, Palliative Care	Observational, chart review, retrospective	771; ≥65; Cancer	esas - ESAS	esas – ESAS
Delgado-Guay MO et al (2016)	USA, Palliative Care	Observational, chart review, retrospective	400; Median 56 (Range 48–64); Cancer	esas - ESAS	esas – ESAS

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Ekström M et al (2016)	Australia, Palliative Care	Observational, longitudinal, prospective	12778; 73 (14); Different conditions: Lung cancer, Colorectal cancer, Other gastrointestinal cancer, Breast cancer, Neurologic disease, Hematological cancer, Pancreas cancer, Prostate cancer, Cardiovascular disease, Other non-malignancy, Respiratory failure, Other diagnosesb (Neurologic disease included stroke, dementia, and neuromuscular disease Other diagnoses included end-stage kidney, liver, multiorgan failure, and other cancers)	Symptom Assessment Scale	Symptom Assessment Scale
				esas - ESAS	esas – ESAS
					kps - AKPS (Australia-modified Karnofsky Performance Scale)

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Freeman S et al (2014)	Canada, Palliative Care	Observational, cross-sectional, retrospective	6769; 70.0 (Range 18-107); Different conditions: Cancer, No cancer, Unspecified	Documented - no further information on identification	
Gomutbutra P et al (2013)	USA, Palliative Care	Observational, chart review, retrospective	115; 64 (17); Different conditions - Cancer, Heart Failure, COPD, Pneumonia, Pleural or pericardial effusion	Categorical scale	Categorical scale
Hately J et al (2003)	UK, Palliative Care	Evaluation (prospective)	30; Median - 71; Cancer	Respiratory symptom scales (adapted from the MRC Respiratory Symptoms Questionnaire (RSQ) and the Dyspnoea Scale (DS)	Respiratory symptom scales (adapted from the MRC Respiratory Symptoms Questionnaire (RSQ) and the Dyspnoea Scale (DS)
					Functional Capacity Scale
				Rotterdam Symptom Checklist	Rotterdam Symptom Checklist
				VAS	VAS
Kang JH et al (2013)	USA, Palliative Care	Observational, retrospective study	1612; 59.2 (13.2); Cancer	esas - ESAS	esas – ESAS

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Kavalieratos D et al (2014)	USA, Palliative Care	Observational, database review, retrospective	1031 (334 HF data); Median 84; Range 33–102; Heart Failure	McCorkle Symptom Distress Scale	McCorkle Symptom Distress Scale
					PPS - Palliative Performance Scale
Lefkowits C et al (2015)	USA, Palliative Care	Observational, chart review, retrospective	95; Median - 59; Cancer		PPS - Palliative Performance Scale
				esas - ESAS (Modified)	esas - ESAS (Modified)
Mancini I et al (2002)	Belgium, Palliative Care	Observational, retrospective study	155; 61±14 (Median - 61; Range 21–93); Different conditions: Cancer, No cancer, Others		kps - Karnofsky Performance Status Scale
				VAS (Dyspnea)	VAS (Dyspnea)
Mercadante S et al (2016)	Italy, Palliative Care	Observational, chart review, retrospective	56; 73.7 (11.4); Cancer	esas - ESAS	esas – ESAS
					kps – KPS
Morita T et al (2005)	Japan, Palliative Care	Audit, prospective	211: PCT - 111, PCU - 100; PCT - 68 ± 12, PCU - 72 ± 12; Cancer		STAS - Schedule for Team Assessment Scale

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Murphy EL et al (2009)	UK, Palliative Care	Clinical audit, prospective	55; 82 ± 5.5 (Median 83; Range 66–96); Chronic Kidney Disease	POSs (Patient Outcome Scale) Symptom Module	POSs (Patient Outcome Scale) Symptom Module
Olson K et al (2008)	Canada, Palliative Care	Observational, longitudinal, retrospective	82; 64 (Range 37 - 93); Cancer	esas - ESAS	esas - ESAS
Pang GSY et al (2015)	Singapore, Palliative Care	Observational, descriptive, retrospective study	2726; Subset 1 - 65.6 (14.2) Subset 2 - 65.6 (14.1); Different conditions: Cancer, Noncancer, Coexisting cancer and noncancer	Symptom Assessment Scale (NRS)	Symptom Assessment Scale (NRS)
Parsons HA et al (2008)	USA, Palliative Care	Observational, chart review, retrospective	68; 58 (Range 28-87); Cancer	esas - ESAS	esas – ESAS

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Pinna MAC et al (2009)	Spain, Palliative Care	Observational, longitudinal, retrospective	195; 73 (Range 31-95); Cancer	esas - ESAS/verbal visual scales	esas - ESAS/verbal visual scales
					kps - KPS
					Lung function measurements (SaO2)
				Documented - no further information on identification	
Porta-Sales J et al (2017)	Spain, Palliative Care	Observational, chart review, retrospective	67; 68.6 (11) (Range 39-88); Cancer	esas - ESAS	esas – ESAS
					PPS - Palliative Performance Scale
Porzio G et al (2005)	Italy, Palliative Care	Observational, retrospective study	208; Median 64.7 (Range 28–90); Cancer		kps – KPS
					Palliative Prognostic Score (PaP)
				esas - ESAS	esas - ESAS
Ryan A et al (2002)	USA, Palliative Care	Evaluation (retrospective)	265; 20 - 91; Different conditions: Cancer, Non-cancer (AIDS, Other)	Clinician assessment (asked)	

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Schroedl C et al (2014)	USA, Palliative Care	Observational, case-series, retrospective	36; Median - 70 Range - 66–89; COPD		Lung function measurements (FEV1)
				CAT	CAT
				Clinician assessment (asked)	
Shin SH et al (2014)	USA, Palliative Care	Observational, retrospective cohort	312; 59.1; Cancer	esas - ESAS	esas – ESAS
Strasser F et al (2004)	USA, Palliative Care	Observational, descriptive, retrospective study	215 (77 >18 Data); Median 54 (Range 21–91); Cancer	esas - ESAS	esas – ESAS
Webb M et al (2000)	USA, Palliative Care	Observational, charts audit, retrospective	72; 72.46 (Range 40-97); Different conditions: End-stage lung disease, Lung cancer		kps - Karnofsky Performance Status Scale
				Clinician assessment (observation/asked)	

Author and Year	Location and Setting	Study Design	Participants (Sample Size, Age [Mean (SD) unless specified], Condition)	Methods of Identification	Methods of Assessment
Wysham NG et al (2015)	USA, Palliative Care	Observational, database review, prospective	238; 71.4 (Q1-Q3 - 42.3–94.7); Different conditions: Chronic Respiratory Disease (86): COPD - 71 (82.6%) Pulmonary Fibrosis - 15 (17.4%) Lung Cancer (152): Non-small cell lung cancer - 132 (86.8%) Small cell lung cancer - 20 (13.2%)	McCorkle Symptom Distress Scale (Dyspnea)	McCorkle Symptom Distress Scale (Dyspnea)
Yennurajalingam S et al (2013)	USA, Palliative Care	Observational, medical records review, retrospective	1373; Median (IQR) 59 (51–68); Cancer	esas - ESAS	esas - ESAS

AKPS: Australian modified Karnofsky Performance Status; CAT: COPD Assessment Test; ESAS: Edmonton Symptom Assessment Scale; KPS: Karnofsky Performance Status; Lung function Measurements (FEV1: Forced Expiratory Volume in one second; MIP: Maximal Inspiratory Pressure; Sao2: Oxygen Saturation; VC% predicted: Vital capacity % predicted); NRS: Numerical Rating Scale; PaP: Palliative Prognostic Score; POSs: Patient Outcome Scale Symptom Module; PPS: Palliative Performance Scale; STAS: Schedule for Team Assessment; VAS: Visual Analogue Scale

APPENDIX K – DIFFERENT TYPES OF BREATHLESSNESS IDENTIFICATION AND ASSESSMENT MEASURES ACROSS HEALTH CARE SETTINGS

Symptom severity measures of breathlessness: Tools n=17, Studies n=70	**Primary care**	**Secondary Care**	**SPC**	**Total**
Medical Research Council Dyspnea Scales[1]*	6	21		n=27
Edmonton Symptom Assessment Scales*[2]		4	18	n=22
BORG[3]*		13		n=13
Visual Analogue Scale*		1	3	n=4
*University of California San Diego Shortness of Breath Questionnaire**		3		n=3
McCorkle Symptom Distress Scale*			2	n=2
Symptom Assessment Scale*			2	n=2
*Baseline and Transition Dyspnoea Index**		1		n=1
Categorical scale (0 = none, 1 = mild, 2 = moderate, 3 = severe)*			1	n=1
*MD Anderson Symptom Inventory**		1		n=1
Numerical Rating Scale*		1		n=1
Patient Outcome Scale Symptom Module*			1	n=1
Quantitative Scale		1		n=1
Respiratory symptom scales (adapted from the MRC Respiratory Symptoms Questionnaire and Dyspnoea Scale*			1	n=1
*Rotterdam symptom checklist**			1	n=1
Unknown - dyspnea assessed		1		n=1
*Van Den Bongard's Score (none (0), slight (1), severe (2) and high-grade stenosis with cyanosis or stridor (3))**		1		n=1
Total number of measures used	*n=6*	*n=48*	*n=29*	*n=83*
Total number of distinct measures	*n=1*	*n=11*	*n=8*	*n=20*
Total number of studies using measures of severity of breathlessness	***n=6***	***n=38***	***n=26***	*n=70*
Number of studies as a proportion of total (97) studies	*6.2%*	*39.2%*	*26.8%*	

Measures of the impact of breathlessness (on wider factors): Tools n=20, Studies n=55	**Primary care**	**Secondary Care**	**SPC**	
Medical Research Council Dyspnea Scales[1]*	6	21		n=27
Walk tests[4]		19		n=19
BORG[3]*		13		n=13
COPD Assessment Test*	2	4	1	n=7
St. Georges Respiratory Questionnaire*		7		n=7
KPS Scales[5]			6	n=6
Palliative Performance Scale			4	n=4
*University of California San Diego Shortness of Breath Questionnaire**		3		n=3
Chronic Respiratory Diseases Questionnaire		2		n=2
New York Heart Association Functional Classification		2		n=2
Palliative Prognostic Score			2	n=2
Schedule for Team Assessment			2	n=2
*Baseline and Transition Dyspnoea Index**		1		n=1
Breathing Problems Questionnaire		1		n=1
Clinical COPD Questionnaire*	1			n=1
Functional Capacity Scale			1	n=1
Lung Information Needs Questionnaire	1			n=1
*MD Anderson Symptom Inventory**		1		n=1
Palliative Care Assessment Tool*			1	n=1
*Rotterdam symptom checklist**			1	n=1
Total number of measures used	*n=10*	*n=74*	*n=18*	*n=102*
Total number of distinct measures	*n=4*	*n=11*	*n=8*	*n=23*
Total number of studies using impact measures of breathlessness	***n=6***	***n=33***	***n=16***	*n=55*
Number of studies as a proportion of total (97) studies	*6.2%*	*34.0%*	*16.5%*	
Measures of the cause/diagnosis of breathlessness: Tools n=12, Studies n=47	**Primary Care**	**Secondary Care**	**SPC**	
Lung Function Measurements[6]	8	30	3	n=41
Imaging (CT, MRI, Chest X-Ray, HRCT)		5		n=5

New York Heart Association Functional Classification		2		n=2
Bronchoscopy		1		n=1
Canadian Thoracic Society Screening Questions*	1			n=1
Doppler echocardiography (2D)		1		n=1
ECG (Electrocardiogram)		1		n=1
Echocardiogram		1		n=1
High sensitive C-reactive protein		1		n=1
*Van Den Bongard's Score (none (0), slight (1), severe (2) and high-grade stenosis with cyanosis or stridor (3))**		1		n=1
Video Assisted Thoracic Surgery		1		n=1
Waveform capnography (ETCO2)		1		n=1
Total number of measures used	*n=9*	*n=45*	*n=3*	*n=57*
Total number of distinct measures	*n=2*	*n=11*	*n=1*	*n=14*
Total number of studies using cause/diagnosis measures of breathlessness	***n=8***	***n=36***	***n=3***	*n=47*
Number of studies as a proportion of total (97) studies	*8.2%*	*37.1%*	*3.1%*	

[1] Includes MRC, mMRC (modified mRC) and eMRC (extended MRC).
[2] Includes ESAS and Modified ESAS.
[3] Includes BORG, Modified BORG and BORG RPE (Rate of Perceived Exertion).
[4] Includes 6MWD (6 minute walk distance), 6MWT (6 minute walk test), ESWT (Endurance Shuttle Walk Test), ISWT (Incremental Shuttle Walk Test), Shuttle Walk Test and Treadmill Walk Test.
[5] Includes KPS and AKPS.
[6] Includes FEV1, FEV% pred, FEV1%, FEV1% pred, FVC, FVC%, FVC% pred, FEV/FVC, FEV1/FVC, FEV1/FVC%, FEV1/VC, FEV1/VC%, VC, VC% pred, TLC, TLC%, TLC% pred, TLCO, TLCO% pred, DLCO, DLCO%, DLCO% pred, DLCO/VA%, KCO% pred, RV, RV% pred, RV/TLC, RV/TLC%, RV/TLC% pred, FRC% pred, IC% pred, IC/TLC%, PaO2, PaCO2, pH, PEFR, SaO2, SO2, SpO2, MIP, MEP, MVV% pred.
* Measures used for both identification and assessment
Italics are used if measures are found in more than one category.

APPENDIX L - DIFFERENT TYPES OF BREATHLESSNESS ASSESSMENT MEASURES

Symptom severity measures of breathlessness: Tools n=17, Studies n=70	**Measures of the impact of breathlessness (on wider factors): Tools n=20, Studies n=55**	**Measures of the cause/diagnosis of breathlessness: Tools n=12, Studies n=47**
BDI/TDI	*BDI/TDI*	Bronchoscopy
BORG Scales	*BORG Scales*	CTS
Categorical scale (0 = none, 1 = mild, 2 = moderate, 3 = severe)	BPQ	Doppler echocardiography (2D)
ESAS Scales	CAT (COPD)	ECG (Electrocardiogram)
McCorkle Symptom Distress Scale	CCQ (COPD)	Echocardiogram
MDASI	*MDASI*	High sensitive C-reactive protein
NRS	CRQ (Chronic Respiratory Diseases)	Imaging (CT, MRI, Chest X-Ray, HRCT)
Patient Outcome Scale Symptom Module	Functional Capacity Scale	LFM
Quantitative Scale	KPS Scales	VATS
Respiratory symptom scales (adapted from MRC and RSQ)	*NYHA*	*NYHA*
Van Den Bongard's Score (none (0), slight (1), severe (2) and high-grade stenosis with cyanosis or stridor (3))	LINQ	*Van Den Bongard's Score (none (0), slight (1), severe (2) and high-grade stenosis with cyanosis or stridor (3))*
MRC Scales	*MRC Scales*	Waveform capnography (ETCO2)
SAS	Palliative Care Assessment Tool	
Unknown - dyspnea assessed	Palliative Prognostic Score	

Symptom severity measures of breathlessness: Tools n=17, Studies n=70	Measures of the impact of breathlessness (on wider factors): Tools n=20, Studies n=55	Measures of the cause/diagnosis of breathlessness: Tools n=12, Studies n=47
UCSD	*UCSD*	
VAS	Palliative Performance Scale	
Rotterdam symptom checklist	*Rotterdam symptom checklist*	
	SGRQ (Respiratory Diseases)	
	STAS (Schedule for Team Assessment)	
	Walk tests	

BDI/TDI: Baseline and Transition Dyspnea Index; Borg Scales (Borg, MBS, Borg RPE); BPQ: Breathing Problems Questionnaire; CAT: COPD Assessment Test; CTS: Canadian Thoracic Screening Questionnaire; CCQ: Clinical COPD Questionnaire; CRQ: Chronic Respiratory Disease Questionnaire; ESAS: Edmonton Symptom Assessment Scale (ESAS; Modified ESAS); KPS: Karnofsky Performance Status (Karnofsky Performance Status; Australian modified Karnofsky Performance Status); LINQ: Lung Information Needs Questionnaire; LFM: Lung Function Measurements; MDASI: MD Anderson Symptom Inventory; MRC: Medical Research Council Dyspnea Scale (MRC, mMRC, emRC); NRS: Numerical Rating Scale; NYHA: New York Heart Association Functional Classification; SAS: Symptom Assessment Scale; SGRQ: St. George's Respiratory Questionnaire; STAS: Schedule for Team Assessment); UCSD: University of California San Diego Shortness of Breath Questionnaire; VATS: Video Assisted Thoracic Surgery; VAS: Visual Analogue Scale; Walk tests (ESWT; ISWT, 6MWD, 6MWT, Shuttle/Treadmill Walk Test).
Italics are used if measures are found in more than one category.

HULL YORK MEDICAL SCHOOL

PACE
Proactive Anticipatory Care Evaluation

NHS
Hull
Clinical Commissioning Group

Patient Information Sheet

A large-print version of this sheet is available on request.

Invitation to take part in a research study

We would like you to take part in a research study. To help you to decide if you would like to take part, we have written this information sheet. It should explain why the research is being done, what you will be asked to do, and why we would like you to take part. Please take your time to read the information. You can talk with your friends or family about it if you like.

What is this study about?

We are trying to find out how the new service you have been invited to or just visited has helped improve your overall health and wellbeing; compared to how you have been cared for until now. Your answers will help in the improvement of this service.

Why have I been invited to take part?

We would like you to take part in this study because you have recently been invited to attend an appointment at the new service at the Jean Bishop integrated care centre or at you care home by your GP. Your GP has identified you as being eligible for this study.

What will happen if I take part?

If you take part in the study, you will be asked to sign a consent form. You will be asked to complete a short questionnaire at the first meeting either at the Jean Bishop Integrated Centre or at the care home you live in. Someone from the research team will help you fill in the questionnaire. If you are unable to complete the questionnaire at the first meeting, another date and time convenient for you will be set. It will take you about 45minutes to complete the questionnaire. Someone from the research team will contact you to ask if you are happy to complete a shorter version of the questionnaire in 2-4 weeks and in 10-14weeks time.

We would like you to answer the questions as honestly as you can and there are no right or wrong answers. You will be asked if you would like to nominate a family member or carer to help fill in the questionnaire for you. There is a separate consent form (consultee form) to be completed by the nominated person, please ask for a copy of this.

What else will happen if I take part?

Some people taking part will be asked if they would like to take part in an interview with a researcher if they are affected by any of the following; chronic breathlessness, unintentional weight loss or use of medicine for pain and possible side effects. The interview can be held on the same day you complete the questionnaire or at a different time and place if it is easier for you.

If you take part, a member of the research team will do the interview and it will last around 45 minutes. Each topic will have a slightly different focus but will involve questions around your experience of one of topics listed above. It will also involve your opinion on caring experience, management of care, communication with health professionals, information and support needs, and the impact or potential concerns around these issues.

Do I have to take part?

No. It is up to you to decide if you would like to take part. If you decide not to take part, this will be noted and you will not be asked again. You will also continue to receive care and support from your GP practice or any health professional as usual. If you were to take part, you can still change your mind and stop taking part at any time without giving any reason.

What are the possible benefits of taking part in the study?

It is unlikely that there will be any direct personal benefit for you taking part. However, the information that you will give us will help decide if your overall health and wellbeing has improved by using this new service and give us ways to improve this service in the future.

Are there potential risks of taking part?

There is no significant risk in taking part, other than the time the study will take. However if you have any worries, you can talk about them with the research team or your GP. We would like to stress that taking part is up to you and you can stop taking part at any time without reason.

Will my involvement be confidential?

Yes. All the information we collect will be kept confidential, to fit with the General Data Protection Regulation (GDPR) 2018. The University of Hull is the sponsor for this study based in the United Kingdom. We will be using information from you and your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Hull will keep identifiable information about you for 10 years after the study has finished.

Your rights to access change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.

You can find out more about how we use your information at https://www.hyms.ac.uk/research/research-centres-and-groups/wolfson/pace or by contacting PACE@hyms.ac.uk.

The GP Practice will collect information from you and your medical records for this research study in accordance with our instructions.

The GP practice will use your name, NHS number and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from the University of Hull and regulatory organisations may look at your medical and research records to check the accuracy of the research study. Your GP Practice will pass these details to University of Hull along with the information collected from you and your medical records. The only people in the University of Hull who will have access to information that identifies you will be people who need to contact you to collect data/information or audit the data collection process. The people who analyse the

information will not be able to identify you and will not be able to find out your name, NHS number or contact details.
The research team from the University of Hull will keep identifiable information about you from this study for 10 years after the study has finished.

Expenses

There will be no other costs to you.

What will happen to the results of the research study?

The results from this study will be written as a report for the NHS Hull clinical commissioning group (NHS Hull CCG). The results will be written up into journals, presented at conferences and public engagement events. If you would like to receive a summary of the study result, please inform someone from the research team. All personal details will be anonymised in all publications and public documents.

If I find it necessary to make a complaint, who should I contact?

If you have any concerns, questions or complaints about this research, you can contact Dr Maureen Twiddy (01482 463279, 8am to 5pm weekdays) or email Maureen.Twiddy@hyms.ac.uk Dr Twiddy is based at University of Hull but is independent of the research team.

How can I get involved in the study?

Thanks you for taking the time to read this information sheet. **If you would like to know more, please contact the research team using the details below:**

Dr Mabel Okoeki (Project Lead)

Telephone: (01482) 463728

Email: PACE@hyms.ac.uk

APPENDIX N – CONSULTEE INFORMATION SHEET

Consultee information sheet

Proactive Anticipatory Care Evaluation
Information for Consultee

Introduction

We feel your relative/friend is unable to decide for himself/herself whether to participate in this research.

To help decide if he/she should join the study, we would like to ask your opinion whether or not they would want to be involved. We would ask you to consider what you know of their wishes and feelings, and to consider their interests. Please let us know of any advance decisions they may have made about participating in research. These should take precedence.

If you decide your relative/friend would have no objection to taking part, we will ask you to read and sign the consultee declaration that will be provided. We will then give you a copy to keep. We will keep you fully informed during the study, so you can let us know if you have any concerns or you think your relative/friend should discontinue the study.

If you decide that your relative/friend would not wish to take part, it will not affect the standard of care they receive in any way; just let us know.

If you are unsure about taking the role of consultee, you may seek independent advice.

We will understand if you do not want to take on this responsibility.

A participant information sheet, the same as would have been provided to your relative/friend, will be provided to you along with this information sheet.

APPENDIX O – INFORMED CONSENT FORM

HULL YORK MEDICAL SCHOOL

PACE
Proactive Anticipatory Care Evaluation

NHS
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Clinical Commissioning Group

Participant consent form

	Please Initial each box
I confirm that I have read and understood the participant information sheet for the above study. I have had the opportunity to consider the information, ask questions and these have been answered satisfactorily.	☐
I understand that my participation is voluntary and I am free to withdraw at any time, without giving any reason, without my medical and legal rights being affected.	☐
I understand that responsible individuals may look at relevant sections of any data collected during this study from the research team, regulatory authorities or the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.	☐
I understand that by filling in and signing this form I give permission for my GP records and hospital records to be accessed by the research team for the purpose of this study.	☐
I understand that my information may be subject to review by responsible individuals from the University for monitoring and audit purposes.	☐
I understand that the information collected about me may be published or will be used to support other research in the future, and may be shared anonymously with other researchers.	☐
I agree to take part in the above study	☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of person taking consent	Date	Signature

☐ Tick here if participant has given consent but is physically unable to sign and has requested a witness

I witness that _____ has agreed to participate in this research study. I confirm that I have initialled the consent statements as per their wishes.

Name of witness (Print)	Date	Signature
Name of person taking consent (Print)	Date	Signature

Office Use Only

Tick the appropriate box once completed

Participant's copy	☐
Research team/site file copy	☐
Medical record's copy	☐

APPENDIX P – CONSULTEE DECLARATION FORM

Consultee declaration form

Please initial each box

I_____have been consulted about [……..]'s participation in this research project. I have had the opportunity to ask questions about the study and understand what is involved ☐

In my opinion he/she would have no objection to taking part in the above study. ☐

I understand that I can request he/she is withdrawn from the study at any time,without giving any reason and without his/her care or legal rights being affected. ☐

I understand that by filling in and signing this form I give permission for his/her GP records and any hospitals records to be accessed by the research team for the purpose of this study. ☐

I understand that relevant sections of his/her care record and data collected during the study may be looked at by responsible individuals from the University of Hull or from regulatory authorities, where it is relevant to their taking part in this research. ☐

I agree to their GP or other care professional being informed of their participation in the study. ☐

I agree to take part and advice on behalf of the potential participant in the above study. ☐

_____	_____	_____
Name of consultee	Date	Signature

Relationship with participant: _____

_____	_____	_____
Researcher	Date	Signature

Office Use Only

Tick the appropriate box once completed

consultee's copy	☐
research team/site file copy	☐
medical/care record	☐

APPENDIX Q – TABLE OF COMORBIDITIES

Overarching Comorbidity Category	**Included Comorbidities**
Alcohol Problems	Alcoholic, Alcoholism, Previous alcohol excess
Anxiety & other neurotic, stress related & somatoform disorders	Anxiety, Chronic anxiety, Post traumatic stress disorder
Autoimmune inflammatory conditions and autoimmune disease	Giant cell arteritis, Pernicious anaemia, Wegeners
Blindness and low vision/eye conditions	Age related macular degeneration, Amaurosis, Cataracts, Charles Bonnett syndrome, Glaucoma, Macular Degeneration, Neuropathy and retinopathy, Ocular Hypertension, Partial blindess (one eye), Registered blind, Retinal Vein Occlusion
Blood disorders	Essential thrombocythemia, Monoclonal gammopathy of undetermined significance, Probable Myelodysplasia, Thrombocythemia, Thrombocytopenia
Benign tumours	Meningioma (brain), Ovarian fibroma
Cancer	Bladder cancer, Bone cancer, Bowel cancer, Breast cancer, Ca Larynx - laryngectomy 2000, Cancer - Renal Neoplasm/Renal Carcinoma, Cancer of Kidney, Colon cancer, Liver metastases, Lung cancer, Lymphoma, Melanoma, Myelodysplasia (Cancer), Neuroendocrine tumour-lung, Nodular sclerosing Hodgkin Lymphoma, Non-Hodgkins Lymphoma, Prev prostate cancer, Previous breast cancer, Prostate Cancer, Renal cancer, Renal neoplasm/renal carcinoma, Squamous cell carcinoma, Stomach cancer, Tumours in glands, Whipple's Procedure (Pancreas cancer)
Dementia	Alzheimer's, Dementia, Dementia – mixed, Dementia – vascular, Lewy body dementia, Vascular Dementia
Depression	Chronic depression, Depression, Low mood
Diabetes	Diabetes, Type 1 Diabetes, Type 2 Diabetes
Hearing loss/problems	Deaf, Hearing, Hearing loss, Tinnitus

Heart disease	Angina, Aortic stenosis (valve disease), Aortic valve disease, Arrhythmia, Atrial fibrillation, Chronic heart disease, Chronic Ischaemic Heart Disease, Coronary heart disease, Heart Disease - non specified, Heart valve disease, High cholesterol, Ischaemic Heart Attacks, Ischaemic Heart Disease, Mitral Regurgitation valve disease, Mitral Stenoses (valve disease), Myocardial Infarction, Pericarditis, Prev infarct, Severe aortic stenosis (valve disease), Transcutaneous aortavelography (aortic valve disease)
Heart failure	CCF, Chronic cardiac failure, Chronic congestive heart failure, Congestive cardiac failure, Congestive heart disease, Heart Failure, HF (mod-severe LV impairment), IHD/Heart Failure (ICD in place), Left Ventricular Failure, LVSD, Severe LVD
Hypertension	Hypertension
Kidney disorders/disease	Atrophic right kidney, Chronic kidney disease, Chronic kidney failure, Chronic renal failure, IgA nephropathy, Renal failure
Liver-biliary tract diseases	Cirrhotic changes to liver, Cholecystitis, Deranged liver function, Fatty liver, Gallstones, Gilbert syndrome, Primary biliary cirrhosis
Neurological conditions	Benign essential tremor, Brain atrophy, Epilepsy, Migraines, Multiple sclerosis, Normal pressure hydro cephalus – Shunted, Quadriplegic, Subdural haematoma
Non-malignant gastrointestinal conditions including Dyspepsia's	Appendicitis, Chronic constipation, Coeliac disease, Colitis, Colonic polyps, Colostomy (bowel disease unspecified), Colovesical fistula ?cause, Constipation, Crohns, Diverticular disease, Diverticulitis, GI bleed, Haemorrhoids, Inflammatory bowel disease, Irritable bowel syndrome, Pancreatitis, UGI erosions, Barrett's, Gastritis, Gastro-oesophageal reflux disease, Gastro-oseophageal Reflex, Hiatus hernia, Oesophageal dysmotility, Oesophagitis/duodenitis, Reflux
Non-malignant lung disease	Asbestosis, Asthma, Bronchiectasis, COPD, Interstitial lung disease, Mild Alpha I Antitrypsin Deficiency, Pulmonary fibrosis, Pulmonary hypertension
Obesity	Obesity, Gastric bypass

Painful condition	Arthritis, Carpal Tunnel, Chronic headaches, Chronic hip and leg pain, Chronic pain, Degenerative changes to left shoulder, Degenerative lumbar spine, Degenerative lumbar spine disease, Degenerative spine, DISH, Fibromyalgia, Gout, Hip Bursitis, L3-5 Stenosis, Laminectomy (invertebral disc disease)Lumbar spondylosis, Lumbar stenosis, Neuralgia, Multiple Fragility Fractures, Multiple Vertebral Fractures, Osteoarthritis, Osteoarthritis – Knees, Osteopenia, Osteoporosis, Osteoporosis/Vertebral Fracture, Osteoporotic Vertebra Collapse, Peripheral neuropathy, Polymyalgia Rheumatica, Sciatica, Severe Osteoarthritis, Severe spinal degeneration, Shoulder impingement, Spinal Stenosis, Spondylosis, Total hip replacement, Total knee replacement, Trigeminal neuralgia, Trochanteric bursitis, Vertebral compression, Vertebral fractures
Parkinson's disease	Parkinson's, Parkinson's Disease with Dementia
Peripheral vascular disease	Abdominal aortic aneurysm, Claudication, Intermittent claudication, Leg ulceration, Leg ulcers, Lower limb ischaemia, Peripheral arterial disease, Peripheral vascular disease, Poor circulation, Popliteal aneurysm, Prev abdominal aortic aneurysm, Vascular disease, Venous ulcers
Prostate disorders	Benign prostate hypertrophy, Benign prostatic hyperplasia, Enlarged prostate, Previous benign prostatic hyperplasia
Rheumatoid arthritis, other inflammatory polyarthropathies & systematic connective tissue disorders	Bilateral toe amputation/Rheumatoid deformities, Lupus, Rheumatoid Arthritis, Sjogrens
Skin diseases/conditions (including skin cancers)	Actinic keratosis, Basal cell carcinoma, Blepharitis, Bullos pemphigoid. Eczema, Pemphigoid, Psoriasis, Verrucas
Sleep disorders	Sleep Apnoea, Obstructive sleep apnea
Stroke and transient ischaemic attack	Brain haemorrhage, Cerebral haemorrhage, Cerebral vascular disease, Cerebrovascular accident, Cerebrovascular disease, CVA, Prev CVA, Prev CVA and TIA, Previous stroke, Previous stroke and TIA, Previous TIA, Stroke, Stroke and transient ischaemic attack, Transient ischaemic attack
Thyroid disorders	Graves Disease, Hypothyroid, Hypothyroidism, Thyroid, Underactive thyroid
Venous thromboembolism	Bilateral pulmonary emboli, DVT, Previous DVT, Previous pulmonary embolism, Pulmonary embolism

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PATIENT AND FAMILY CARER INFORMATION SHEET

Qualitative Interviews

A large-print version of this sheet is available on request.

Introduction

We would like to invite you to take part in our study. Your participation will help us to understand your thoughts on and experiences of one of the following topics:

- Chronic breathlessness
- Unintentional weight loss
- Use of medicines for pain

To help you to decide if you would like to take part, we have created this information sheet. It explains why the research is being done, what you will be asked to do, and why we are asking you to take part. Please take time to read the following information carefully and talk about it with others if you wish. You can contact someone from the research team and ask them to explain anything that is not clear to you. The Wolfson Palliative Care Research Centre based at the University of Hull runs the study.

What is the study about?

The purpose of this study is to explore your experiences of chronic breathlessness, unintentional weight loss, and the use of medicines for pain and possible side effects. This will help us better understand these problems as well as how they can be managed better.

Why have I been invited to take part?

You have been invited to take part in an interview because you have indicated that you have experience of or care for someone who is affected by chronic breathlessness, unintentional weight loss, or use medicines for pain. You have indicated when you completed the survey questionnaires that you are willing to be contacted about taking part in an interview or have a family member who might also want to participate but was not present on your assessment visit.

Do I have to take part?

No. It is up to you to decide if you would like to take part. If you decide not to take part, this will be noted and you will not be asked again. You will also continue to receive care and support from your GP practice or any health professional as usual. If you to take part, you can change your mind and stop taking part at any time without giving any reason.

What will happen if I take part?

If you take part, you will be asked to sign a consent form and then take part in an interview with one of our researchers, which will take about 45 minutes. The interview can be at the Jean Bishop Integrated Care Centre, your resident care home or at a place and time convenient for you. Each topic will have a slightly different focus but will involve questions around your experience of one of topics listed above. After the interview, members of the research team will carry out the transcription. Information collected, which can identify you will be anonymised at the time of the transcription.

What are the possible benefits of taking part in the study?

Although there is no direct benefit, you may value the chance to talk through your experiences. However, the information that you give us will help us to better understand experiences of chronic breathlessness, unintentional weight loss and effects of use of pain medicines, so this will help others with these problems in the future.

Are there any potential risks of taking part?

There are no significant risks in taking part. . We would like to stress that taking part is up to you and you can stop taking part at any time without reason and without your medical care or legal rights being affected.

Will my involvement be confidential?

Yes. All the information we collect will be kept confidential, to fit with the General Data Protection Regulation (GDPR) 2018. The University of Hull is the sponsor for this study based in the United Kingdom. We will be using information either from you or him/her in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your or his/her information and using it properly. The University of Hull will keep identifiable information about you or him/her for 10 years after the study has finished.

Your or his/her rights to access change or move your or his/her information are limited, as we need to manage your or his/her information in specific ways in order for the research to be reliable and accurate. If you or he/she withdraw from the study, we will keep the information about you or him/her that we have already obtained. To safeguard your or his/her rights, we will use the minimum personally identifiable information possible.

You or him/her can find out more about how we use your or his/her information at https://www.hyms.ac.uk/research/research-centres-and-groups/wolfson/pace or by contacting PACE@hyms.ac.uk.

The research team from the University of Hull will collect information from you or him/her for this research study in accordance with our instructions.

The research team from the University of Hull will use your or his/her name and contact details to contact you or him/her about the research study, and make sure that relevant information about the study is recorded for you or his/her care, and to oversee the quality of the study. Individuals from the University of Hull and regulatory organisations may look at your or his/her research records to check the accuracy of the research study. Your or his/her details will be passed to University of Hull along with the information collected from you or him/her. The only people in the University of Hull who will have access to information that identifies you or him/her will be people who need to contact you or him/her to collect data/information or audit the data collection process. The people who analyse the information will not be able to identify you or him/her and will not be able to find out your or his/her name or contact details.

The research team from the University of Hull will keep identifiable information about you or him/her from this study for 10 years after the study has finished.

However, if you or he/she raise an issue of concern for your or his/her or others' health, we may ask your or his/her permission to contact your or his/her GP or other health professional to seek specific help or advice for you or him/her.

Expenses

You will be provided with prepaid envelopes, if needed, to return any documents to the research team. There will be no other costs to you.

What will happen to the results of the research study?

The results of this study will be presented at conferences and public engagement events, and will be written up for publication in academic journals. If you would like to receive a summary of the

study findings please inform the researcher. With your permission, publications may include anonymised quotations.

If I find it necessary to make a complaint, who should I contact?

If you have any concerns, questions or complaints about this research, you can contact Dr Maureen Twiddy (01482 463279, 8am to 5pm weekdays) or email Maureen.Twiddy@hyms.ac.uk Dr Twiddy is based at University of Hull but is independent of the research team.

How can I get involved in the study?

Thank you for taking the time to read this information sheet. **If you would like to know more or wish to take part, please contact the research team using the details below:**

Helene Elliott-Button, Ugochinyere Nwulu, or Sophie Pask
Telephone: (01482) 463728
Email: PACE@hyms.ac.uk

APPENDIX S – INTERVIEW PARTICIPANT/CARER CONSENT

HULL YORK MEDICAL SCHOOL

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Consent Form for Research Participants
(Qualitative Interviews)

	Please initial each box
I confirm that I have read and understood the participant information sheet for the above study. I have had the opportunity to consider the information, ask questions and these have been answered satisfactorily.	☐
I understand that my participation is voluntary and I am free to withdraw at any time, without giving any reason, without my medical and legal rights being affected. Furthermore, I understand that I am able to withdraw my data up to the time of transcription and analysis	☐
I consent to be interviewed and agree to the interview being recorded and direct quotes used during data/result presentation anonymously.	☐
I understand that responsible individuals may look at relevant sections of any data collected during this study from the research team, regulatory authorities or the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.	☐
I understand that my information may be subject to review by responsible individuals from the University for monitoring and audit purposes.	☐
I understand that the information collected about me may be published or will be used to support other research in the future, and may be shared anonymously with other researchers.	☐
I agree to take part in the above study.	☐

Name of Participant	Date	Signature
Name of person taking consent	Date	Signature

☐ Tick here if participant has given consent but is physically unable to sign and has requested a witness

I witness that _____ has agreed to participate in this research study. I confirm that I have initialled the consent statements as per their wishes.

Name of witness (Print)	Date	Signature
Name of person taking consent (Print)	Date	Signature

Office Use Only

Tick the appropriate box once completed

Participant's copy	☐
Research team/site file copy	☐
Medical record's copy	☐

APPENDIX T – INTERVIEW HEALTH CARE PRACTITIONER INFORMATION SHEET

PACE
Proactive Anticipatory
Care Evaluation

Hull
Clinical Commissioning Group

HEALTH PROFESSIONAL INFORMATION SHEET

Qualitative Interviews

A large-print version of this sheet is available on request.

Introduction

We would like to invite you to take part in our study. Your participation in this interview will help us to understand your views on one of the following topics:

- Chronic breathlessness
- Unintentional weight loss
- Use of medicine for pain

Before you decide whether you want to take part, it is important for you to understand, why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. The research team are happy to answer any questions, clarify any points that are unclear or provide more information. The Wolfson Palliative Care Research Centre based at the University of Hull runs the study.

What is the study about?

The purpose of this study is to explore your views and experiences of issues of chronic breathlessness, unintentional weight loss, or the use of medicine for pain and possible side effects in frail older people. This will help us to better understand these problems, as well as how these issues can be managed better.

Why have I been chosen?

You have been invited to take part in an interview because of your background as a healthcare professional working at the Jean Bishop Integrated Care Centre or at a local GP practice or care home.

Do I have to take part?

It is up to you to decide whether to join the interview study or not. If you would rather not take part, this will be noted and you will not be asked again.

What will I have to do?

If you agree to take part, you will be asked to sign a consent form and then take part in an interview with one of our researchers, which will take about 45 minutes. The interview can be held at the Jean Bishop Integrated Care Centre, your GP practice/care home or at a workplace and time convenient for you. Each interview will involve questions around views on and recognising these problems among the patients you see, your experiences of

providing care for someone with one of these problems, possible challenges around managing these problems (including physical and/or psychological side effects), and the wider impact of these problems on delivering healthcare. After the interview, members of the research team will carry out the transcription. Information collected, which can identify you, will be anonymised at the time of the transcription.

What are the possible benefits of taking part in the study?

It is unlikely there will be any personal benefit to you for taking part. However, the information that you could give us will help us to better understand experiences of chronic breathlessness, unintentional weight loss and use of medicines for pain in primary care.

Are there any potential risks of taking part?

There are no significant risks in taking part. We would like to stress that your participation is voluntary and you can decide to discontinue at any time, without having to give a reason. From experience with previous studies, the risk of distress is very low.

Will the information I share be kept confidential?

Yes. All the information we collect will be kept strictly confidential, in accordance with the General Data Protection Regulation (GDPR) 2018. The University of Hull is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Hull will keep identifiable information about you for 10 years after the study has finished.
Your rights to access change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.
You can find out more about how we use your information at https://www.hyms.ac.uk/research/research-centres-and-groups/wolfson/pace or by contacting PACE@hyms.ac.uk.

The research team from the University of Hull will collect information from you for this research study in accordance with our instructions.
The research team from the University of Hull will use your name and contact details to contact you about the research study, and make sure that relevant information about the study is recorded to oversee the quality of the study. Individuals from the University of Hull and regulatory organisations may look at your research records to check the accuracy of the research study. Your details will be passed to University of Hull along with the information collected from you. The only people in the University of Hull who will have access to information that identifies you will be people who need to contact you to collect data/information or audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.
The research team from the University of Hull will keep identifiable information about you from this study for 10 years after the study has finished.

What will happen to the results of the research study?

The results of this study will form a part of three PhD theses. They will be presented at conferences and public engagement events, and be written up for publication in academic journals. If you would like to receive a summary of the study findings, please inform the researcher. With your permission, publications may include anonymised quotations.

If I find it necessary to make a complaint, who should I contact?

If you have any concerns, questions or complaints about this research, you can contact Dr Maureen Twiddy (01482 463279, 8am to 5pm weekdays) or email Maureen.Twiddy@hyms.ac.uk Dr Twiddy is based at University of Hull but is independent of the research team.

How can I get involved in the study?

Thank you for taking the time to read this information sheet. **If you would like to know more or wish to take part, please contact the research team using the details below:**

Helene Elliott-Button, Ugochinyere Nwulu, and Sophie Pask

Telephone: (01482) 463728

Email: PACE@hyms.ac.uk

HULL YORK MEDICAL SCHOOL

PACE
Proactive Anticipatory Care Evaluation

NHS
Hull
Clinical Commissioning Group

Health Care Professionals Consent Form (Qualitative Interviews)

	Please Initial each box
I confirm that I have read and understood the participant information sheet for the above study. I have had the opportunity to consider the information, ask questions and these have been answered satisfactorily.	☐
I understand that my participation is voluntary and I am free to withdraw at any time, without giving any reason, without my medical and legal rights being affected. Furthermore, I understand that I am able to withdraw my data up to the time of transcription and analysis	☐
I consent to be interviewed and agree to the interview being recorded and direct quotes used anonymously during data/result presentation.	☐
I understand that responsible individuals may look at relevant sections of any data collected during this study from the research team, regulatory authorities or the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.	☐
I understand that my information may be subject to review by responsible individuals from the University for monitoring and audit purposes.	☐
I understand that the information collected about me may be published or will be used to support other research in the future, and may be shared anonymously with other researchers.	☐
I agree to take part in the above study.	☐

Name of Participant	Date	Signature
Name of person taking consent	Date	Signature

Name of witness of oral consent	Date	Signature

☐ Tick here if participant has given consent but is physically unable to sign and has requested a witness

I witness that _____ has agreed to participate in this research study. I confirm that I have initialled the consent statements as per their wishes.

Name of witness (Print)	Date	Signature

Name of person taking consent (Print)	Date	Signature

Office Use Only

Tick the appropriate box once completed

Participant's copy	☐
Research team/site file copy	☐

APPENDIX V – QUALITATIVE FINDINGS - MAIN THEMES, SUB-THEMES, AND CODES

Qualitative Theme	Sub-themes	Codes
Theme 1: The Widespread Impact of Chronic Breathlessness on Patients and Carers	-	Total dyspnoea – psychological; fear associated with breathlessness; guilt (related to breathlessness); anxiety-breathlessness-anxiety cycle; total dyspnoea – physical; lack of physical activity/activities in general/restricting activities; total dyspnoea – social; activities forgone; activities – still partaking but restricted; doesn't want to bother others; loss of independence; restricting life space; carers – impact on; carers – in primary care health encounter; carers or family understanding of breathlessness; carers provide social or medical support; caring for others
Theme 2: Barriers to Health-Seeking Behaviour and the Identification of Chronic Breathlessness	Experiences of identification/assessment	Clinician assessment; holistic/impact assessment; HCP's asking about impact of breathlessness; exercise tests; imaging/scans; lung functions tests; outcome measurements; patient volunteered; nothing
	Experiences of barriers to effective identification of chronic breathlessness	Difficult to manage; breathlessness is common in primary care; breathlessness is one of many symptoms/conditions; breathlessness main (or one of main) symptoms; breathing space – help-seeking in crisis only; breathlessness symptom as by-product of something else; not enough time; need more resources/time to deal with chronic conditions; practitioners don't have time or facilities; practice appointment timings; one appointment one symptom; difficulty getting appointments; different practitioner each time; practitioners not paying direct attention/not interested; need more GP's; lack of faith in

		HCPs for health with breathlessness; not seeing PC HCP/little interaction with primary care services about breathlessness; patient mentions breathlessness; HCP mentions breathlessness; easy to talk about breathlessness; HCP thinks easy for P to talk about breathlessness; HCP thoughts on barriers to patients talking about breathlessness
	Use of 'chronic breathlessness syndrome' terminology	HCP - HCP thoughts and understanding of definition; HCP positive about definition; more labels create anxiety; over labelling/missing the patient; HCP belief definition increases patient understanding; HCP thoughts definition may not matter to patients; framework or criteria needed for diagnosis (of CBS); name useful if creased access to services/greater resources/management/financial support; name creates legitimacy; visibility of breathlessness Patients – Lack of understanding of CBS definition; partial understanding; ambivalent about definition; 'chronic' sounds too bad/doesn't apply to them; definition doesn't matter; stoic suffering
Theme 3: Variations in the Clinical Practice and Management of Chronic Breathlessness	Variations in treatment and management	Patient and HCP agendas may differ; Learning to live with or manage patients breathlessness; Treatment – pharma; non-pharma; Management - inhaler; nebuliser; breathing exercises; calming hand; fan; relaxation; rest; referral to secondary care; breathlessness clinics via hospices; community palliative care; COPD rehab/clinic; Pulmonary rehab; physio; smoking cessation; none; self-directed – patients self-management of breathing difficulties; mobility aids; exercise; breathing exercises; sit

		down/rest; stay calm/relax; take things slow; don't think about it/keep mind occupied; think good/happy/positive thoughts; practical solutions; inhaler; nebuliser; oxygen; total dyspnoea – existential; faith/religious belief; Breathing space – engaged coping; carers – in primary care health care encounter; carers or family understanding of breathlessness; carers provide social or medical support; carers urging individual to go to doctor for breathlessness; condition; treatments for breathlessness in SC preferred to those in PC
	Examples of good practice	Breathing space – clinician responsiveness to breathlessness and underlying condition; handholding patients through their management; HCP going over and above (examples of excellence); education; peer support/colleague discussion/guidance/advice; education/other advice; important aspects of HCP encounter; happy with treatment
Theme 4: The Need for Education and Information about Chronic Breathlessness	Practitioner's knowledge and expectations of care regarding chronic breathlessness	Considering the experience of breathlessness; HCP prepared to deal with symptom; HCP understanding of breathlessness impact on wider/financial/other matters; HCP understanding of widespread impact of breathlessness; HCP considering the psychological impact of breathlessness; useless; helpless/powerless; confidence; not enough knowledge about breathlessness or management techniques; feeling like they've done enough for the patient; can always do more; GP's becoming deskilled (specialist nurses doing LTC management/referrals to nurses); try to diagnose underlying condition or cause of breathlessness first/biomedical; breathing space – clinician responsiveness to underlying disease only

	Patient's knowledge and expectations of care regarding chronic breathlessness	Lack of knowledge of treatments for breathlessness; understanding of breathlessness VS condition (inc. conflation); patient under-reporting of breathlessness; patients 'used' to breathlessness (so not considered an issue); elderly patients/age related; patient understanding of breathlessness; lack of faith in HCPs for help with breathlessness; happy with treatments; inhaler; patients want immediate fix for breathlessness; epistemic injustice; need for education, information, and promotion about health conditions to public

GLOSSARY

Acronym	Full Term
AAU	Acute Assessment Unit
ACP	Advanced Clinical Practitioner
ADL	Activities of Daily Living
AKPS	Australian Karnofsky Performance Status
BAI	Beck Anxiety Inventory
BASDEC	Brief Assessment Schedule Depression Cards
BDI	Baseline Dyspnoea Index
BDI	Beck Depression Inventory
BIS	Breathlessness Intervention Services
BMI	Body Mass Index
BOLD	Burden of Obstructive Lung Disease Study
BSS	Breathlessness Support Service
BTF	Breathing, Thinking, Functioning clinical model
CAT	COPD Assessment Test
CCG	Clinical Commissioning Group
CDS	Cancer Dyspnoea Scale
CFS	Rockwood Clinical Frailty Scale
CHF	Chronic Heart Failure

CI	Confidence Interval
CIS	Critical Interpretive Synthesis
CKD	Chronic Kidney Disease
COPD	Chronic Obstructive Pulmonary Disease
CRDQ	Chronic Respiratory Disease Questionnaire
D-12	Dyspnoea-12
DMD	Duchenne Muscular Dystrophy
DMQ	Dyspnea Management Questionnaire
ED	Emergency Department
EQ-5D-5L	EuroQol-5D
eFI	electronic Frailty Index
ELSA	English Longitudinal Study of Ageing
EPESE	Established Populations for Epidemiological Studies of the Elderly
ESAS	Edmonton Symptom Assessment Scale
ESRD	End-Stage Renal Disease
fMRI	functional Magnetic Resonance Imaging
GCP	Good Clinical Practice
GDPR	General Data Protection Regulations
GOLD	Global Initiative for Chronic Obstructive Lung Disease
GP	General Practitioner

GPPS	English General Practitioner Patient Survey
GPwER	GPwER – General Practitioner with Extended Role
HAD	Hospital Anxiety and Depression scale
HCP	Health Care Practitioner
HRQoL	Health Related Quality of Life
HSE	Health Survey for England
ICC	Integrated Care Centre
ILD	Interstitial Lung Disease
IMD	Index of Multiple Deprivation
IPCRG	International Primary Care Respiratory Research Group
IPF	Idiopathic Pulmonary Fibrosis
IPOS	Integrated Palliative care Outcome Scale
IQR	Inter Quartile Range
LFM	Lung Function Measurements
MDP	Multidimensional Dyspnea Profile
MDT	Multi-Disciplinary Team
MeSH	Medical Subject Headings
MGUS	Monoclonal Gammopathy of Undetermined Significance
mMRC	modified Medical Research Council breathlessness scale
MND	Motor Neurone Disease

NEADL	Nottingham Extended Activities of Daily Living
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NRS	Numerical Rating Scale
OACC	Outcome Assessment and Complexity Collaborative
OR	Odds Ratios
PACE	Proactive Anticipatory Care Evaluation
PC	Primary Care
PCOC	Palliative Care Outcome Collaborative
PE	Pulmonary Embolism
PIF-ILD	Progressive Idiopathic Fibrotic Interstitial Lung Disease
PNE	Pain Neurophysiology Education
POSs	Patient Outcome Scale Symptom Module
PPI	Public and Patient Involvement
PRIME-MD	PRIME-MD – Primary Care Evaluation of Mental Disorders
PRISMA	Preferred Reporting Items for Systematic Review and Meta-Analyses
PROMS	Patient Reported Outcome Measures
QALY	Quality Adjusted Life Years
QOF	Quality and Outcomes Framework
QoL	Quality of Life

RCT	Randomised Controlled Trial
SC	Secondary Care
SCAPIS	Swedish Cardiopulmonary bioImage Study
SF-12	12 Item Short Form Survey
SF-36	36 Item Short Form Survey
SPC	Specialist Palliative Care
USA	United States of America
VAS	Visual Analogue Scale
WHO	World Health Organisation