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Might significant events have the potential to trigger assessment of the needs (palliative and supportive) of COPD patients and carers?

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Abstract

Background

Chronic Obstructive Pulmonary Disease (COPD) is a leading cause of morbidity and mortality. The prognostic uncertainty within the trajectory of severe COPD makes identification of a transition point to palliative care difficult. When to assess the needs of an individual with severe COPD, as well as the needs of their carer, is widely debated. Various triggers have been suggested, both palliative and supportive, such as post-acute, hospitalised exacerbations, low FEV_1, long term oxygen therapy (LTOT) and low body mass index (BMI), but there is currently no agreed consensus. Coupled with this, is national and international literature highlighting the lack of formal palliative care pathways or models of care that are able to meet the challenge of palliation of symptoms, alongside optimised medical management.

Methods

The narrative accounts of individuals with severe COPD and their carers in a previous piece of primary, empirical research, were explored for events that could act as potential triggers for a holistic assessment of needs. Having identified events within the severe COPD disease trajectory, the potential for these events to act as triggers was explored through a consensus methodological approach, with health and social care professionals and then explored with patients and carers.

Results

The eight identified events from the secondary qualitative data analysis were discussed within a nominal group technique approach to attempt to gain consensus. Identifying triggers and events had some resonance with professionals, but patients and carers struggled with this approach. Patients and carers did however, welcome a holistic assessment of needs and how this could be integrated into current services.

Conclusions

The relatively unexplored area of trigger identification in aiding a holistic assessment of needs within severe COPD has been debated in this study with professionals, patients and carers alike. However, the acceptability and feasibility of this approach has had varied responses from the perspectives of the different stakeholders involved in this process, in particular those of patients and carers. In response, any approach to aid a holistic assessment of needs in severe COPD in the future, will require careful exploration with these stakeholders about the initial concept of the research, with the aim of linking their understanding of what will enhance the patient experience to the design of the research process.

Keywords: COPD, holistic assessment of needs, palliative, supportive

Glossary of Terms

BMI: Body Mass Index is used to act as an objective measure to calculate crudely whether an individual's weight lies within normal or abnormal ranges.

BOFA: The *Breath of Fresh Air Study* is a primary, empirical study conducted by Professor Hilary Pinnock and colleagues looking at individuals with severe COPD and their experiences over 18 months, including those of their carers (informal and nominated by the patient).

Carer (informal/ formal): An individual who is identified by the patient by their role; unpaid and usually a spouse, family member or neighbour, who is the dyadic support for the patient (informal). This is different to that of a formal, paid, professional carer.

Clinical Utility: This refers to how useful an intervention is in terms of ameliorating a patient's palliative or supportive care need. Clinical utility has resonance for professional, patient and carer perspectives and in this study, primarily concerns clinicians as opposed to the wider remit of care professionals involved in COPD care.

COPD: Chronic Obstructive Pulmonary Disease is a condition associated with symptoms of progressive breathlessness, cough or sputum production and may have a history of exposure to risk factors for the disease (e.g. tobacco smoke, occupational exposure or indoor/outdoor pollutants).

FEV_1: Forced Expiratory Volume is the amount of air a person can forcefully exhale within one second. Its measurement is then expressed as a percentage of Forced Vital Capacity (FVC) i.e. FEV_1/FVC to ascertain the severity of COPD.

Holistic Assessment: Refers to the multi-dimensional assessment incorporating the four domains of physical, psychological, social and spiritual needs that is synonymous with palliative care.

LTOT: Long Term Oxygen Therapy can be a sign of progressing disease in that supplementary oxygen is required for at least 16 hours of the day.

NCROP: This refers to the collaboration of the British Thoracic Society (BTS), Royal College of Physicians (RCP) and the British Lung Foundation (BLF) to conduct an audit of COPD care across the UK hospital NHS Trusts.

Palliative Care: This aims to improve the quality of life of patients and their families facing the problems associated with illness, through the prevention and relief of suffering by means of the identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative Care Approach: This describes a way to integrate palliative care methods and procedures in settings not specialised in palliative care. This includes not only pharmacological and non-pharmacological methods for symptom control, but also communication with the patient and their family, as well as with other healthcare professionals, and decision-making and goal-setting in accordance with the principles of palliative care.

Supportive Care: This is care that helps the person and people important to them, to cope with life-limiting illness and its treatment, from before diagnosis, through diagnosis and treatment, to cure or continuing illness, or death and bereavement. This definition can be applied to conditions other than cancer (e.g. COPD).

Trigger: This is the concept by which its attributes need to be sufficiently visible, have significant meaning for those individuals involved within the care and usefulness for all parties involved.

Acknowledgements

Chapter 1: Introduction

The Holistic Assessment within Severe COPD

The main thrust of this piece of work is to develop an approach that ensures individuals with Chronic Obstructive Pulmonary Disease (COPD) and their carers, have a holistic needs assessment in a timely manner. In this chapter, the foundations of the project are discussed, and the work on which it draws. The issues within COPD from the patient and carer perspective, through to the professionals caring for them will be explored and from here the origins of the research question will be explained. The confusion of terms: palliative care, a palliative approach and holistic needs assessment, will be discussed and how service configuration has a part to play in some of the challenges within care delivery. The study components will be discussed in terms of how the research question could be answered and in doing so, describe the theoretical framework underpinning the empirical work. The research process and key considerations will be discussed and the chapter will conclude with an outline of the remainder of the study.

1.1 The Scope of the Issues

COPD is the 4th leading cause of mortality and the 12th leading cause of morbidity worldwide (Pauwels *et al.*, 2001; Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2006). It is a global health problem that, coupled with an ageing population, will only further increase the burden of disease, both in terms of patient experience and healthcare provision. As the countries of the industrial world worry about their environmental footprint, the legacy of exposure to tobacco smoke and indoor biomass fuels has significant morbidity and mortality for individuals with COPD (GOLD, 2006). By 2020, COPD is predicted to be the 3rd leading cause of mortality and the 5th leading cause of morbidity worldwide (Murray and Lopez, 1997). This is also related to an ageing population, with significant risk factors for COPD, such as tobacco use and deprivation (GOLD, 2006; WHO, 2013).

Accurate understanding of COPD mortality data is pivotal in the planning and development of palliative and supportive care services (National Health

Service End of Life Care Intelligence Network (NHS EOLC), 2011) but is complicated by the frequency of life-threatening multi-morbidity. Additionally, the spectrum of COPD and the changing care needs of sufferers, as well as the increasing burden of symptoms, are other considerations in the challenge of delivering care. Figure 1 demonstrates a steady linear model of disease progression but what clinicians see are step changes; their timings vary from patient to patient and there are peaks and troughs in between.

Figure 1: **Spectrum of COPD** *(with permission from Department of Health December, 2010)*

Spectrum of COPD
End of Life Care

Defined as:
•Very severe airflow obstruction (FEV1< 30 % predicted);
•History of two or more severe exacerbations requiring a hospital admission in the preceding year;
•Too breathless to leave the house, or breathless when undressing
•Low BMI (< 20);
•Established respiratory failure or with previous ventilation for respiratory failure.

•Access to supportive care for patient and family through to bereavement stage

•Managed according to guidelines, e.g. Liverpool Care Pathway

Damage

| Unaware of lung health | Aware of lung health | No symptoms | Symptoms but no diagnosis | MILD stage | MODERATE stage | SEVERE stage | VERY SEVERE stage |

Well   **At-risk**   **With COPD diagnosis**
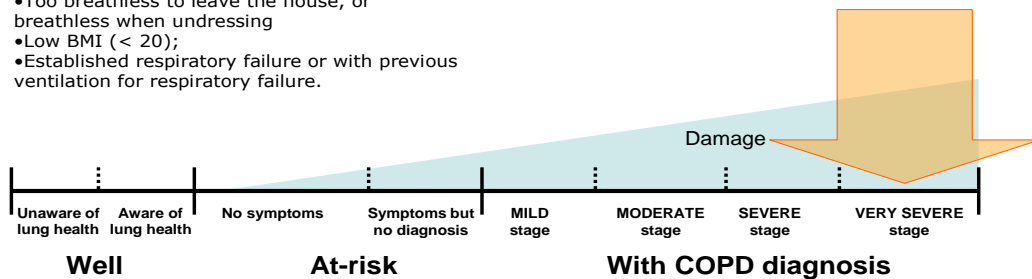
1.2 Origins and Development of the Research Question

The main driver for this research was to ensure that individuals with COPD have a timely assessment of their needs, be they palliative, supportive or both. However, given the multiple agencies, settings and professionals involved with the delivery of care, the requirement to understand these multiple perspectives is a challenge. Ultimately, the patient and carer voice, with what they deem to be important and what they need, should be the key

focus for health and social care professionals, as well as those commissioning these services.

Denzin (2002) describes contextualisation as the ability to gain greater meaning across individual experiences, therefore providing a more systematic awareness of the phenomenon, because it is depicted from the participant point of view "in their terms, in their language, and in their emotions. It reveals how the phenomenon is experienced by ordinary people" (Denzin, 1989, p. 60). Therefore, this study came about as there is no agreed consensus on when and how to holistically assess patients with COPD and their carers, with no clear understanding of patients' views on such assessment, and suggested interventions as a result.

The study evolved into a project looking at potential events or nodal milestones, within the COPD disease trajectory that might lend themselves more intuitively, to facilitating a holistic assessment of needs. However, it could be argued that these events in themselves might well serve more as proxy measures within the prognostication of the actual progression of COPD. As such, they could have more resonance with care professionals than patients or carers, particularly when dealing with care on an individual or cohort level. The notion that holistic needs assessment is an on-going process and not just occurring at certain triggering events might also avert such triggers from happening, e.g. hospital admissions. With this in mind, it was important to explore what professionals, patients and carers perceived of this approach and whether the concept of triggers had any resonance.

As a result, the following research question was developed: might significant events have the potential to trigger an assessment of the needs (palliative and supportive) of COPD patients and their carers?

1.3 Distinction between Palliative Care, a Palliative Approach and Needs

According to the World Health Organisation (WHO), palliative care is:

> An approach that improves the quality of life of patients and their families facing the problems associated with illness, through the prevention and relief of suffering by means of early identification and

impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO, 2013).

For COPD patients and their carers, along with their health and social care professionals, the challenge is in identifying those with 'needs' that would benefit from palliative care services and how to deliver these within the current landscape of services (Murray, Pinnock and Sheikh, 2006). This is also complicated by the global economic constraints that are affecting the provision of healthcare services (Frisina Doetter and Götze, 2011).

Palliative care is not synonymous with end of life or specialist hospice care (Hardin, Meyers and Louie, 2008) and its benefits are not limited to the last days of life. Palliative and supportive care can be provided at any time during a person's illness, even from the time of diagnosis, in any environment, and may be provided simultaneously with curative treatment, creating an integrated approach. Palliation of symptoms and supportive care is integral to the role of generalist healthcare professionals (e.g. family doctors, community nurses) who provide care for patients with progressive and potentially life-limiting illnesses. If an individual's needs are complex or their symptoms are difficult to control, they may benefit from specialist advice from clinicians with specific experience in supportive and palliative care (National Institute for Health and Clinical Excellence (NICE), Improving Supportive and Palliative Care for Adults with Cancer, 2004a; National Council for Palliative Care (NCPC), 2008).

1.4 The Challenges within COPD

When assessing the palliative and supportive care needs of people with COPD and their carers, it is helpful to understand the illness trajectory and the challenges this presents. The physical decline of people with organ failure (such as heart failure) is that of a slow decline, punctuated by potentially serious exacerbations. This is in contrast to that of cancer where people usually maintain their level of physical activity until late in the course of the disease and often, a clear delineation can be seen from curative to palliative treatments.

In particular with COPD, the need for palliation of symptoms overlaps with active management of exacerbations, with no clear-cut transition to an end of life phase. An accurate prognosis in COPD care is very difficult as the timing of the final event is unpredictable (Murray *et al.*, 2005) and even the outcome of severe exacerbations cannot be certain (Connors *et al.*, 1996). The unpredictable clinical situation makes it difficult to plan for the future and there is concern that this uncertainty may lead to 'prognostic paralysis' rather than 'proactive holistic care' (Murray, Boyd and Sheikh, 2005; Murray, Pinnock and Sheikh, 2006).

The American Thoracic Society (2008) advocates an individualised, integrated model of care for patients with progressive respiratory disease, such as COPD (cited in Lanken, Terry and Delisser, 2008). This model emphasises the concurrent provision of palliative and supportive care, along with respiratory medical management, but advocates earlier involvement in the disease trajectory that is explicitly directed to patients' needs and preferences. This model combines the holistic, patient-centred approach to care, with coordination and continuity of care within the healthcare economy, being extremely important. This approach concentrates on the 'needs' identified and not on time, nor prognosis.

1.5 Current Care Provision within COPD and Palliative Care

When considering what management people with COPD and their carers require, it is important to consider that in many healthcare systems, patients are managed between primary and secondary healthcare teams interchangeably. When symptoms or situations are complex, specialist input from additional health and social care professionals may be required to support generalist care and ensure that those with the greatest and most debilitating of needs, receive appropriate services. However, within the UK, the National COPD Resources and Outcomes Project (NCROP) conducted an audit of NHS hospital trusts and found that only 42% had formal palliative care arrangements for patients with COPD (Roberts *et al.*, 2008). The study concluded that "prospective research in the area of COPD palliative care is

much needed" (Roberts *et al.*, 2008). This is supported by literature that warns of the difficulties in transferring a cancer model of care delivery to non-malignant diseases, in particular COPD and heart failure (NICE, 2004b; Murray *et al.*, 2005; Murray and Sheikh, 2006; NCPC, 2008).

Despite the significant symptom burden and needs of COPD patients, very few received palliative care in the last year of life compared to those with lung cancer (Gore, Brophy and Greenstone, 2000; Goodridge, 2006). Patients with COPD have "twice the odds of being admitted to an intensive care unit and receive fewer opioids and benzodiazepines compared with patients with lung cancer" (Au *et al.*, 2006), although these treatments are recognised as being effective in the palliation of the symptoms of breathlessness in advanced disease (Jennings *et al.*, 2001; Seamark, Seamark and Halpin, 2007; Booth *et al.*, 2009; Rocker *et al.*, 2009; Simon *et al.*, 2010).

1.6 Theoretical Work

This work aims to address the issues of when to assess the needs (palliative and supportive) of individuals with COPD and their carers. The work has evolved from the use of an existing data source from a primary study, capturing patients', carers' and professionals' perspectives and then testing the findings, the candidate events, with the very individuals, namely the patients, carers and health and social care professionals, who would benefit from such a novel approach. The concept of triggers evolved with the aim of raising the visibility of an individual's needs to the professional radar, coupled with a more holistic enquiry of needs within the progressive and declining disease trajectory of severe COPD. This approach was cognisant of various stakeholders holding different views about theoretical explanations of how care is delivered. Opposing theories in service development are critical of the lack of attention given to how different perspectives are accommodated and as a consequence, frequently excluded (Funnell and Rogers, 2011). This study therefore, aimed to explore the multiple perspectives of patients, carers and professionals, within the care arena of severe COPD, exploring, building and refining the concept of events triggering a holistic assessment of need

across different care settings in each successive stage of the study (Corbin and Strauss, 2008; Craig *et al.*, 2008). The component parts of the project, qualitative, secondary data analysis, consensus methodology and qualitative interviews, followed the Medical Research Council (MRC) framework for evaluating complex interventions (Craig *et al.*, 2008).

1.7 Epistemological and Ontological Considerations of the Research Design

Identification of the epistemological and ontological issues at the start of the research process is critically important as it determines the choice of the research design (Green and Thorogood, 2004). With the main crux of this thesis aiming to explore the concept of triggers from multiple perspectives (patient, carer and professional), stakeholders' initial standpoints and understandings were important to ascertain. This area of enquiry has arisen given the lack of consensus amongst professionals concerning at what stage of COPD a holistic needs assessment should take place. Research by Giacomini *et al.* (2012), echoed this view, highlighting a real lack of clarity about the progressive, burdensome nature of COPD and the insidious onset of symptoms. Giacomini *et al.* (2012) also acknowledged the disparity in understandings, expectations and availability of resources regarding COPD care. This was echoed by Pinnock *et al.* (2011), who stated that living and dying with COPD is a dynamic continuum with different understandings and different needs throughout the lifetime of the condition (Pinnock *et al.,* 2011). By looking at the epistemological assumptions from the perspectives of professionals, patients and carers, using the different components of this thesis (secondary data analysis, nominal group technique and qualitative interviews), the author attempted to unravel some of these assumptions, with the aim of forming a more cohesive understanding of how to facilitate a holistic needs assessment in severe COPD. This was fundamentally rooted in an approach that aimed to listen to and contrast the viewpoints of its participants, rather than making assumptions, with the aim of building on and contributing to the knowledge base in this field of work (Blaikie, 2010).

Ontology can be defined as "the science or study of being" and it deals with the nature of reality (Blaikie, 2010). Ontology is a system of belief that reflects an interpretation by an individual about what constitutes a fact. In other words, ontology is associated with a central question of whether social entities should be perceived as objective or subjective. Accordingly, objectivism (or positivism) and subjectivism can be specified as two important aspects of ontology. Objectivism "portrays the position that social entities exist in reality external to social actors concerned with their existence" (Saunders, Lewis and Thornhill, 2012). Alternatively, objectivism "is an ontological position that asserts that social phenomena and their meanings have an existence that is independent of social actors" (Bryman, 2012). Subjectivism (also known as constructionism or interpretivism) on the contrary, perceives that social phenomena are created from the perceptions and consequent actions of those social actors concerned with their existence. Formally, constructionism can be defined as an "ontological position which asserts that social phenomena and their meanings are continually being accomplished by social actors" (Bryman, 2012). Therefore, when deciding on the research design and methodological approaches for this study, given the complexity of the multiple perspectives and the factors (actors) interplaying, it was important to have three distinct pieces of work (as outlined in Chapters 3, 4 and 5), with Chapter 6 bringing together and trying to triangulate some similarities within the process, but also contrasting any clear differences or assumptions (e.g. all patients perceive their needs equally or all professionals will assess individuals with severe COPD holistically).

Therefore, in trying to unravel some of the understandings coming from the different perspectives (epistemological issues) in looking at this relatively unexplored area of trigger identification facilitating holistic assessment of needs, attention was paid to the healthcare system (ontological issues) that these perspectives operate within.

1.8 Empirical Work

As echoed above, one of the strengths of this research lies in capturing the multiple perspectives involved within care delivery in COPD. Therefore, this piece of work will have a more holistic understanding of any proposed intervention and will aim to resonate with all those involved. As such, the research has primarily, three significant pieces of empirical work to contribute.

The work starts with a qualitative, secondary analysis of transcripts (n= 92) from a primary research study, *Breathe of Fresh Air study (BOFA)* (Pinnock *et al.*, 2011). The use of the data and the merits of qualitative, secondary analysis are discussed in Chapter 3, namely, developing the concept of triggers, exploring the attributes of a trigger and how particular events within the COPD disease trajectory may have the potential to shine their visibility onto a professional lens. The potential events (eight in total) are then explored using consensus methodology with the very professionals (health and social care) who were frontline staff involved in the delivery of COPD services. Chapter 4 allows, through its use of nominal group technique, a capturing of the issues, with the concept of triggers within different settings and across different disciplines. The multiple rounds and discussion facilitated the main themes with the implementation of triggers as a concept within COPD care. Finally, having canvassed the perspectives of professionals, Chapter 5 explores the concept of triggers with patients and carers, capturing their thoughts on the concept, the candidate events as identified in the qualitative, secondary data analysis and an exploration of how needs are perceived by individuals and the utility of holistic enquiry within this.

The considerations of the methodology employed, the ethical considerations and the recruitment strategies used, are discussed within each of the chapters with a particular focus on that component of the study.

1.9 Outline of the Study

This study initially looks critically at the literature and where there is a paucity of evidence in holistically assessing the needs of patients and carers in

severe COPD, whilst contrasting the multiple variables at play in the configuration and delivery of COPD care (Chapter 2). Exploring the concept of triggers and identifying events with the potential to facilitate a holistic needs assessment are discussed, with particular emphasis on the attributes required within a triggering system (Chapter 3).

These concepts were then further explored with professionals, gaining an understanding of their perspectives with this novel approach (Chapter 4). The many considerations when implementing a new approach, were considered, with particular focus and debate around the clinical utility of the actual process, i.e. the potential of the identified events being sufficiently visible to trigger a holistic assessment of need.

These concepts were further explored with patients and their nominated carer to, again, gain valuable insight and understanding of the clinical utility of triggers (Chapter 5). This exploration gained further insight into how individuals with severe COPD view their illness and subsequently perceive their needs within a more holistic lens.

The findings are then discussed in relation to the published literature within the current service delivery of COPD, and what considerations are required with the investigation of any novel approach aiding the timely holistic assessment of needs (palliative and supportive) (Chapter 6).

Chapter 2: Literature Review

Interfacing Chronic Obstructive Pulmonary Disease (COPD) and Palliative Care

2.1 Review Methodology Employed

In this chapter, the current literature is critically reviewed, looking at studies with a focus on COPD and palliative care from a patient and professional perspective, and how this is delivered. Empirical studies were identified using multiple bibliographic databases. The literature search was carried out between September 2009 and January 2010 on the Medline (Ovid), PubMed, EMBASE, PsychINFO, Cochrane Library and CINAHL databases and updated in November 2016 to January 2017, given the time elapsed from the initial inception of the project and final write up. The search terms used were:

> Palliative care OR end of life care OR hospice care AND COPD, Chronic Obstructive Pulmonary Disease AND needs AND holistic assessment.

Search terms were adjusted slightly to fit the different search systems, such as the use of MeSH in PubMed. Additionally, hand searches in palliative care, respiratory and general practice journals (BMC Palliative Care, BMJ Supportive and Palliative Care, Journal of Hospice and Palliative Care Nursing, Journal of Palliative Care, Palliative Medicine, Primary Care Respiratory Journal, Thorax, British Journal of General Practice) and in reference lists of included studies, were also conducted. The hand searches were limited to those journals that were physically accessible. The literature search was set up broadly so that relevant studies would not be overlooked.

The lack of literature on how COPD and palliative care services interface was notable: there were few explicit references, highlighting the need and strengthening the debate for an approach that addresses this very issue. The lack of literature may also point to the possibility that the drive to intersect the condition of COPD and its palliation, may come from policy initiatives rather than evidence. Consideration of when the needs of COPD patients and their carers should be assessed is lacking.

The literature, although limited, has described certain key areas concerning COPD and the involvement with palliative care, as will be discussed below.

2.1.1 COPD

In the context of this thesis, the abbreviation COPD refers to the progressive, life-limiting condition known as Chronic Obstructive Pulmonary Disease, the severity of which is assessed by spirometry (breathing tests) to diagnosis and subsequently assess severity (GOLD, 2006). COPD with its associated mortality and morbidity have already been discussed in Chapter 1.

Hospital admissions and associated mortality

COPD is an illness of great variability in terms of its progression and prognosis (Lunney *et al.*, 2003; Lehman, 2004). Studies have shown that 13.9% of patients die within 90 days of an admission from an exacerbation of COPD (National COPD Resources and Outcomes Project (NCROP), Roberts *et al.*, 2008). NCROP refers to the collaboration of the British Thoracic Society (BTS), Royal College of Physicians (RCP) and the British Lung Foundation (BLF) to conduct an audit of COPD care across the UK hospital NHS Trusts. One aspect of the audit was a survey of the organisation and resources allocated to COPD, including a section on palliative care services and good clinical practice in this area. Other research has shown that between 36% and 50% of people admitted with respiratory failure, die within two years of their first hospital admission (Connors *et al.*, 1996; Almagro *et al.*, 2002). However, these figures also show that between 50% and 64% of patients continue to live with COPD, even after severe exacerbations.

COPD patients have significant co-morbidities, with Ischaemic Heart Disease being the most prevalent at 25.4% (NCROP, as cited in Roberts *et al.*, 2008), but these other co-morbidities are often related to a history of smoking or other lifestyle issues, and may contribute to morbidity and mortality. There is a significant mortality associated with hospitalisation (Elkington *et al.*, 2004; Ambrosino and Simonds, 2007; Teno *et al.*, 2010), coupled with patients not readily identifying a downward trajectory in their health over time. Some patients attribute worsening symptoms not to the progression of their disease,

but rather to temporary, immediate causes, such as self-management failures or environmental changes (Victorson *et al.*, 2009; Pinnock *et al.*, 2011). In hindsight, the steady decline in COPD becomes most recognisable at later stages of the disease (Wilson *et al.*, 2008; Gott *et al.*, 2009; Gysels and Higginson, 2010). Thus, there is uncertainty in estimating prognoses or how the disease will progress, which differs significantly with many other life-threatening illnesses, such as cancer or progressive neurological disease (Lynn, 2001; Lehman, 2004). Despite the importance of having some certainty or understanding of the illness trajectory for COPD (Lynn, 2001; Lynn and Adamson, 2003; Murray *et al.*, 2005), attempts at accurately predicting survival remain challenging, with methodological issues of using separate cohorts and reporting of advancing severity of COPD physiological parameters, being the main spotlight for attention (Giacomini *et al.*, 2012). There is a current paucity of literature that examines longitudinally, the functional decline trajectory, along with potential changes in symptoms and subsequent needs for COPD patients and their carers.

Prognostic uncertainty within COPD

Although it is certain that COPD will eventually be fatal, the timing of decline and death is highly uncertain (Crawford, 2013). As such, this uncertainty may make physicians unsure about whether and when to discuss the prognosis of COPD with their patients (Oliver, 2001). Indeed, patients often learn about their prognosis from a source other than their physician, and typically after their initial diagnosis (Curtis *et al.*, 2002). Patients tend to be poorly informed about the long-term prognosis of their disease and what to expect towards the end of their lives, especially compared to other diseases such as cancer or acquired immune deficiency syndrome (AIDS) and this lack of understanding, impairs their quality of life as the disease progresses (Gore, Brophy and Greenstone, 2000; Curtis *et al.*, 2002; Gardener *et al.*, 2018). Some patients may envisage their death from COPD occurring at the end of their natural life, rather than prematurely (Oliver, 2001; Gardiner *et al.*, 2010; Pinnock *et al.*, 2011), and some may deliberately avoid contemplating death altogether (Hall, Legault and Cote, 2010). Nevertheless, although the long-term picture may be fuzzy, patients may fear and think about death, particularly during acute

exacerbations, not knowing which one may be their last (Spence *et al.*, 2008; Hall, Legault and Cote, 2010; Lindgvist and Hallberg 2010; Pinnock *et al.*, 2011).

2.1.2 Palliative Care

Palliative care vs. palliative care approach

According to the World Health Organisation, palliative care is:

> An approach that improves the quality of life of patients and their families facing the problems associated with illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO, 2013).

Palliative care is not synonymous with end of life or specialist hospice care (Hardin, Meyers and Louie, 2008) and its benefits are not limited to the last days of life. The definition of palliative care is complex and the European Association for Palliative Care White Paper, (as cited in Radbruch and Payne, 2009), suggested that palliative care may be seen in three main ways:

1. The palliative care approach is a way to integrate palliative care methods and procedures in settings not specialised in palliative care. This includes not only pharmacological and non-pharmacological methods for symptom control, but also communication with the patient and their family, as well as with other healthcare professionals, and decision-making and goal-setting in accordance with the principles of palliative care.
2. General palliative care is provided by primary care professionals and specialists treating patients with life-threatening diseases who have good, basic palliative care skills and knowledge. This includes professionals who are involved more frequently in palliative care, such as oncologists or geriatric specialists, but who do not provide palliative care as the main focus of their work. They may have acquired specialist knowledge and had training in palliative care, thus providing additional expertise.

3. Specialist palliative care describes services whose main activities are the provision of palliative care for patients with complex problems, not adequately covered by other treatment options. Specialist palliative care services require a team approach, combining a multi-professional team with an interdisciplinary mode of work. Team members must be highly qualified and should have their main focus of work in palliative care.

(Radbruch and Payne, 2009).

Palliative care may be provided at any time during a person's illness, from the time of diagnosis and in any environment. It may be provided simultaneously with curative treatment, creating an integrated approach. Palliation of symptoms and supportive care is integral to the role of generalist healthcare professionals (e.g. family doctors, community nurses) who provide care for patients with progressive, potentially life-limiting illnesses. If an individual's needs are complex or their symptoms are difficult to control, they may benefit from specialist advice from clinicians with specific experience in supportive and palliative care (NICE, 2004a; 2004b).

Whilst national strategy documents suggest that 'quality' end of life care should be available to all disease conditions (NICE 2004a; NCPC 2008; NICE 2010b), and be a priority for NHS services (NICE, 2017), the evidence for this is lacking (Roberts *et al.*, 2008; Partridge, Karlsson and Small, 2009; The King's Fund, 2010). With the advent of these national drivers comes the difficulty of definitions and different interpretations for healthcare professionals and patients alike. It has been emphasised that palliative care is not synonymous with end of life or hospice care (Hardin, Meyers and Louie, 2008), as previously mentioned. Therefore, Hardin and colleagues highlight that:

In contrast, palliative and supportive care can be provided at any time during a person's illness, even from the time of diagnosis, in any environment, and may be provided simultaneously with curative treatment, creating an integrated disease directed approach. Its

benefits are not limited to the last days of life (Hardin, Meyers and Louie, 2008).

This approach is echoed by the WHO's updated definition of palliative care (WHO, 2013). The confusion regarding definitions of terms, can lead to issues in the accurate identification of needs and priorities for service provision and development (Shipman *et al.*, 2008). Therefore, the term 'supportive and palliative care' should be used to combine the composite needs of individuals with life-limiting illnesses.

Hynes and colleagues (2015) argue that in order to meet the demand for palliative care in COPD and in particular to deliver this, healthcare professionals need to have basic or non-specialist skills in palliative care. However, their action research project, specifically looking at up-skilling community respiratory professionals with the clear remit for improving the care of the most complex COPD cases, was at best hopeful that end of life care may improve. They issued a clear proviso that to embed palliative care into everyday practice, there needs to be a more fundamental shift in the organisation of care. They found that inter-level dynamics at individual, team, interdepartmental and organisational levels are an important factor in the capacity of respiratory nurses to embed non-specialist palliative care in their practice (Hynes *et al.*, 2015).

This was echoed by Horton and colleagues, who attempted to improve community provision of palliative care services for patients with advanced COPD (Horton *et al.*, 2013). However, they found there were limitations within current palliative care service models and caregivers were often not adequately supported. As a result, caregivers felt disempowered and ultimately required a "forced hospital admission", even when the stated preference of 53% of the patients in the study was to die at home (Horton *et al.*, 2013).

2.2 Palliative Care and COPD

2.2.1 Disease Trajectories

The crucial first step is to identify people with end-stage disease, so that their holistic, physical, psychological, social and spiritual needs can be fully assessed and appropriate care planned (The Gold Standards Framework, 2014). However, identifying the transition point when specialist palliative care becomes appropriate is not clearly defined, especially in non-malignant disease. Three different trajectories of physical decline are described below to help understand where COPD sits within the wider trajectories of illnesses (Lynn and Adamson, 2003; Murray *et al.*, 2005).

Figure 2: Trajectories of Physical Decline at the End of Life *(with permission: Murray et al., 2005)*
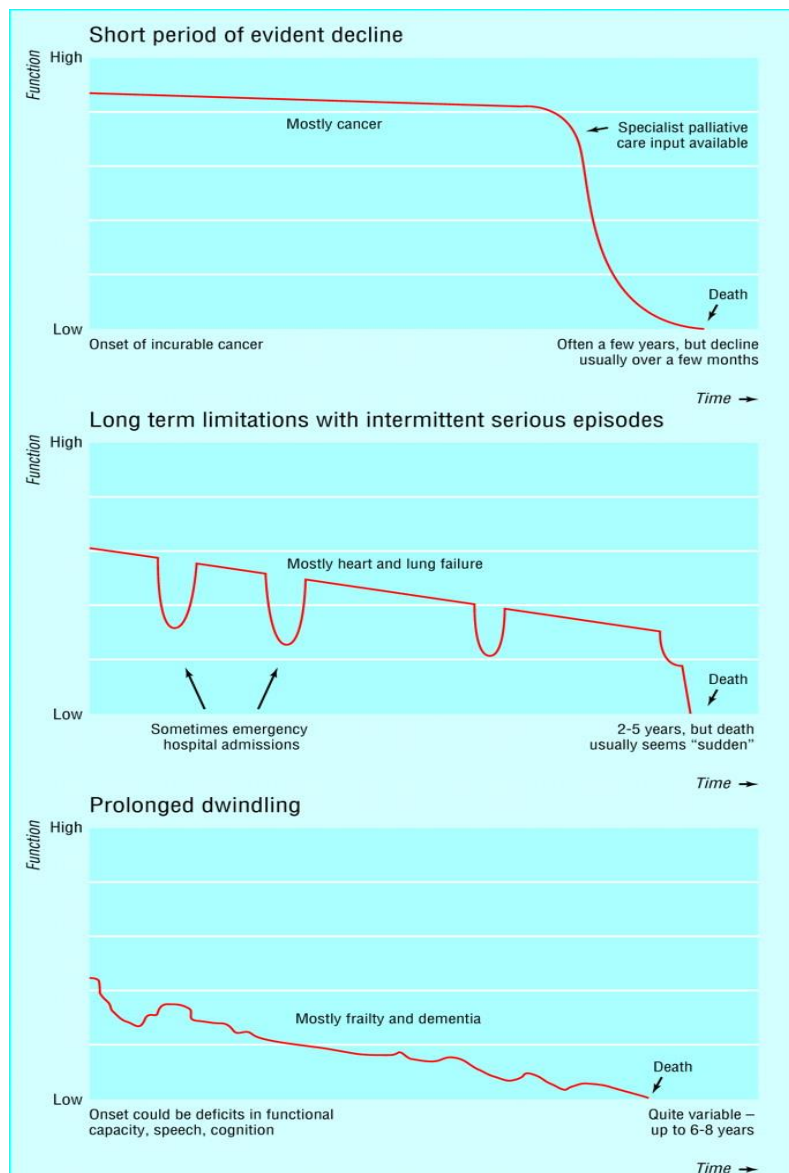
*Cancer (*Top graph)

The top graph illustrates that people dying with cancer usually maintain their level of physical activity until late in the course of the disease and the transition to the terminal phase is relatively easy to identify. Typically, this is the point at which curative, surgical radiotherapy or chemotherapy is acknowledged to be unhelpful and attention turns to palliation of symptoms during the relatively short, terminal decline. Although clinicians may be wary of offering a prognosis, it is normally possible to predict those who will die within a year with reasonable accuracy (Christakis and Lamont, 2000). Furthermore, it is usually possible to identify the last few days of life and step up care appropriately. Whilst recognising that needs and situations will evolve, in this scenario, anticipatory care can enable patients and their carers to plan for their end of life with a degree of certainty.

Organ failure (middle graph)

By contrast, the middle graph shows that the physical decline of people with organ failure (e.g. heart failure, COPD, renal failure) is that of a slow decline, punctuated by potentially serious exacerbations. The need for palliation of symptoms overlaps with active management of exacerbations with no clear-cut transition to an end of life phase. There is concern that this uncertainty may lead to "prognostic paralysis", rather than proactive holistic care (Murray, Boyd and Sheikh, 2005; Murray, Pinnock and Sheikh, 2006).

Frail elderly (bottom graph)

In the bottom graph, the prolonged 'dwindling' seen in the frail elderly follows a poorly understood trajectory. An accurate prognosis is impossible and the combination of active treatment for multiple co-morbidity and supportive management of long-term symptoms is familiar to all those caring for the very elderly. Consideration of preferences for end of life care is likely to have less immediacy than in the context of the rapid decline of a patient with cancer (Murray *et al.*, 2005).

Indicators of a poor prognosis in COPD

COPD is an example of a condition which follows the organ failure trajectory (Lynn and Adamson, 2003), but characteristically has an insidious onset and potentially exceptionally long duration of disease. Typically, it is due to a lifetime of smoking and the symptoms of breathlessness, cough and sputum production develop very gradually, making it difficult to identify either the beginning of the condition or the point at which it becomes potentially life-threatening (Coventry *et al.*, 2005). Even when it is clear that a patient has very severe disease, the timing and severity of exacerbations are unpredictable, and co-morbidity means that two-thirds of people with COPD will die of other (often smoking-related) conditions, such as coronary heart disease or lung cancer. This unpredictability is compounded by a tendency for doctors who are familiar with patients, to over-estimate survival (Christakis and Lamont, 2000).

Nevertheless, there are well-recognised indicators of a poor prognosis in COPD (Connors *et al.*, 1996; Almagro *et al.*, 2002; Coventry *et al.*, 2005), which are:

- Hospitalisation with an exacerbation.

- Severity of COPD (including dyspnoea, prior functional status and presence of hypoxia/hypercapnia).

- Long-term oral steroid use.

- Poor nutritional status (body mass index (BMI) and serum albumin).

- Co-morbidity with heart disease (congestive heart failure and cor pulmonale).

- Depression and impaired quality of life.

- Dependency in activities of daily living.

- Older age.

Despite these 'indicators', prognosis for any individual is extremely inaccurate (Christakis and Lamont, 2000). The median survival of COPD patients referred for hospice care in the US (by definition with an anticipated prognosis of less than six months), was 77 days, but a third survived more than 180

days (Christakis and Escarce, 1996). The only condition where prognosis was less accurate was dementia.

Challenges with prognosis in COPD

For COPD patients and carers, along with their health and social care professionals, the challenge is in identifying those with 'needs' whom would benefit from palliative care services and how to deliver these within the current landscape of services (Murray *et al.*, 2005); a situation further compounded by the global economic constraints that are affecting the provision of healthcare services today (Frisina Doetter and Götze, 2011).

The COPD trajectory, as explained by Lynn and colleagues (Figure 2), identified the differences with a cancer trajectory and how patient and clinician experiences of this are different (Lunney *et al., 2003*; Pinnock *et al.*, 2011). Lynn acknowledged a lack of clear transitions in COPD, unlike in cancer which is punctuated with a gear change to end of life care, when no further treatments are offered as the disease has progressed despite systemic interventions (Lynn and Adamson, 2003). However, over recent years there has been an improvement in the treatment of many cancers, with an increased prognosis and often varying function related to the development of further metastases or further intervention with chemotherapy (Temel *et al.*, 2010).

A study by Reinke and colleagues (2008), remarked on the differing perspectives of clinicians and patients regarding functionality. Within the patient arena, the activity limitations due to functional decline and initiation of oxygen therapy, prompted the possibility of progression of COPD. However, for clinicians it was acute exacerbation of illness or hospitalisation that alerted them to a transition to end of life care (Reinke *et al.*, 2008). Thus, there would appear to be a differing awareness between patients and professionals of the changes occurring as COPD progresses, emphasising the importance of capturing the patient view of when and how to assess their needs.

Kendall and colleagues (2015) used a qualitative enquiry when looking at the different experiences and goals of patients and their families with different

advanced diseases (cancer, heart failure, COPD and liver failure), and they clearly identified contrasting illness narratives. These differing accounts affect and shape the experiences, thoughts and fears of patients and their carers in the last months of life. The study concluded that "palliative care offered by generalists or specialists should be provided more flexibly and equitably, responding to the varied concerns and needs of people with different advanced conditions" (Kendall *et al.*, 2015).

2.2.2 The Differences between COPD and Lung Cancer

Similar to COPD, lung cancer is more likely to occur in the poor and in the less-educated (Meara, Richards and Cutler, 2008). Poor lung function is an established risk factor for lung cancer and amongst smokers, those with airflow obstruction have the greatest risk of developing the disease. Several studies (Tockman *et al.*, 1987; Mannino *et al.*, 2003; Purdue *et al.*, 2007), have shown that having moderate-to-severe COPD, increases the risk of developing lung cancer up to 4.5-fold. Interestingly, some data (Ueda *et al.*, 2006) has demonstrated that the presence of emphysema is associated with poor prognosis in those with lung cancer. Complementary to this, is the observation that the incidence of lung cancer is associated with specific stages of COPD severity. Lung cancer is assigned as the cause of death in 33% of patients with mild-to-moderate COPD and in 14% of patients with more severe disease (Anthonisen *et al.*, 1994; McGarvey *et al.*, 2007).

Patients with end-stage COPD experience poor health-related quality of life, comparable to or worse than that of patients with advanced lung cancer (Habraken, 2008, with 62% of COPD patients experiencing pain, compared to 72% of lung cancer patients. In this study, the majority of COPD patients had a Medical Research Council (MRC) (1986) dyspnoea score of four, compared to two for lung cancer patients, and only 21% of patients with COPD scored highly on 'General Health Perceptions', compared to 30% of lung cancer patients.

COPD and lung cancer exhibit similar symptoms, such as pain, insomnia, fatigue, low mood and dyspnoea (Joshi, Joshi and Bartter, 2012), yet studies report even worse physical and emotional functioning for COPD than for lung

cancer (Gore, Brophy and Greenstone, 2000; Habraken, 2008. Given the significant symptom burden and needs of this group of patients, a significantly smaller proportion of patients received a palliative care approach (referral to a designated palliative care service (either at home or in the hospital)), compared to those with lung cancer in the last year of life (Gore, Brophy and Greenstone, 2000; Goodridge *et al.*, 2008). A more recent study confirmed that 37.3% of COPD patients compared to 73.5% of lung cancer patients, received a palliative care approach in the last year of life, with timing of referral to services being very close to death; a median of six days for COPD patients and 16 days for lung cancer (Scheerans *et al.*, 2018). When considering palliation of symptoms, patients with COPD have "twice the odds of being admitted to an intensive care unit and receive fewer opioids and benzodiazepines compared with patients with lung cancer" (Au *et al.*, 2006), when these treatments are commonly used to palliate the symptoms of breathlessness in advanced disease (Jennings *et al.*, 2001; Booth *et al.*, 2009; Rocker *et al.*, 2009; Simon *et al.*, 2010).

Breathlessness is the most predominant and disabling symptom, followed by anxiety and depression, but pain, fatigue, anorexia, weakness, sleep disturbances and mouth problems have also been reported (Jablonski, Gift and Cook 2007; Boland *et al.*, 2013; Sundh and Ekstrom, 2016). Coupled with the physical decline in functioning, is the resultant social isolation (Rocker *et al.*, 2007; Ek and Ternestedt, 2008; Gardiner *et al.*, 2010; Jackson *et al.*, 2012), compounded by the inadequate housing and deprived localities (White, White and Edmonds, 2011; Lowey *et al.*, 2013). The burden on carers is high (Goodridge, 2006; Rocker *et al.*, 2007; Currow *et al.*, 2008; Spence *et al.*, 2008) as they have an extended caring and house-keeping role which may continue over many years (Currow *et al.*, 2008).

2.3 Holistic Needs Assessment

As mentioned already, patients with severe COPD, can experience a range of debilitating physical symptoms, resulting in loss of functionality and high levels of psycho-social distress (Pinnock *et al.*, 2011; Sundh and Ekstrom, 2016; Kardos *et al.*, 2017; Quellette and Lavoie, 2017). National strategy documents

(NICE 2004a; 2004b; NCPC 2008; Adlington and White, 2015; NICE, 2017), highlight the need to address individual, physical, psychological, social and spiritual needs experienced by these patients through holistic assessment, thus facilitating patient-centred care. Understanding the patient's view of their needs, particularly those aspects of managing life with COPD with which they need support e.g. support to manage their symptoms or access to financial benefits, is key to facilitating this approach (Gardener *et al.*, 2018).

Assessment

Higginson and colleagues (2007) argue that there are different approaches to defining and assessing needs, with, to date, little analysis or comparison and "whatever definition is used, it must have clinical utility for an assessment of needs to be carried out" (Higginson *et al.*, 2007). Clinical utility, in this sense, refers to how useful an intervention is in terms of ameliorating a patient's palliative or supportive care need. Others have emphasised that 'need' is equated "as the ability to benefit from health care" (Stevens, 2004). Benefit is not restricted to clinical benefit, but can also include reassurance, supportive care, and relief to carers (Stevens and Gillam, 1998). Several assessment tools aimed specifically at identifying the holistic (palliative and supportive care) needs of individuals have been developed, e.g. Sheffield Profile for Assessment and Referral to Care (SPARC) (Ahmedzai *et al.*, 2008; Ahmed *et al.*, 2009), Palliative Outcome Scale (POS) (Hearn and Higginson, 1997), Support Team Assessment Schedule (STAS) (Bausewein *et al.*, 2011) and Edmonton Symptom Assessment System (ESAS) (Breura *et al.*, 1991). Originally designed for use in cancer populations, adaptations have been suggested for use in non-malignant conditions including COPD, though their use in clinical practice is currently limited.

When assessing the needs of patients, the terms 'palliative' and 'supportive' have been used interchangeably when discussing needs being met by services with a palliative and supportive approach (NICE, 2004a; 2011; 2018). NICE defines supportive care as "care that helps the person and people important to them to cope with life-limiting illness and its treatment, from before diagnosis, through diagnosis and treatment, to cure or continuing

illness, or death and bereavement". This definition can be applied to conditions other than cancer (e.g. COPD), although it may be less understood or applied in other conditions. Supportive care is not related to the patient's condition or prognosis, but rather to the needs of the person and those important to them. Palliative care is defined as:

> Care towards the end of life that aims to provide relief from pain and other distressing symptoms, integrates the psychological and spiritual aspects of the person's care, and provides a support system that allows people to live as actively as possible until their death (NICE, 2004a).

The 2004 guideline defined palliative care as "the active holistic care of patients with advanced, progressive illness" (NICE Supportive and Palliative Care, 2004a), yet it also recommends that it should be applied early in the course of illness, alongside investigations and therapies intended to prolong life (such as chemotherapy in cancer or pulmonary rehabilitation in COPD). This policy statement does in fact offer some contradictions, as on the one hand it advocates active, holistic care of patients with "advanced, progressive illness", yet it also states that a needs assessment should happen early on in the course of their illness, as opposed to throughout the journey of a progressive condition. This lack of clarity in policy and guidance is a challenge for patients, carers and professionals alike and adds to the confusion in this field. In practice, palliative care has usually been associated with care in the last months and weeks of life, whilst supportive care covers the earlier stages of progressive illness. The NICE guidance has been more helpful here, clarifying that the holistic needs (physical, psychological, social and spiritual) of an individual with progressive illness, and/or their carer, can be both supportive and palliative and form an umbrella term to be used interchangeably. Therefore, for the purposes of this thesis, needs are discussed in terms of their supportive and palliative care context and how this informs the delivery of individualised patient care.

Patient and professional understanding of needs

COPD patients often suffer poor relationships with health care providers and experience hastiness, poor listening, or lack of compassion (Oliver, 2001). Patients can feel that their subjective distress seems invisible to clinicians, who focus on objective health indicators (Oliver, 2001; Bailey, 2004; Gysels and Higginson, 2008; Wilson *et al.*, 2008), as the current literature continues to identify these measures and fails to address patients' distress. Physicians infrequently investigate, address, or refer to their substantial, non-medical assistance needs (e.g. psychological support or housing support) (Habraken *et al.*, 2008; Gysels and Higginson, 2010). Habraken refers to the 'silence' of people with end-stage COPD as individuals attribute their limitations as 'normal' and regard themselves as ill only during acute exacerbations (Habraken *et al.*, 2008). Pinnock *et al.* (2011) and colleagues echo these findings, identifying the insidious onset of this illness for individuals as "not so much an illness, more a way of life". The participants of this study attributed the symptoms experienced, as a lifetime exposure to fumes, smoking, or both and just a "part of getting older" (Pinnock *et al.*, 2011).

The term 'biographical disruption' describes the major disruptive experience of developing chronic illness and the consequent rethinking of a person's biography and self-concept (Bury, 1982; Chamaz, 1983; Williams, 1984). This concept was applied by Pinnock *et al.* (2011) in their multi-perspective, longitudinal study of severe COPD, suggesting that given the very slow, progressive nature of COPD, patients may have no sense of biographical disruption at all. In such individuals, there was "no illness narrative separate from life narrative, rather people adjust their sense of self over years to fit within the limitations imposed by their condition". This lack of disruption has been suggested to be pivotal in patients' and carers' acceptance and passivity, such that they neither demand nor use services. Clinicians, especially those who have a long-term relationship with the patient, may share this 'passive acceptance' of the patients 'way of life', contributing to the difficulties in identifying a transition point to palliative care (Pinnock *et al.*, 2011). Work by the same research collaborative, used a qualitative enquiry when looking at the various experiences and goals of patients and their families with different advanced diseases (cancer, heart failure, COPD and

liver failure), and they clearly identified contrasting illness narratives (Pinnock *et al*., (2011).

The perception of illness will therefore impact on an individual's expression of their needs, especially in terms of their understanding and recall. Kendall and colleagues have explored the concept of need within COPD (Kendall *et al.* 2015), using a qualitative approach to explore the perspectives of the patient, carer and professional. The needs were identified and categorised using Bradshaw's classification of need (Table 1).

Table 1: Summary of Bradshaw's Classification of Need (*with permission from Kendall et al., 2015*)

Table 1	Summary of Bradshaw's classification of need
	Description
Felt need	Felt need is want, desire or subjective views of need which may, or may not become expressed need.[17] It may be limited by individual perceptions and by lack of knowledge of available services. Felt need may be influenced by comparison with peers or others with a similar condition, and whether it is elicited may depend how (and by whom) the question is asked.[18]
Expressed need	Expressed need is demand or felt need turned into action, and help is sought.[17] However, to express need it is necessary to have heard of a service, consider the service to be acceptable, accessible and priced appropriately.[18]
Normative need	Normative needs are defined by experts, professionals, doctors, policymakers.[17] Often a desirable standard is laid down and compared with the standard that actually exists. They are not absolute and different experts set different standards.[18] Assessment of normative needs can also be used to judge the validity of an expressed need.[18]
Comparative need	Comparative need has to do with equity:[17] if some people are in receipt of a service and others, in similar circumstances, are not, then the latter are considered to be in need. Relative availability will influence comparative need as the benchmark is to achieve equal access[19]

The results show that patients rarely perceived themselves as 'needy', accepting their 'felt' needs as a result of a disability to which they had now adapted. There was an over-arching theme of the importance of "retaining a sense of independence and autonomy, considering themselves as ageing rather than ill." This was in contrast to professionals who had a different perception of patients' needs, identifying them within a very clinical arena, and therefore classifying them as 'normative'. The authors concluded that approaches that are sensitive to the fostering of independence may enable patients to 'express' needs that are amenable to help, without disturbing the adaptive equilibrium they have achieved (Kendall *et al*., 2015).

These differing accounts affect and shape the experiences, thoughts and fears of patients and their carers in the last months of life. The study

concludes that "palliative care offered by generalists or specialists should be provided more flexibly and equitably responding to the varied concerns and needs of people with different advanced conditions" (Kendall *et al.*, 2015), perhaps implying that triggers are not as relevant to patients and carers as they are to health care professionals.

2.4 Models of Palliation within COPD

In attempting to improve the services for individuals with COPD, the NCROP was established in the UK (NCROP, as cited in Roberts *et al.*, 2008). The remit of NCROP was to reduce health inequalities and improve the standards for delivery of NHS patient care with a particular focus on COPD. Roberts *et al.* (2008) concluded from their review that "it is accepted that the examples provided here are only perceived to be of best practice, and evaluation of such models of care and prospective research in the area of COPD palliative care is much needed" (Roberts *et al.*, 2008). This view is supported by literature further warning about transferring a cancer model of care delivery to non-malignant diseases, in particular COPD and Heart Failure (George, 2002; Cooley, Short and Moriarty, 2003; NICE, 2004b; Murray *et al.*, 2005; Murray and Sheikh, 2006). The reviews highlighted prognostic uncertainty, the insidious nature of COPD, the frequent exacerbations and the multiple transitions between different healthcare providers (e.g. GP services, specialist community respiratory teams, hospital specialist respiratory teams) and across different settings (hospital, hospice, community) as potentially being problematic (Giacomini *et al.*, 2012).

The IMPRESS initiative; a joint initiative between the two leading respiratory clinical societies in the UK: the British Thoracic Society and the Primary Care Respiratory Society (PCRS)-UK, was established in 2007 to provide clinical leadership to drive improvements in care across and beyond the traditional boundaries of primary and secondary care. The aim was to achieve high-quality, integrated patient-centred care for the population living with, or at risk of developing respiratory disease. The spotlight of their enquiry highlighted the current inequalities in supportive and palliative care for patients with respiratory diseases, in particular COPD (IMPRESS, 2009).

In a more recent review looking at the interplay of palliation within COPD and taking a more international view of provisions, there was a paucity of literature looking at services and linking their provision of care to patient-reported outcome measures. The reviewers recommended that going forward, service composition, in terms of provision within the wider health economy, needed to link patient and care outcomes in terms of satisfaction, experience of care and general wellbeing (Boland *et al.*, 2013).

In 2008, the American Thoracic Society suggested an individualised, integrated model of palliative care, especially for patients with progressive respiratory disease such as COPD (cited in Lanken, Terry and Delisser, 2008) as shown in Figure 3.

Figure 3: Models of Palliation in COPD (*reprinted with permission from American Thoracic Society, February 2010*)
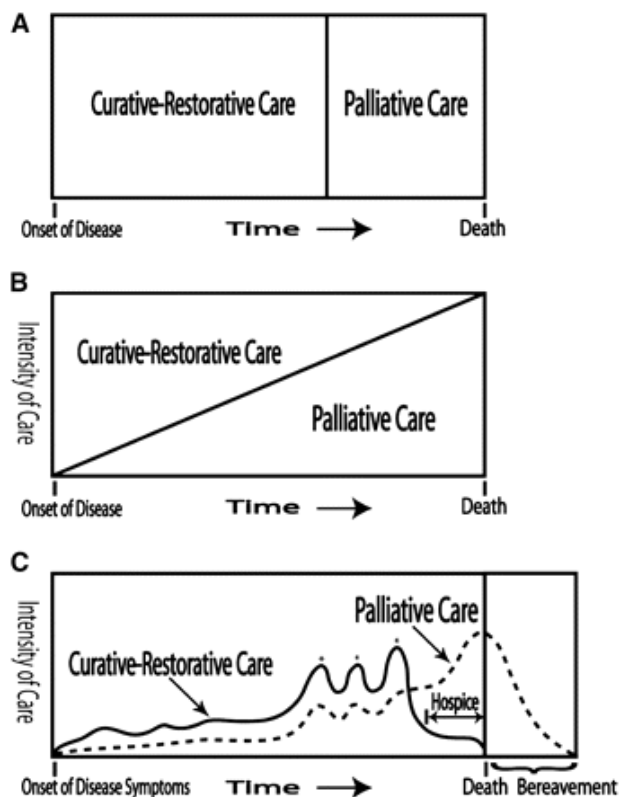
The Society argued that the traditional dichotomous model of palliative care, in which patients receive curative-restorative care until it fails and then receive palliative care, (Model A) was not helpful. The more recent model of overlapping curative/restorative care and palliative care, in which patients

receive a gradually increasing degree of palliative care whilst receiving a gradually decreasing degree of curative/restorative care (Model B), also has limitations. This is particularly apparent when there is variability in the needs (palliative and supportive) of the individual over time, since they may improve initially with treatment, even if this is to a lesser level than before. The authors argue for an individualised, integrated model of palliative care in which a patient receives palliative care (shown as the dashed line) at the onset of symptoms from a progressive respiratory disease and then concurrently with curative/ restorative care (shown as the solid line) in an individualised manner (Model C). The asterisk indicates periods of high intensity of curative/ restorative care, such as, hospitalisations for lower respiratory tract infections. The intensity of palliative care increases and decreases to reflect the needs and preferences of the patient and their carers. This model also emphasises that palliative care may be appropriate early on in the disease progression and encompasses both hospice care and care during the period of bereavement for the family, which may begin before the death of a patient.

This model also emphasises the concurrent provision of palliative and supportive care with respiratory medical management, but earlier on in the disease and with care that is directed to the patients' needs and preferences. The model affirms life and focuses on the coordination and continuity of care over its continuum, based on acuity of need and not on time, nor prognosis. Hardin, Meyers and Louie (2008) argue that "patients should not be asked to arbitrarily choose between disease-directed care and palliative care but an assessment of COPD patients and their families, needs be instituted in order to help them live as actively as possible" (Hardin, Meyers and Louie, 2008). However, Hardin, Meyers and Louie (2008) fail to identify the nodal or intersecting milestones for palliative and supportive care to interact within the COPD disease trajectory which is disappointing, since the assessment of needs (palliative and supportive) and what it comprises and when it is facilitated, are crucial steps as COPD progressively worsens over time.

Moreover, the concept of matching needs of individuals with COPD with provision, does not seem to fit in with the patient's view of what is happening to them and what potentially they need, as the 'time point' or transitional point

is not easily identifiable for patient, carer, nor health professional (Pinnock *et al.*, 2011).

Crawford (2013) and colleagues agree with the principles of Hardin and the model of concurrent provision with the need for a 'flexible model' of care. They advocate a patient-centred approach, with the integration of a multidisciplinary, palliative care focus, coordinated across primary, acute and community sectors (Crawford, 2013). The biggest criticism from all stakeholders (patients with COPD, family, health and social care professionals and community and hospital services) was that the current system was not meeting the needs of individuals with severe COPD and therefore needed to fundamentally change. This study, although completed in Australia, does have significant resonance within the United Kingdom as the healthcare systems have broad similarities, however it is noteworthy that they have different fiscal drivers (Currow and Phillips, 2014).

2.5 Triggering Systems

The question of when to assess or consider the palliative and supportive care needs of individuals with COPD and their carers, is widely debated (Coventry *et al.*, 2005; Murray, Pinnock and Sheikh, 2006; Rocker *et al.*, 2007). Various triggers have been suggested as to when to explicitly consider their needs, such as preceding and post-acute exacerbations, low FEV_1, long term oxygen therapy (LTOT) and low BMI (Murray, Pinnock and Sheikh, 2006; Lanken, Terry and Delisser, 2008). Currently, there is no agreed consensus. However, Hardin, Meyers and Louie (2008), suggested the "integration of intensive palliative care at transition or nodal points in an illness, when psychosocial and family trauma is often the greatest, has the potential to remedy shortfalls in health care quality" (Hardin, Meyers and Louie, 2008). The challenge is identifying these triggering events or nodal points that will prompt a holistic assessment of needs (palliative and supportive), within the progressive COPD disease trajectory that will have significant clinical utility for patients and carers and can be tangibly visible to the health and social care professionals providing care.

2.6 Conclusions and Outstanding Questions

The literature provides little evidence of current provision of palliative care in the care of people with COPD, the assessment of palliative care needs, when palliative care should/could be provided and any potential triggers to trigger professionals to holistically assess the needs of an individual in the context of progressive disease. The studies do identify the complexity of coping with a variable illness, where the patient may have acute and potentially life-threatening exacerbations but then recover, even if this is to a lower functional state. Moreover, there is evidence that patients and families do not see that there is a progression in the illness with deterioration to death. Thus, there is a need to canvas from patients, carers and professionals how palliative care can be best provided for people with advancing COPD and the potential triggers that may facilitate a holistic needs assessment, to direct care (palliative and supportive), to be available in a timely way for effective management of symptoms, enhancing quality of life and preparing for the advancing stages of the COPD illness, in particular, death and dying. This thesis will now aim to look at these various issues, given the current paucity of literature on triggering the holistic needs assessment in advancing COPD.

Chapter 3

Generating the Concept: Qualitative Secondary Analysis of the Breath of Fresh Air (BOFA) Study Transcripts

3.1 Introduction

To recap, the literature suggests that triggering the holistic needs assessment at transition or nodal points may be warranted in the Chronic Obstructive Pulmonary Disease (COPD) illness, when psychosocial and family trauma is often the greatest (Hardin, Meyers and Louie, 2008), but currently there is no agreed consensus. The focus of this chapter is to explore the perspectives of professionals, patients and carers, regarding such events within the COPD disease trajectory, that have the potential utility in triggering a holistic assessment of needs (palliative and supportive).

Research Question

Might significant events have the potential to trigger assessment of the needs (palliative and supportive) of COPD patients and carers?

Aim (overall)

To identify significant events within the COPD disease trajectory, that can trigger a holistic assessment of needs, palliative and supportive, for patients and their carers.

The objectives therefore from Chapter 3 were (Figure 4):

1. To identify key events in the COPD disease trajectory, as identified by patients, carers and clinicians, that can act as trigger points to facilitate an assessment of their supportive and palliative needs.

2. To explore the needs, palliative and supportive, of patients with severe COPD and their carers at these identified events.

Figure 4: Project Overview with Focus for Chapter 3
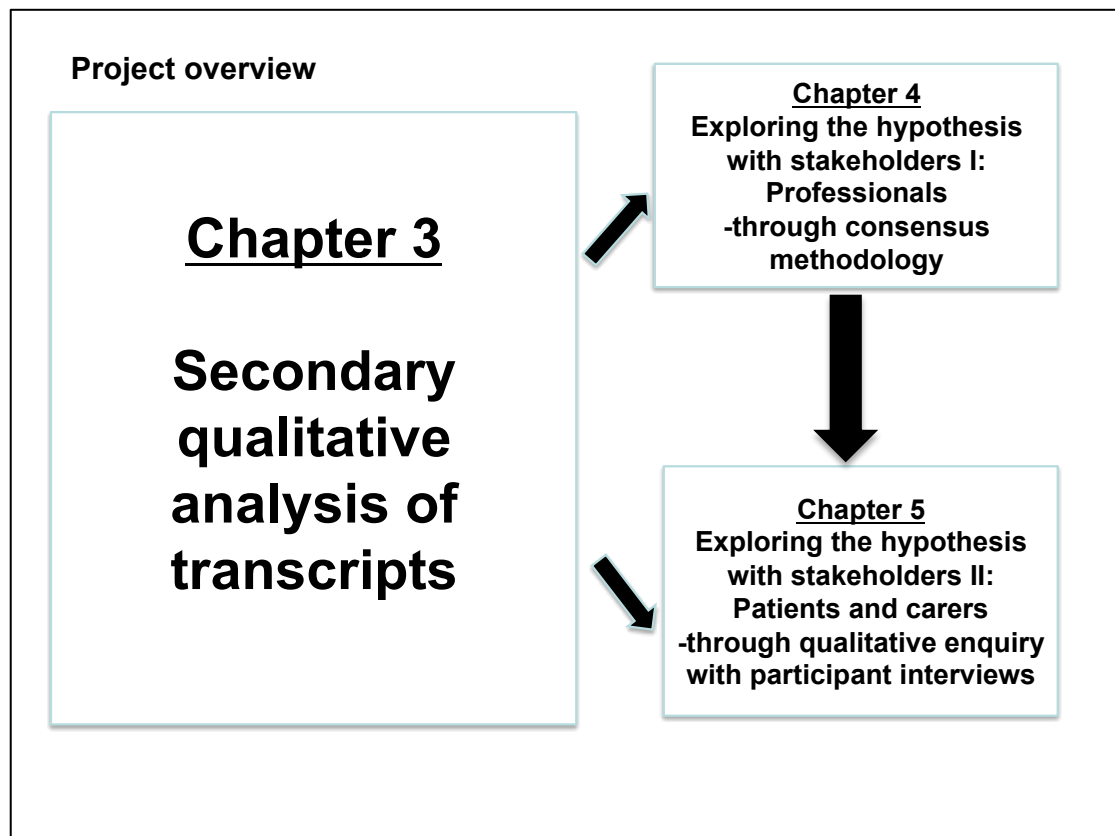
The reporting will be on the secondary qualitative analysis of a primary qualitative study, namely the *Breath of Fresh Air (BOFA)* study (Pinnock *et al*., 2011).

3.2 Methods

This section reports the evolving conceptual approach underpinning the analysis and the rationale for adopting this approach over others.

3.2.1 Starting the Conceptual Approach

This approach was cognisant of various stakeholders holding different views about theoretical explanations of how care is delivered. Opposing theories in service development are critical of the lack of attention given to how different perspectives are accommodated and as a consequence, frequently excluded (Funnell and Rogers, 2011). This study therefore, aimed to explore the multiple perspectives of patients, carers and professionals, within the care

arena of severe COPD, exploring, building and refining the concept of events that might trigger a holistic assessment of need across different care settings with each successive stage of the study (Corbin and Strauss, 2008).

3.2.1.1 Qualitative, secondary analysis - rationale for its use

Secondary analysis of qualitative data is widely debated in the literature and is a more recent incarnation (Heaton 2004; Cisneros, Mruck and Roth, 2005; Boydell, Gladstone and Volpe, 2006). Heaton (2004) defines secondary analysis as the "reuse of existing data, collected for prior purposes with the purpose of investigating new questions or applying a new perspective to an 'old' question and can be used as a means of substantiating, validating or redefining original, primary analysis" (Heaton, 2004). Within health and social care literature, secondary analysis is normally considered within the rubric of deductive, quantitative research methods (Thorne, 1994; Heaton, 1998; 2000; 2004). The text produced through the collection of primary, qualitative data is seldom examined as a source outside of the intended original research (Thorne, 1994).

Qualitative, secondary data analysis is now considered a legitimate method for generating new knowledge, creating new hypotheses and questions, expanding understanding of a particular phenomenon and supporting existing theories (Thorne, 1994; Szabo and Strang, 1997; Corti and Thompson, 2004). Given the considerable investment in qualitative databases, qualitative, secondary data analysis is also seen as an economical approach in terms of time and money, both by researchers and funders alike (Thorne 1994; Sandelowski, 1997; Corti and Thompson, 2004). Additionally, researchers working with 'sensitive', 'vulnerable' and 'hard-to-reach' populations find that secondary data analysis limits the burden placed on particular participants to 'talk more' (Sandelowski, 1997) especially those who are environmentally restricted or experiencing health-related debility (Fielding and Fielding, 2002). This is particularly pertinent for patient participants and their carers, who are burdened with a 'dwindling' trajectory and progressive nature of severe COPD (Murray *et al.*, 2005). As such, this approach was deemed entirely appropriate to use for this study.

The advantages of adopting the secondary data analysis approach for this piece of work have been discussed but there are other considerations to be aware of.

Consent is an important issue and once granted, the researcher has consent for on-going use of the data within the spirit of the original agreement. Therefore, if an unanticipated research focus (secondary data analysis) emerges, then the process of consent needs to be re-negotiated. This presents practical limitations in terms of the researcher re-consenting the original participants and the potential for causing annoyance by repeated returns for consent. Given this considerable ambiguity, there is little guidance about what specific circumstances require further consent (Grinyer, 2009).

Issues of digital archiving of data and the apparent lack of policy and guidelines, also means that data can be susceptible to being copied, manipulated and de-contextualised. Darlington and Scott (2002) point out that allowing other researchers access to data for the purposes of secondary analysis can be an important safeguard against fraudulent research. A balance therefore needs to be struck between the research community's wider need for confidence in the legitimacy of research data and participants' confidence that researchers will protect their interests.

Anonymised interview transcripts from an empirical study exploring the experiences of living and dying with severe COPD through a multi-perspective, longitudinal, qualitative study, acted as the data source for this research (Pinnock *et al.*, 2011). The transcripts, having captured multiple perspectives, enabled an in–depth and rich exploration of patient, carer and professional groups. This facilitated interpretation of meaning from the different storytellers' perspectives and the identification of potentially significant events (Denzin, 2002). Denzin (2002) describes contextualisation as the ability to gain greater meaning across individual experiences, therefore providing a more systematic awareness of the phenomenon, because it is depicted from the participant point of view "in their terms, in their language, and in their emotions. It reveals how the phenomenon is experienced by ordinary people" (Denzin, 1989, p. 60).

The focus of the qualitative, secondary data analysis was to ask questions and generate the hypothesis of events commonly occurring within the COPD disease trajectory, having the ability to trigger a holistic needs assessment.

3.2.2 Identification and Recruitment

The qualitative, secondary data analysis used data from a multi-perspective, longitudinal, qualitative study, looking at serial interviews with patients with severe COPD, their carers and the professionals caring for them, over an 18-month period between 2007 and 2009 (Pinnock *et al.*, 2011). Section 3.2.2 summarises the recruitment and data collection of the BOFA study as relevant to this secondary analysis.

3.2.2.1 Participant recruitment

Patients with severe COPD and their carers, as well as the professionals involved within their care, were recruited from a variety of settings, including primary and secondary care, as well as specialist community respiratory teams in Lothian, Tayside and Forth Valley in Scotland. The researchers provided information to the recruiting centres about known predictors of a poor prognosis (Coventry *et al.,* 2005) as well as utilising the 'surprise question' i.e. 'Would I (the clinician) be surprised if my patient were to die in the next 12 months?' (Murray *et al.,* 2005*).*

3.2.2.2 Sampling characteristics

Purposive sampling facilitated the recruitment of men and women of different ages, social class and rurality, the presence of an informal carer within the home and current smoking status. Significant comorbidity was expected; the only exclusion criteria were inability to participate, for example, because of dementia or other imminently life-threatening illness, such as lung cancer. A clinical assessment by a respiratory nurse established eligibility, indicators of severity, and markers known to be associated with poor prognosis.

3.2.2.3 Recruitment to the 'interview set'

At each time point, patients nominated an informal carer to be interviewed, if they had one, as well as a key health or social care professional whom they

regarded as important to their care, thereby creating 'interview sets' (Pinnock *et al.,* 2011).

3.2.2.4 Conducting the interviews

The interviews with patients and carers were conducted by an experienced, qualitative researcher (MK) at a location of their choice, and professional carers by telephone. In-depth interviews with the patient and their carer (jointly, if preferred by the patient) were participant-led, allowing people to tell their story in their own terms and at their own pace. Issues covered ranged from the experience of living with COPD, patients' main concerns (whether physical, psychological, social, or spiritual), views on care and treatment and carers' needs and concerns. Interviews lasted between 40 and 150 minutes and were all audio-recorded.

Health and social care professionals were asked about their perceptions of patients' and their informal carers' needs, available services, and barriers to the provision of care. Bereavement interviews were, where possible, conducted with both informal and professional carers. The longitudinal nature of the study facilitated patients to tell the 'story' of their condition (Pinnock *et al.,* 2011).

3.2.3 Data Generation

The interview transcripts

The transcripts from the empirical study, looking at the experiences of living and dying with COPD (Pinnock *et al.*, 2011) were the original, raw, uncoded data but anonymised for participant confidentiality in compliance with the ethical, regulatory and approval requirements of the primary study. Digital audio recordings were not available as they were destroyed as per the ethics arrangements from the empirical study, but the transcripts were available in electronic format (Word, Microsoft Office, 2008). The original, uncoded, unmarked and anonymised transcripts were used.

3.2.4 Data Analysis

3.2.4.1 Thematic content analysis

The data generated for the qualitative secondary data analysis were analysed using a thematic content analysis, with codes developed into a framework of themes, exploring the events themselves as potential triggers for the holistic assessment of needs.

The characteristics of a potential candidate 'event' to act as a trigger were important to define, and were categorised according to the work of Hardin, Meyers and Louie (2008) and Lester and Campbell (2010) as:

a) An event having significant meaning for the patient and/or their carer.
b) An event that was clearly visible to the professionals involved in the care of the patient with COPD.
c) An event that was seen to have utility and/or usefulness for the individual with COPD and the professionals involved in their care, once an assessment was completed.

This approach aimed to try and standardise that any event identified, had to have certain characteristics to be suitable for consideration.

Individual transcripts were read initially, then read as part of the interview set, both within and across the participant groupings. This facilitated re-reading the participant groups in batches of patients, carers and clinicians, and finally re-reading the transcripts as a 'set' (linking patient, carer and professional). Content was identified that was in keeping with the characteristics of a trigger, which were then regrouped to categorise them into a code. The characteristics of a trigger guided a framework for assigning codes that would have meaning and relevance across the data sets. Coding occurred until no new themes emerged.

According to Berelson (1952), the crucial requirement for coding is that the categories are sufficiently precise to enable different coders to arrive at the same results when the same body of material is examined. Therefore, thematic content analysis pays particular attention to the issue of reliability of its measures, ensuring that different researchers use them in the same way,

but enhance the validity of the findings through the precise use of words and phrases (Seltiz *et al.*, 1964, pp. 335- 42).

3.2.4.2 Process of the analysis

In this study, transcripts that were already transcribed were subject to manual analysis initially and then assisted with NVivo8^{TM} (QSR International, 2008), a computer-aided, qualitative software package, to support the analytical process.

To maintain rigour in qualitative research, coding was undertaken initially by the researcher, but coded transcripts were then shared with the wider research team (HP, DO, JB) to discuss emergent themes, aid data synthesis and interpretation, thus ensuring no new themes emerged (Mays and Pope, 2000; Emslie *et al.*, 2005). Throughout the data analysis, the research supervisors reviewed transcripts individually and then collectively, gaining consensus and shared understanding of the data and its analysis (Silverman, 2005). The development of the codes, the coding strategy and framework applied were discussed and checked with individual transcripts to ensure all emergent themes were identified. The codes identified were deemed appropriate, with only minor suggestions for refinement and clarity. As data coding occurred with concurrent analysis, supervisory meetings were used to discuss emerging interpretations and their significance. The iterative changes to the research process were repeatedly discussed and debated.

3.2.5 Reporting

The consolidated criteria for reporting qualitative research (COREQ) checklist, aims to promote complete and transparent reporting with the aim of improving rigour, comprehensiveness and creditability of qualitative data findings, both in terms of its generation but more importantly in terms of its analysis (Tong, Sainsbury and Craig, 2007). This framework was utilised for reporting the findings from this phase of the study (Appendix A: COREQ checklist)

3.2.5.1 Seeking external validation of findings

Standard qualitative methods of achieving validity, such as checking that developing themes remain true to the primary sources, and presenting the verbatim text, have been used (Huberman and Miles, 2002). Given that this stage of the research was concerned with secondary data analysis, it was important to involve the original authors of the primary study in this process. Informal discussions with the lead researcher (MK) who conducted the interviews from the empirical study took place by telephone. This process helped contextualise the data used and gave an insight into the researcher's knowledge not captured by the published report. This allowed an opportunity to explore any significant findings from additional data e.g. field notes and project group discussions but did not form part of the formal analysis of this piece of work.

In addition, all codes and transcripts were subject to 'back coding'; that is a return to the original transcripts and codes once the first round of coding with each participant group and each data source had been completed. This process aimed to align the coding approaches of concept-driven coding (characteristics of an event as a trigger) versus data-driven coding (candidate events that were identified within the participant transcripts) (Silverman, 2005).

3.2.6 Ethical Considerations

3.2.6.1 Ethical approval process

The study was considered by the University of Kent's Ethics Committee and National Health Service Local Research Ethics Committee (NHS LREC) and approval was not required for this piece of work (as per personal correspondence with the ethics committee chairperson, January 2011 (Appendix B: Email from ethics committee)). The empirical study, which is the data source for this study, obtained ethical approval from the Multi-Centre Research Ethics Committee for Scotland (B), as well as governance approvals from NHS Lothian, NHS Tayside, and NHS Forth Valley.

The ethical issues related to studies of this nature are discussed in detail by Burgess (1989), Merlens and Ginsberg (2009) and in the National Health Service research guidelines (IRAS, 2011). The more pertinent ethical issues relating to this piece of work are discussed below.

3.2.6.2 Consent

The qualitative, secondary analysis of transcripts as a data source holds significant debate about the need for re-consenting of participants. However, given the anonymised nature of the data (Heaton, 2004) and the fact that one of the research supervisors was the lead investigator for the initial primary, qualitative study, it was agreed to seek formal ethical advice and potential approval. This was deemed necessary as the use of the data for secondary data analysis had not been explicitly consented to. Permission was sought from the South East Coast-Kent National Health Service Local Research Ethics Committee to use this primary source of data for qualitative, secondary analysis and it was agreed that further consent was not required, and as such, no additional requirements were needed.

3.2.6.3 Confidentiality and information governance

The principles of confidentiality and anonymity were explicit and clarified throughout the research process. The process of written, informed consent for the primary study was obtained from the Multi-Centre Research Ethics Committee for Scotland (B), with the secondary use of this data anonymised for use within this study. HP was the chief investigator for the primary, qualitative study and therefore data custodian, ensuring all relevant governance with data management was adhered to. The research ethics approval processes, as well as local governance approvals within the University of Kent, ensured the legal requirements and intellectual property rights were explicit and adhered to (RESPECT Report, 2004).

Data storage was a key consideration for participant data, both as paper copies and electronic format. Data were protected within a locked cabinet at the research base and all electronic data were stored on encrypted devices that were password-protected and on organisational networks with high-level

encryption. Paper records will be kept for five years, as per the Ethics Committee's recommendations, and in keeping with data protection and confidentiality requirements (RESPECT, 2004; Caldicott Review, 2013).

3.3 Results

3.3.1 Participants and the Dataset

The available transcripts for the secondary data analysis consisted of 21 patients, 13 informal carers and 18 professionals, who provided a total of 92 interviews at four-time points over 18-months. Eleven patients died during the course of the study. The schedule of interviews and characteristics of the participants are given in Tables 2, 3 and 4.

Table 2: BOFA Recruitment Schedule: Overview of participants and the interview schedule for the BOFA study

Time point (months after recruitment)	Informal carers (nominated by patient)	Surviving patients	Professional carers (nominated by patient)
0	Spouses (n=10) (joint interviews with patients) Daughters (n=1)	Patients (n=21)	Hospital doctors (n=2) Respiratory nurses (n=7) (regarding 10 patients) Professional carers (n=1)
	Deaths (n=5)		
6	Spouses (n=9) (joint interviews with patients) Daughters (n=2)	Patients (n=16)	General practitioners (n=3) (regarding 4 patients) Respiratory nurses (n=5) (regarding 9 patients)
	Deaths (n=6)		Bereavement interviews Wives (n=2), nurses (n=3)
12	Spouses (n=2) (joint interviews with patients)	Patients (n=10) (2 too ill to be interviewed)	General practitioners (n=2) Respiratory nurse (n=1) (regarding 3 patients)
18	Spouses (n=2) (joint interviews with patients)	Patients (n=10) (3 too ill to be interviewed)	General practitioners (n=3) Respiratory nurses (n=2)

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Table 3: Characteristics of the Patient Participants (n=21): BOFA Study

	Number of patients
Sex (male/female)	14/7
Age (years; mean (SD; range)	71 (8; 50-83)
Demography[*] -Inner city -Urban -Rural	 8 5 8
Carer -living with family carer -family carer local -no family carer	 10 5 6
Smoking status -Ex-smoker -Smoker	 16 5
Co-morbid disease (one or more co-morbidities)	19
Clinical history -Duration of symptoms (years; mean (SD)) -Using oxygen at home -History of admissions with exacerbations of COPD -History of admissions with respiratory failure	 18 (8) 9 13 6
[*](none from ethnic minority background)	

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Table 4 explains the convention for describing the participants and the interviews.

Table 4: Convention for describing Patients and Interviews

	Criterion	Example
Patients		
Identified by a consecutive study number and the health board in which they are registered	L= Lothian F= Forth Valley T= Tayside	 [LO1], [LO2]
Interviews		
Patient interviews identified by the time point at which the interview took place	1=Baseline 2=6 months 3=12 months 4= 18 months	[T03.1] is Tayside patient 3, baseline interview
Informal and professional carers' interviews indicated with reference to the patient		[FO6.3 GP] is the GP nominated by Forth Valley patient 6 at the 12month time point

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3.3.2 Overview of Findings and Categories of Events

To recap, the aim of the overall project was to identify significant events within the COPD disease trajectory that can trigger a holistic assessment of needs, palliative and supportive, for patients and their carers. The objectives therefore from Chapter 3 were:

1. To identify key events in the COPD disease trajectory, as identified by patients, carers and clinicians, that can act as trigger points to facilitate an assessment of their supportive and palliative needs.

2. To explore the needs, palliative and supportive, of patients with severe COPD and their carers at these identified events.

Through their narrative accounts, patients, informal carers and professionals recalled many events that marked out the prolonged disease trajectory of COPD. These events fell broadly into two categories (see Table 5):

1. Events that signified increasing burden of disease; and

2. Events that corresponded to interventions addressing the consequences of advancing disease.

Within the two broad categories, eight candidate events were identified and assessed for their suitability to act as potential triggers with reference to their meaning, visibility and utility.

Table 5: Potential Candidate Events as Triggers within the COPD Disease Trajectory

Lifelong trajectory of COPD	Potential candidate events
1. Events that signify increasing burden (3.3.3)	• Increasing burden of disease. • Shifting priorities of care. • Increasing carer burden.
2. Events that correspond to interventions addressing the consequences of advancing disease (3.3.4)	• Requesting a 'disabled parking / 'blue' badge. • Home adaptations. • Hospital admissions. • Appointment frequency. • Housebound.

Exemplar quotes are provided in Table 6 in the results section.

3.3.3. Events that Signified Increasing Burden of Disease

3.3.3.1 The meaning of events

An event that signified the increasing burden of disease was highlighted by patients, carers and professionals as being important. In particular, such an event acknowledged a deterioration in physical and social functioning though this can be over a varying timeframe so more insidious than very sudden in terms of onset. Almost all of the patients spoke of the significant burden of symptoms, which impacted on their everyday functioning and activities. Progressive breathlessness and the limitations this imposed caused frustrations, as habitual and practical activities become a daily struggle, sometimes affecting psychological health. The majority of the patients related how their condition had caused a change in their activities, including many from which they derived pleasure:

> "*Nobody likes not being able to breathe properly but what really gets me is not being able to do anything, I used to do all my own decorating, painting… I quite enjoyed doing it, can't do it any more… it's all small things!*" [F02.1 (patient)]

> "*Well won't say I can't do, I can't do them as quickly as I used to, like gardening, which I love-it takes me three days to mow the lawn… yes, it is frustrating… I just have to do what I can… I won't let it beat me.*" [T01.1 (patient)]

For carers, watching the continued deterioration of their loved one and acknowledging the significant impact of their breathlessness, was similarly frustrating. A daughter, who watched her mother struggle to maintain her independence, remarked:

> "*I mean the highlight of my mum's week is going to Tescos on a Saturday morning for her shopping… that is a real strain for her, she really struggles… but she is a fighter and she doesn't like to give up you know… she hides things well, and that can be a bit annoying sometimes, you can see yourself that she is struggling but she will keep going.*" [F06.2 (daughter)]

Professionals also acknowledged the significant impact of debility associated with the progressive nature of COPD, and in common with patients and carers, often expressed this in a language of functional and environmental limitations:

> *"She doesn't get out any more, but I have no idea how she manages it because all those stairs are a problem and even just getting around the flat she is really breathless!"* [L03.1 (GP)]

> *"I mean any time she has an infection she really goes backwards very, very much and it takes her almost three months usually for her to get really a bit of her potential back. She knows she deteriorates every time she has an interval like that."* [T03.1 (GP)]

3.3.3.2 Visibility and invisibility of events

When patients articulated what breathlessness meant for them, it was in a language of functional limitations and the accompanying frustration. Along with the insidious, almost imperceptible progress of breathlessness, patients appeared to have assumed this reduced level of activity as their new normal pattern:

> *"I mean I got a lovely routine worked out… I can move around to get my jobs done and then I sit down and you see 10 minutes after I sit down and have this* [oxygen] *back on again, I am as right as rain. It takes me longer to do things… I mean I do everything myself still!"* [F06.1 (patient)]

The invisibility of the ever-expanding role of informal carers was coupled with the insidious way in which this role had evolved. The demands and burdens had become an enmeshed 'way of life' for carers, with their responses making it invisible to the radar of support services:

> *"Well yes it's true that not a lot of people understand really. You say your husband's short of breath, 'Oh that's a pity, that's a shame'… they don't know the impact on your life… it is a big… big impact on your life. Even I didn't realise it. Things have got to get done… I just try to make life as comfortable for him as I can you know."* [F02.1 (carer)]

For professionals, the issue of visibility was complex. They clearly saw the visible changes indicative of progressive and severe COPD, often punctuated

with acute exacerbations, although only one professional recalled a specific discussion with a patient about the challenges of this variability:

> *"It is a relentlessly progressive problem… we have certainly spoken about it, and she certainly knows it is progressing and getting worse… it isn't going to get any better."* [F10.1 (GP)]

Visibility in terms of consultation frequency had some significance with professionals, and they noted that patients were typically at either end of the spectrum. Some professionals felt that patients with severe COPD "*tend to be quite high users of our services*" whilst others thought they did not consult as much as they would expect:

> *"I think given her physical health she is probably a relatively low consulter actually, which is interesting."* [L03.1 (GP)]

It was recognised that consulting frequency might be indicative of wider social issues, rather than specifically health-related problems, and that these might need more holistic evaluation:

> *"I don't know that his chest bothers him quite as much as it has in the past! I think he feels quite socially isolated and I think to some extent that's why we get lots of phone calls from him in the practice, and we get lots of requests for visits which, taken at medical face value are not necessarily particularly valid. I think that… he's lacking close informal social support."* [L04.3 (GP)]

One professional observed that the repeated consultations and very visible requests for help from one particular patient, prompted them to act, despite limited evidence that medical intervention would be effective:

> *"His main problem was coping with disability and I think he just couldn't cope with it. He pressurised and pressurised and pressurised for something to be done and I think the indication was that he wanted something done rather than there was good evidence that it was going to help him."* [F02.1 (Consultant)]

3.3.3.3 Utility: frustration and a move to holistic care

Professionals recognised the progressive burden of COPD and some expressed their frustration at feeling unable to help:

"You do hit a brick wall at the end when there isn't really anything that you can do other than trying to keep symptoms as few as possible." [F10.1 (GP)]

"Well he is quite severely depressed and he just wants to die." [T08.1 (nurse)]

Others seemed to have subtly changed the focus of care from disease-orientated, medical intervention to holistic, symptom-driven care:

"Probably just to improve his quality of life at home… it is difficult… to try and control his pain or make him a bit more asymptomatic if we can." [F01.1 (nurse)]

"I look at it from a holistic point of view and it is not COPD that I am treating, it is a patient I am treating." [T03.1 (GP)]

3.3.4 Events that Correspond to Interventions: Addressing the Consequences of Advancing Disease

3.3.4.1 Meaning: markers of need

These specific, often 'one-off' interventions seemed to have a wider meaning within a holistic assessment of needs, broadening the understanding of clinical utility to a more supportive and beneficial approach that integrates the health and social aspects of living with COPD, as the disease progresses and becomes more burdensome. Some healthcare professionals articulated this with examples of how a specific event, such as moving the bed downstairs, was symptomatic of general deterioration and required further support, such as the provision of a commode:

"I mean he is just deteriorating – I wouldn't say fairly quickly but over the four years I have known him, or five years, quite dramatically… he has moved his bedroom downstairs so I have got him a commode and a urinal." [T01.1 (Nurse)]

3.3.4.2 Visibility: visible, but needs to be noticed

Interventions might be self-initiated by patients or carers or initiated by professionals. Some, such as moving a bed downstairs, deciding not to book a holiday or accepting help for a task, might be very visible to patients and carers but go completely undetected by professionals:

"I have accepted the fact that I can't go on holiday… it was a walking holiday for us. It annoys me when people say 'Are you never getting fed up sitting in the house all the time, you never go away on holiday?' They don't seem to understand, it is impossible… I don't want to go abroad… I'm not capable of doing it!" [F06.1 (patient)]

In contrast, confinement to one's house not only had a significant, existential meaning for patients, but was a potentially visible event; a tangible consequence of advancing disease:

"You just have to accept that you are a prisoner in your own home… prisoner in your own mind." [T06.1 (patient)]

Hospital admission was also a highly visible event for patient, carer and professional alike. Its significance for patients provoked polarised attitudes; some patients tried to avoid it, identifying it as a last resort and others acknowledged it as a clinical necessity:

"Well I've got to feel really bad before I go into hospital, I try and stay at home as much as possible… even the last time I didn't want to go but I didn't get a choice, they said I was going and that was it!" [L03.4 (patient)]

"No, I try and stay clear of hospitals… well at my age, hospital is the last stop." [T01.1 (patient)]

The challenge with any event that is a single occurrence or omission is that it may, in itself, not be very significant for the professional or patient. However, the underlying pattern or trend which may be symptomatic of wider concerns, can be highly significant and have more meaning for all parties e.g. more frequent hospital admissions, being 'labelled' as housebound and needing home visits, rather than being expected to attend the GP surgery:

"He has been in hospital a number of times, more so in the last year really… he was a 'revolving door admission.'" [F02.2 (nurse)]

"They've got me down as housebound so they come and see me now." [T07.2 (patient)]

3.3.4.3 Utility

The usefulness of identifying these events lies in recognising that they are indicative of wider issues of disease progression that impact on patients' carers within the home environment, as well as their general functioning. Patients clearly articulated how interventions no matter how small, made a significant difference in terms of their functional ability:

> *"I have trouble getting up and down stairs, simple thing like a stick, that has made a big difference getting up."* [T01.2 (patient)]

The need for one home adaptation was thus indicative of a bigger issue, i.e. the suitability of the home environment, and this therefore, could act as a trigger to alert professionals to this broader need.

3.3.5 Candidate Events that might be used to Trigger a Holistic Needs Assessment

The candidate events were considered in terms of their significance to patients, carers and professionals (e.g. hospital admissions), their frequency of occurrence (e.g. home adaptations) and how they resonated across healthcare systems and processes (e.g. consultation requests, both in terms of frequency and location). This facilitated the evaluation to assess the potential of the candidate events to act as triggers (see Tables 5 and 6).

Additional supporting data to endorse the events as potential triggers is presented in Table 6.

Table 6: Additional Supporting Data for Triggers Identified

I. Events that signify increasing burden of disease	
Potential events as triggers	**Examples**
• Shifting priorities of care	"Just gradually got worse over the years and I now, I am at the stage now that I need oxygen all the time and my breathing is very hard… Nowadays I have bad days, very, very bad days… I tell you it is frightening!" [T02.1 (patient)] "I didn't want to go out at all, in fact I'd even stopped… I'd sit in my dressing gown all day, because getting dressed I was losing my breath... Everything is an effort and to be quite honest… in fact at one time I didn't want to carry on... No, I had had enough. Apart from the fact of my husband, I would have, I would have taken my own life... I mean I just didn't want to go out… It is not worth it!" [T03.1 (patient)] "He sat there a week before he went into hospital… And I said, 'What is it?' 'Nothing' he said, 'Well it is', he said, 'I just wish this was over and done with because I can't take any more of this. It's wearing me down', he said. 'I dinnae want to leave you but I've had enough." [F02.BRB (wife)] "I suppose you just… you try and think about not just their disease, you try and think about things more holistically and the support that they are getting and… you know, benefits they are getting and social things, and I suppose it makes you try and think a bit more globally, not about each acute episode but about planning a bit." [L03.3 (GP)]
• Increasing carer burden	"Well, yes, it's true that not a lot of people understand really, you say your husband's short of breath, oh that's a pity, that's a shame. They don't really know the impact on your life, it is a big, big impact on your life. Even I didn't realise it. Things have got to get done! ... I just try to make life as comfortable for him as I can you know." [F02.1 (wife)] "I mean the other big issue is the burden of it on carers isn't it… it's a very hard thing because it goes on for so long!" [F09.2 (nurse)] "I have another patient… but he just could not cope with it as well but the pressures he put on his family were enormous as well and his poor wife ended up – she gave up her job, she gave up everything to look after him, then of course when he died, she had nothing left, so I think carer support is also important." [F02.1 (Consultant)]
• Increasing burden of disease	"I got breathless more or less when I stopped work, because I worked on till I was 70-odd and it was afterwards, going down the pub now and again… I seemed to get more breathless by the day." [L07.1 (patient)]

	"I can't work, I can't get a job, I can't get in my garden and I've not many pleasures left so I am not going to change... nothing is a pleasure now... I was just getting breathless and breathless. Not got the effort to do things and now that is what is wrong with me now!" [T08.1 (patient)]
	"Like I said, my breathing is getting slower, my moaning is getting more and more, my frustration is getting more and more!" [F06.2 (patient)]
	"I think people underestimate what it's like to be breathless." [F02- F09.2 (nurse)]
	"Yes, he just wants to curl up and die. He feels a huge burden!" [T07.2-T08.2 (nurse)]

II. Events that correspond to interventions addressing the consequences of advancing disease	
Potential events as triggers	**Examples**
• Housebound	"You just have to accept that you are a prisoner in your own home... prisoner in your own mind." [T06.1 (patient)]
	"They've got me down as housebound so they come and see me now." [T07.2 (patient)]
	"It's quite a common thing for us to do home visits for people with COPD." [L07.1 (GP)]
	"She doesn't get out any more, but I have no idea how she manages it because all those stairs are a problem and even just getting around the flat she is really breathless!" [L03.1 (GP)]
• Requesting a 'disabled parking badge ('blue badge')	"It's the parking and getting from the car park to the entrance. But there isn't a parking space... you've got to park two miles away you know so what do you do then?" [F06.2 (patient)]
	"I am definitely worse, I can tell, as I say if I'm getting rid of the car, I suppose I can't drive... so... once I get there, I can't walk – know what I mean. So, I'm glad to get rid of it!" [F02.2 (patient)]
	Patient: "Well I'm on motability. Interviewer: Motability, how did you get that? Did you just fill a form in or did somebody suggest it? Patient: My doctor." [F01.1 (patient)]
• Appointment frequency	"I don't know that his chest bothers him quite as much as it has in the past! I think he feels quite socially isolated and I think to some extent that's why we get lots of phone calls from him in the Practice, and we get lots of requests for visits

| | | which, taken at medical face value are not necessarily particularly valid. I think that… he's lacking close informal, social support. I mean he gets the social care package, but other social support, I don't think he gets particularly much of!" [L04.3 (GP)]

"I think given her physical health she is probably a relatively low consulter actually, which is interesting." [L03.1 (GP)] |
|---|---|---|
| • | Home adaptations | "But at the minute I'm… struggle… getting washed and dressed, washing my hair… just a struggle to do it you know… a struggle to do the things that you take for granted… I haven't got a shower I can sit in or anything like that, these days!" [L03.1 (patient)]

"I am getting a shower fitted. I will be going onto slip-on shoes because bending down… just the simple thing like; I have trouble getting up and down stairs, simple thing like a stick, that has made a big difference getting up – I get up to the top of the stairs and I don't have to sit down." [T01.2 (patient)]

"I'd tried to get the toilet done with a walk-in shower and a seat and everything… they wouldn't do it, I had to buy it myself. I said, so I suppose it would be the same with a stair lift!" [F07.3 (patient)]

"In February I have actually referred him for assessment for a chair lift... it is really quite frustrating because he is struggling to get up the stairs and it is taking him hours… I was told, he was 67 on the list and if he had been diagnosed with cancer his chair lift would have been in by now." [F02.2 (nurse)] |
| • | Hospital admissions | "Well I've got to feel really bad before I go into hospital, I try and stay at home as much as possible… Even the last time I didn't want to go but I didn't get a choice, they said I was going and that was it!" [L03.4 (patient)]

"No, I try and stay clear of hospitals… Well at my age, hospital is the last stop." [T01.1 (patient)]

"End stage care… these people tend to bounce in and out of hospital… there is poor communication between community care and the hospital… they tend to arrive in the hospital at 3am, everybody is panicking, running around… they are put on a ventilator or something like that and it is probably not in their best interest…. So, I think communication is critical especially now that community care is sort of a two-tier service, the 9– 6 and the afterhour service and trying to get that continuity of care." [F02.1 (Consultant)]

"He has been in hospital a number of times, more so in the last year really… he was a 'revolving door admission.'" [F02.2 (nurse)] |

3.4 Discussion

3.4.1. Summary of the Findings

The substantial and increasing burden of disease, whilst apparent and meaningful to patients, carers and professionals, was often rendered invisible because of the 'normalisation' of the slowly progressive nature of the disability. Recognition of changing patterns of care could increase visibility, but there was frustration, or sometimes nihilism about the utility of interventions.

Interventions addressing the consequences of advancing disease were more specific and potentially more visible, although they only occurred sporadically. The utility of such interventions can be seen as two-fold: acting as a marker for global debility, but also as a prompt for professionals to see the more holistic needs of the patient with COPD.

3.4.2 Strengths and Limitations

A strength of the study was the multi-perspective data set derived from empirical study, looking at the experiences of living and dying with COPD, exploring the narratives of patients, their informal carers and professionals about living with COPD, collected with serial interviews over 18-months (Pinnock *et al.,* 2011). Although the original aim was to explore the story of COPD and the services provided, rather than specifically to explore events that might trigger a holistic needs assessment, the concept of triggers emerged from the original analysis and was implicit in achieving an understanding of the key events in the COPD narrative (Pinnock *et al.,* 2011). The narrative methodology facilitated the accounts that were cognisant of, and true to the participant's voice "in their terms, in their language, and in their emotions" (Denzin, 1989, p. 83), thus revealing the experiences of people.

The coding for the analysis on triggers was undertaken by a researcher (DC) who did not undertake the original interviews or have access to audio recordings, however, the original researcher (MK) had significant input into the data analysis, triangulating their knowledge and reflections from the

original research. In addition, regular discussion within the multi-disciplinary team contributed to a balanced interpretation of the data.

Although participants represented a broad range of demography, they might not have fully represented the diversity of people with very severe COPD. All the interviews took place in Scotland, and as such, the findings might not be directly applicable to other geographical settings. However, the adaptation of palliative care services, originally designed for those with cancer, to meet the needs of people with non-malignant diseases, appears to be a universal approach (Hall *et al.,* 2011; WHO Definition of Palliative Care, 2013).

3.4.3 Interpretation with Reference to Other Literature

3.4.3.1 The meaning of triggers within current service delivery

Attempts to identify a transition point to palliative care are not congruent with the empirical and narrative work highlighting how COPD is experienced by patients, their carers and professionals involved in the delivery of that care. The supportive and palliative care needs of people with severe COPD are well-described in the literature (Lanken, Terry and Delisser, 2008; Boland *et al.,* 2013) but the dilemma and challenge for the current healthcare system is whether they are sufficiently visible to alert professionals to the need to intervene. The findings from this study, suggest that awareness of certain key events can have meaning beyond their specific significance as they point to wider, functional limitations within the narrative recall of people with COPD. Recognising triggers and detecting unspoken needs could facilitate concurrent provision of palliative and supportive care within the on-going routine management of the condition.

This approach offers an opportunity to facilitate a holistic assessment of needs as COPD clearly (but paradoxically invisibly) progresses and exerts an increasing burden on individuals and their carers. This would acknowledge the medical management in the disease trajectory, whilst affirming life with its multiple dimensions (physical, psychological, social and spiritual), centring on coordination and continuity of care, with a clear focus on the need identified, and not on time, nor prognosis (Lanken, Terry and Delisser, 2008).

3.4.3.2 Triggers - making the needs visible to professionals

The difficulties experienced by individuals with COPD and their carers, as well as the challenges for professionals involved in their care, echo the findings in previous studies (Gore, Brophy and Greenstone 2000; Seamark *et al.,* 2004; Habraken *et al.,* 2007; Rocker *et al.,* 2007). In common with Habraken *et al.* (2008) and Giacomini *et al.* (2012), patients adapt to their debility and are often 'silent' about their situation, instead adapting to the new norms imposed by their condition. This results in infrequent consultations, despite their advancing burden of disease adding to the invisibility. An approach that renders these potentially invisible needs more visible to professionals may thus prove very useful. Events have been identified that traverse the COPD disease trajectory, which could potentially act as triggers, stimulating professionals to enquire about the wider holistic impact of the disease. The concept of triggers facilitating a holistic needs assessment, broadens the understanding of the impact of the disease from a single, presenting problem. Hence, a request for a disability-parking badge ('blue badge') for example, or other mobility aids would increase the visibility of the impact of mobility problems on the physical, psychological, social and spiritual aspects of a patient's life, and more importantly, stimulate interventions that have functional benefit for patients.

3.4.3.3 The utility of triggers

The visible 'roller-coaster'-like disease trajectory of COPD (Murray, Pinnock and Sheikh, 2006), coupled with the functional limitations that it forces (Lehman, 2004), is again echoed by this study in that multiple domains (physical, psychological and social) may be affected simultaneously. Professionals, whilst acknowledging the progressive burden of COPD, displayed a degree of professional nihilism and inactivity, rather than proactively recognising the gear change in terms of disease and goals of care, which could have prompted a more needs-based approach, embracing supportive and palliative care.

This study raises the possibility that, rather than suffering from the 'prognostic paralysis' attributed to the unpredictable clinical condition of COPD (Murray, Boyd and Sheikh, 2005; Murray, Pinnock and Sheikh, 2006) the identification of trigger events could have significant utility in terms of offering an alternative to the difficulty of trying to identify an elusive transition point to an end-of-life phase. The utility of this approach, however, will be determined by whether professionals from diverse clinical and social backgrounds recognise and then act on a triggering event. This will require integrated care, as the wider holistic assessment may not be the responsibility of the person identifying the trigger. Other approaches might be to establish proactive searching for triggers, for example, using structured reviews, protocols or templates.

3.5. Conclusions

Within the illness narrative of COPD, certain events punctuate and traverse the disease trajectory and cross multi-professional boundaries of care. They can be a function of advancing disease or a supportive intervention, addressing the consequences of advancing disease. In themselves, the events have meaning to patients and carers that resonate with the progressive nature of COPD. Such events can have varying degrees of visibility to professionals, patients and carers and this inconsistency will be a challenge for the healthcare system. To achieve this utility, services will need to promote health and social care integration and ensure a clear process of holistic needs assessment occurs when a trigger is detected.

3.6. Implications for the Next Stage of the Research

The concept of events as triggers has the opportunity to bypass the prognostic paralysis that often occurs within the uncertainty of the disease trajectory of COPD. The challenge of engaging services that will support the ongoing and changing needs of patients and their carers, will potentially conflict with existing service models, but afford an opportunity to strategically and clinically commission services that meet the oscillating visibility of need. This approach has the opportunity to ensure patients and their carers have

their needs assessed within a more holistic context, thus addressing the physical, psychological, social and spiritual aspects of their care.

The concept of triggers, as identified by candidate events, needs further exploration with stakeholders on a wider scale, in particular, with frontline health and social care staff. The perspectives of patients and their carers need to be identified, to ascertain whether they resonate with the wider geographical arena of care and not just that delivered in Scotland. Coupled with this, understanding the concept of events as triggers and what this means to individuals with COPD and their carers, needs further exploration in order to facilitate a holistic assessment of needs.

3.7 Chapter Summary

In this chapter, qualitative, secondary analysis of existing qualitative data was used to explore the extent to which identifying events as triggers can facilitate the holistic assessment of needs and subsequent demand for supportive and palliative care services, rather than using transition points. The next chapter will explore this further using consensus methodology with health and social care professionals.

Chapter 4

Exploring the Concept of Candidate Events as Triggers with Stakeholders I: Professionals

4.1 Introduction

Identifying 'triggers' in the life-long trajectory of COPD, may facilitate targeted, coordinated and holistic care for people with COPD. This section reports on the concept of candidate events within the trajectory of severe COPD as triggers for the holistic assessment of need within a professional arena, as outlined in the project overview (Figure 5). This piece of work follows on from Chapter 3 where candidate events (Section 3.4.1 Summary of Findings) were identified from the qualitative secondary analysis of the primary data source (*Breath of Fresh Air (BOFA) Study (*Pinnock *et al*., 2011)).

Figure 5: Project Overview with Focus for Chapter 4
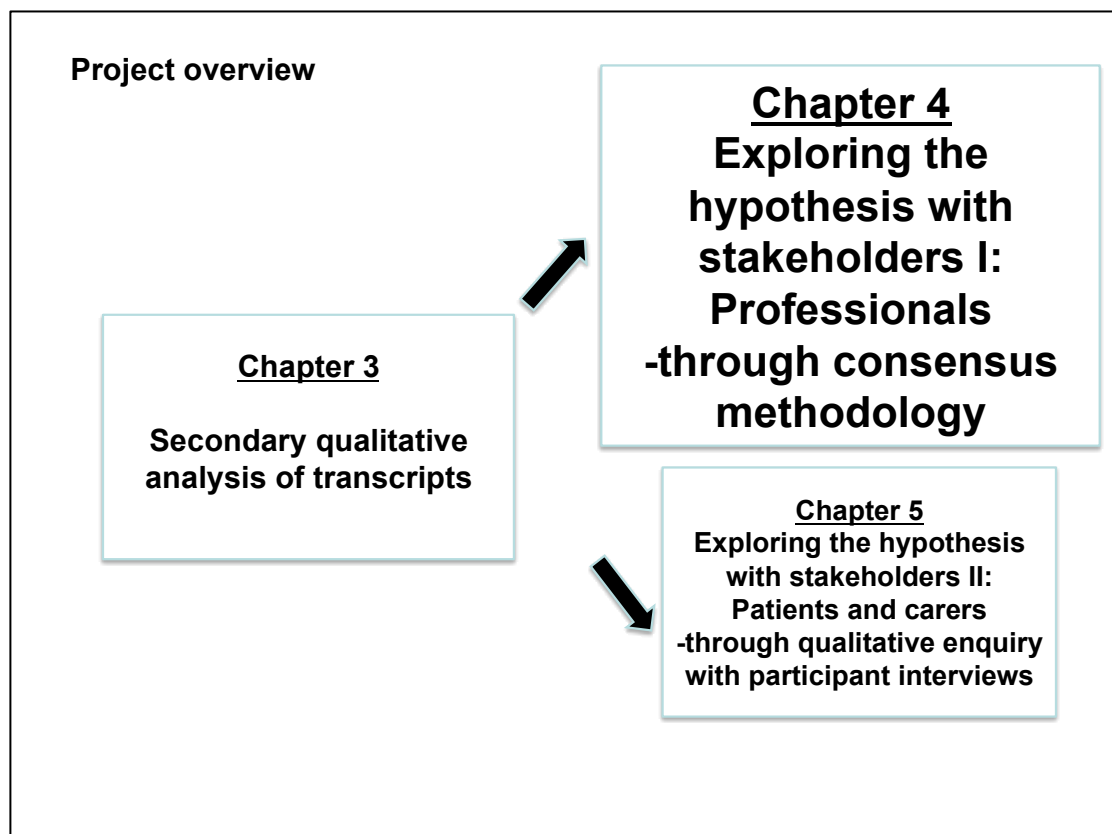
The aim was to explore and prioritise, from the perspectives of a multi-disciplinary group of professionals, the utility of these candidate events as meaningful triggers, whilst gaining consensus from the multiple perspectives of professionals involved in the frontline delivery of care in severe COPD. The consensus methodology employed will be outlined, explaining the rationale for this approach, as well as the reporting of the results and how consensus was obtained.

4.2 Methods

This section reports the consensus methodology used in the study, looking at the rationale for this approach over others and how the process was conducted and how consensus was reached.

4.2.1 Building the Conceptual Approach

To recap from Chapter 3, the eight identifiable candidate events (Table 5), which were grouped into two over-arching themes as a result of applying a conceptual framework. The attributes for identifying candidate events as potential triggers, were described in Chapter 3, section 3.2.4.1. and categorised according to the work of Hardin, Meyers and Louie (2008) and Lester and Campbell (2010) as:

a) An event having significant meaning for the patient and/or their carer.
b) An event that was clearly visible to the professionals involved in the care of COPD patient.
c) An event that was seen to have utility and/or usefulness for an individual with COPD and the professionals involved in their care, once an assessment was completed.

This framework will be explored further with professionals to gain their perspectives as to using the approach of events as triggers for the holistic assessment of need.

4.2.2 Rationale for the Choice of Consensus Technique

Nominal group technique

Nominal group technique is a recognised consensus methodology that utilises available evidence whilst allowing experts in the field to draw on their experience and clinical practice in discussion, debate and decision-making (Delbecq, Van de Ven and Gustafson, 1975; Campbell *et al.*, 2003)**.** The professional consensus group was designed to explore professionals' perspectives of the empirical findings, with the secondary analysis of interview transcripts (as in Chapter 3) (Kvale and Brinkman, 2009), focusing on the discussion of their different perspectives in an attempt to reach consensus (Frey and Fontana, 1991). This process had the advantage over Delphi consensus methodology in that it utilised available evidence whilst combining clinical experience and expertise, facilitating a more qualitative view of the nominal question of 'the suggested candidate events as triggers' (Campbell *et al.*, 2003). The observation of the interactions between professionals provided an understanding of the collective meaning of triggers as a group, which complemented the understanding of each of the professionals within their specific roles and organisations (Morgan, 1997).

4.2.2.1 Professional consensus group – the planning and the process

There is debate in the literature regarding the definitions of focus groups, discussion groups and group interviews, with terms used interchangeably to mean different things (Krueger, 1988; Bryman, 2008). Distinctions have been drawn between focus groups that explore specific themes in-depth and group interviews that cover a wider range of topics, which are interested in how people discuss a theme as members of a group (considering member interactions and joint construction of meaning). Group interviews are also designed to collect data more quickly – or can sometimes be more convenient than individual interviews (Krueger, 1988; Morgan, 1997).

However, as it is described, a group interview is considered a research tool that "can be formal with a specific, structured purpose, such as a marketing focus group, or it can be informal, taking place in a field setting where the

researcher simulates a group discussion with a topical question" (Frey and Fontana, 1991). This suggests that a focus group is one of many forms of group interview. Morgan (1997) goes further, criticising an "exclusive approach" (Morgan 1997, pp. 5-6) that requires determination of whether a group interview is or is not a focus group. They suggest instead that the important elements of group-generated data are that the researcher provides the subject of interest and that the data are generated through the group interaction (Morgan 1996; 1997). This is echoed by other authors such as Kitzinger and Barbour (1999). Despite these differences, there is general agreement that a group of people meeting to discuss shared experiences or views, allows the development of a consensus understanding, or identification of a range of similarities and differences in perceptions of experiences, as participants challenge and refine their views in relation to each other (Krueger, 1988; Frey and Fontana, 1991; Morgan, 1997; Bryman, 2008).

Groups can offer so-called 'safety in numbers', particularly in settings where the organiser of the group is perceived as relatively powerful in comparison to the participants (Langdridge and Hagger-Johnson, 2009). Conversely, people may be reluctant to express disparate views to either the group majority or particularly vocal participants. If this is a real concern then individual interviews can be useful as the sole means of data generation or used in combination with group data generation (Morgan, 1997; Mitchell, 1999).

Typically for group data generation, the researcher will act as a facilitator for the discussion of several topics within an area of interest. Their role is therefore, a combination of chairperson and interviewer as they seek to encourage participation and interaction between the people present, whilst guiding the subject of discussion on topics of interest (Fontana and Frey, 2005). As with interview techniques, different researchers choose to run focus groups in more or less structured ways and situate themselves differently on a spectrum from observation to participation (Frey and Fontana, 1991; Fontana and Frey, 2005).

In this study, the term professional consensus group was used (Langdridge and Hagger-Johnson, 2009). The participants of the group discussed the

emergent findings from the initial qualitative, secondary analysis of interviews (see Chapter 3). The group data generation provided an opportunity to explore and gain insight into the cognitive processes of professionals and the different perspectives in exploring the concept of events as triggers for holistic assessment in severe COPD. The design, organisation and process of the group was specific to this piece of work, but conceptualised as a means to stimulate and explore the perspectives of care professionals in relation to their field of expertise (context), with the feasibility of an approach of events acting as triggers for the holistic assessment of need (content). This approach has previously been used in healthcare settings (Alderson, Farsides and Williams, 2002; Williams *et al.*, 2007).

4.2.3 Participant Selection and Recruitment

4.2.3.1 Participant recruitment to the consensus group

Professionals involved in the care of individuals with severe COPD, i.e. individuals with a defined role responsibility for the delivery of care and/or an academic record of expertise in COPD, were invited by electronic mail to partake in the professional consensus group. The purposive sampling, as described by Denzin and Lincoln (1994), states that the researcher "explicitly and purposively chooses sampling methods to seek out groups, settings, and individuals where… the processes being studied are more likely to occur" (Denzin and Lincoln, 1994, p. 202). Distinct subgroups were purposively selected to allow for the breadth of provision between clinical care (hospital, GP and generalist and specialist community teams) and non-clinical care (social, therapies, voluntary sector, academics), professionals and settings. This approach targeted as many care professional networks as possible (e.g. professional respiratory and palliative care network and loco-regional meetings), as well as contacting individual professionals by virtue of their role (e.g. consultant physiotherapist for COPD, clinical manager for community respiratory team, consultant in respiratory medicine with specialist interest in COPD, occupational therapists, counsellors with specific expertise within COPD).

4.2.3.2 Characteristics of the sample

The sample size was not predetermined but the aim was to recruit a breadth of professionals, so as to aid the discussion, interpretation of preliminary findings and feasibility of the approach of events as triggers, facilitating the holistic assessment of needs in severe COPD. A wide range of professionals would also ensure a rich discussion about the issues pertinent to triggers as a concept and the candidate events already identified from Chapter 3 (Silverman, 2005; Corbin and Strauss, 2008).

Prior to participants attending the meeting, an email was sent (Appendix C: Invitation email) detailing an overview of the topic in question and the aim of the meeting, as well as its location and duration. The email identified individuals as potential participants by virtue of their role, experience and expertise. Being able to relinquish a day from clinical practice is not always possible for healthcare professionals and so a location was chosen that was convenient and feasible for participants to reach in terms of geographical distance from their workplace. Parking was provided and any travel costs were reimbursed but owing to budgetary constraints, professional time could not be reimbursed either directly or to their service directorates. The meeting was to last approximately five hours in total. The professional participants assembled for the meeting in Pilgrims Hospice, Canterbury, in March 2011.

4.2.4 Data Generation and Handling

Data collection from discussions

The professional discussion within the consensus meeting created an opportunity to reflect and explore perspectives emerging from the results within a wider health economy, actively involved in care delivery. The discussion also generated data that highlighted the dynamic interactions between professionals. This facilitated a greater understanding of the collective meaning of what and how triggers were perceived and their feasibility within COPD care delivery, in contrast to their individual, professional grouping, organisational contexts or constructs (Frey and Fontana, 1991). The aim was to explore care professionals' perspectives in as

many settings as possible (e.g. hospice physiotherapist and a hospital physiotherapist), whilst gaining a view collectively from a certain professional grouping (e.g. physiotherapists).

Discussions from the meeting were recorded on a flipchart and the author clarified that the comments captured reflected what participants' perspectives were (Denzin, 1989). The discussions were not digitally-recorded and therefore it was not possible to assign an individual identifier for said participant and their comments, nor listen to the verbatim dialogue. Despite several rehearsals to explore if an audio-recording was feasible, the challenge of the room layout and ensuring all voices were captured using only a single digital recorder, proved too difficult and was thus abandoned. Therefore, the process of capturing the discussions was facilitated by a colleague, unknown to the participants, who recorded key phrases and discussion points.

4.2.4.1 Initial presentation of background information

Within the professional consensus group, an initial presentation highlighted the supportive and palliative care needs of individuals with COPD and their carers. This identified the current service provision, with particular emphasis given to the supporting literature for the content of the workshop. This included important national and international policy documents and an appraisal of the literature to date (as discussed in Chapter 2).

4.2.4.2 The consensus process

Table 7 illustrated how the different rounds took place within the consensus method. There were three in total.

Table 7: The Consensus Process

Round	Purpose	Rationale
1: Introduction to the nominal group technique process **Summary of the concept of triggers and their attributes** **Overview of the findings of the qualitative, secondary analysis and potential eight candidate events as triggers:** • Increasing burden of disease. • Shifting priorities of care. • Increasing carer burden. • Requesting a 'disabled' parking/ (blue) badge. • Home adaptations. • Hospital admissions. • Appointment frequency. • Housebound**.**	Initial rating 1-10 (10= highest utility, 1= lowest) of each event as a trigger after group discussion.	To assess group members' initial perception of the relative utility of each of the candidate events to act as triggers, informed by evidence and drawing on their individual clinical experience and expertise.
2: Overview of the evidence-base for each candidate trigger in turn **Group discussion** **Feedback of the median score from Round 1**	After discussion of each trigger, rating 1-10 (10= highest utility, 1= lowest) of each event.	To assess group members' perception of the relative utility of each of the candidate events to act as triggers following the multi-professional discussion, informed by the initial scores and drawing on the group members' discussion.
3: Further over-arching discussion of the concept of triggers **Feedback of the median score from Round 2**	Final rating 1-10 (10= highest utility, 1= lowest) of each event after group discussion.	To assess group members' perceptions of the relative utility of each of the candidate events to act as triggers following multi- professional discussion of all the candidate triggers, informed by Round 2 scores and the opportunity to the concept of triggers. discuss

Round 1

This round started with an explanation of what the attributes of a trigger should comprise within the context of this piece of work and discussion about the eight potential events as triggers. Participants had an agenda to help orientate and navigate them through the format of the meeting (Appendix D: Agenda for the consensus meeting) and each round had a scoring sheet to help maintain confidentiality and anonymity within the consensus process (Appendix E: Scoring sheets).

The discussions were time-limited so that first impressions of the identified events as potential triggers could be captured. Professionals were asked to rate from 1-10 (10= highest utility, 1= lowest) all eight of the suggested candidate events in their ability to act as triggers for a holistic needs assessment.

Round 2

After the initial rating (round 1), the participants had the opportunity to discuss the merits of each candidate event in turn, seeking clarification and exploring the feasibility of this event within their sphere of clinical practice. Further rating of the candidate events' utility occurred after discussion of each trigger. The ratings aimed to quantify the level of consensus, whilst the discussions that ensued gave a very rich, qualitative component to the process. In this round again, professionals were asked to rate from 1-10 (10= highest utility, 1= lowest) all eight of the suggested candidate events in their ability to act as triggers.

Round 3

Once all candidate events were discussed in turn, a final rating of all eight triggers occurred. This facilitated discussion of the feasibility and applicability of triggers as a concept throughout the disease trajectory of severe COPD.

4.2.5 Data Analysis

Data were entered onto Excel (Microsoft, 2008) spreadsheets and the medians for Rounds 1, 2 and 3 were calculated during the course of the meeting, for feedback in the subsequent rounds.

Definition of consensus

Consensus was defined *a priori* as 75% of the group rating the candidate event with a score of eight or above, using the median scores (Murphy *et al.*, 1998).

4.2.5.1 Process of the analysis

Consensus methodology depends on all participants contributing to every stage in order to reflect the process as they reach consensus. However, five hours is a substantial time commitment in the middle of a working day, and the research team recognised that not all professionals would be able to attend all phases. In view of this, the decision was taken to exclude ratings from participants unable to contribute to every stage, but to include their comments in the discussion.

4.2.5.2 Thematic content analysis from group discussions

This qualitative approach is a method of textual investigation of the content of the data, to categorise recurrent or common themes (Silverman, 2005). The approach is commonly used in health-related, qualitative research and aids data interpretation when views from particular groups, and in this case professionals (health and social care), are required. Given the limitations for capturing the group discussions on a flip chart, the data could not be coded sufficiently to categorise respondents' accounts, limiting the ability to classify them into themes that were common and recurring in the data sources (Green and Thorogood, 2004, pp. 176-177).

4.2.6 Reporting

Addressing the potential for bias

To ensure transparency in reporting, the Guidance on Conducting and Reporting Delphi studies (CREDES) in palliative care has been used as the reporting checklist (Junger *et al.*, 2017). The principles of reporting and assurances suggested by this approach, whilst addressing the nuances of reporting within palliative care, identify it as a suitable and transparent reporting standard for this chapter of the thesis. In the absence of any published checklists specific to the consensus methodology, namely nominal group technique used in this study, the CREDES recommendations were used as a helpful checklist (Appendix F: CREDES checklist).

4.2.7 Ethical Considerations

4.2.7.1 Ethical approval process

The more pertinent ethical issues relating to this piece of work are discussed below, in addition to those already mentioned.

4.2.7.2 Consent

Verbal, informed consent was gained from participants with each member signing an attendance register acknowledging their participation within the professional consensus meeting. Given the subject matter and the discussions that would follow, data confidentiality and an explanation of how the data would be processed and stored, were made explicit to all attendees. Participants were assured that any quotations and examples used in discussions and captured through the flipchart would be anonymised and as such, no identifiable information could be tracked to an individual participant.

4.2.7.3 Confidentiality and information governance

The principles of confidentiality and anonymity were explicit and clarified throughout the research process, and the legal requirements and intellectual property rights were explicit and adhered to (RESPECT Report, 2004). This had already been discussed in chapter 3 (Section 3.2.6.3).

4.3 Results

4.3.1 Participants and their Characteristics

Fourteen participants were recruited from a range of academic and clinical backgrounds (see Table 8).

Table 8:   Professional Consensus Group Characteristics

Participants	Number
General Practitioner (GP)	2
Occupational Therapist	1
Physiotherapist with Specialist Interest	3
Community Respiratory Team	2
Palliative Care Clinical Nurse Specialist	1
Palliative Medicine Consultant/ Academic	2
GP/ Academic	1
Professionals not included (lack of full attendance on the day) (Academic = 1, Social worker = 1)	2

Due to work commitments, two participants were unable to stay for the entire meeting and were thus excluded from the analysis of the consensus ratings.

4.3.2 Overview of Findings with Over-arching Themes

Proportion reaching consensus thresholds

Of the eight candidate events, three achieved the *a priori* consensus level of 75% agreement in Round 3, with ratings of eight or above. These were: hospital admissions, home adaptations and becoming housebound.

The Round 1 ratings identified increasing burden of disease, becoming housebound and increasing carer burden as prioritised events. There was thus a shift during the consensus process from events that were a function of advancing disease, to specific interventions, addressing the consequences of advancing disease (this is illustrated in Figure 6)**.**

Figure 6: Median Scores over the Three Rounds of Ratings

Candidate event	Ratings (0-10)

Disability (blue badge)
Home adaptations
Hospital admissions
Appointment frequency
Becoming housebound
Increasing burden of...
Shifting priorities of care
Increasing carer burden
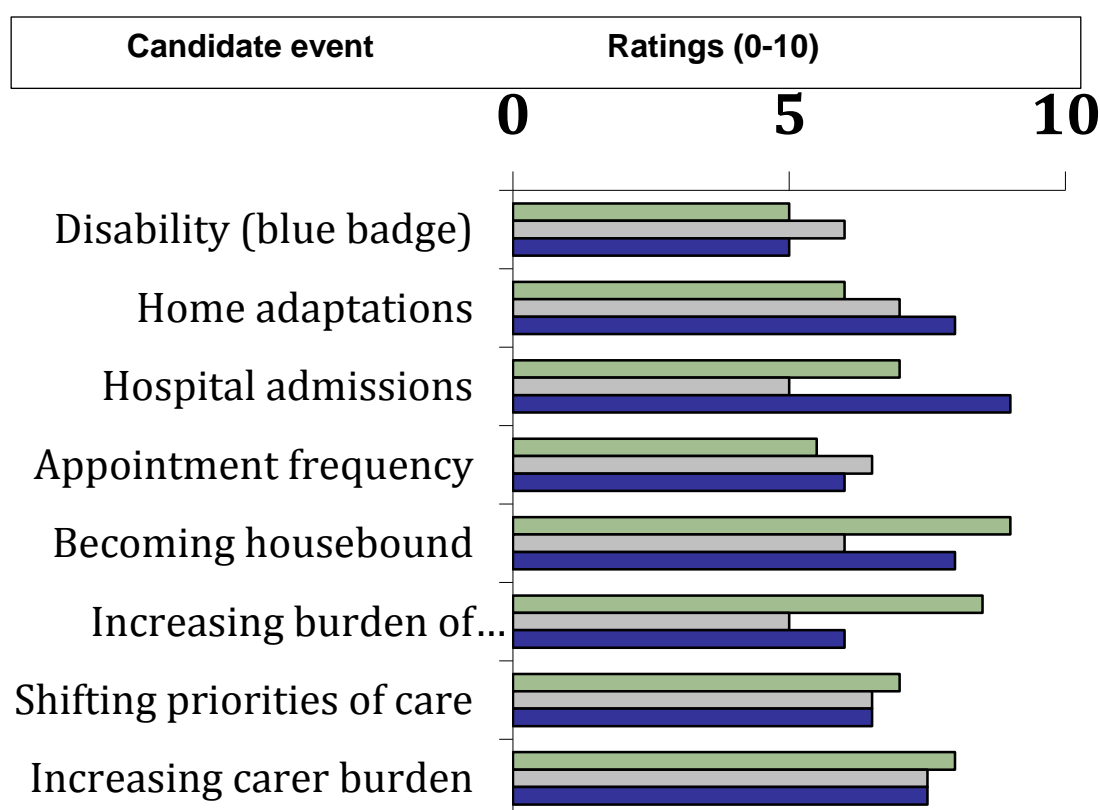
Scores of 0= lowest and 10= highest potential utility as triggers

Key:

Scores for Round 1: green bar

Scores for Round 2: grey bar

Scores for Round 3: dark blue bar

This shift was reflected in the over-arching discussion (see themes below), during which the group's understanding of the concept of triggers and their application in clinical practice evolved.

Over-arching themes from the discussions

Table 9 summarises the discussions related to each candidate event. The emergent themes were categorised into three main groups:

- The attributes of a trigger.
- Visibility of candidate events as triggers to care professionals.
- Visibility of candidate events as triggers - a professional perspective.

Table 9: Summary of the Discussion, Rating and Overall Outcome from the Consensus Process.

Candidate triggers and summary of the discussion points	Attributes of a Trigger √ = Meets criteria X = Does not meet criteria ? = ill-defined/ ambiguous				Median score in the three rounds (0= lowest, 10= highest utility)		
	Visible	Clearly defined	Meaningful	Utility	Initial rating	After discussions	Final rating
Requesting a disability parking badge/ a 'blue badge' • "Middle class to have a car; 40% of patients have no car or access to one." • Wider mobility/general transport issues it raises. • Patient may not be the driver, it may be a carer or sibling. • Maybe suggested by professional than prompted by patient/carer. • What is the motivation to get one? Other people suggesting or recommending or hearing that other COPD patients/carers have them.	√	√	√	√	5	6	5
Home adaptations • Wider housing issues and their overall suitability. • Request for a council house supporting letter on health grounds. • "Timing versus 'point' in the pathway… can happen at any time rather than at a transition point." • Items/adaptations on a 'lower level' e.g. perching stool, items	?	X	√	√	6	7	8

bought independently from mobility aid shops may not be visible. • Difficulty with it being sufficiently visible to all individuals. • Stair lift: varies with the economic landscape the patient resides within; general inequity in provision; equates to an additional handrail; downstairs living.							
Hospital admissions • The 'actionable' component may be more aspirational within the current service delivery model. • Visible and actionable to different people. • 'Severity' may indicate that patient needs Non-Invasive Ventilation (NIV). • Repeated admissions and increasing frequency. • 'Exacerbating' episodes may not actually require hospital admission and much more intensive community care required. • 'Actionable' component depends on the communication and whose problem it is. • Changing community environment. Increased utilisation of community services rather than secondary care; a lot of resources may be front-loaded to prevent hospitalisation (hospital aversion). • Social setup-may be a barometer of how poor it is as there is no buffer/ flexibility/ resilience within the home environment e.g. co-morbidities, inadequate social input, need for escalation of social care input in response to changing care needs.	√	√	√	√	7	5	9
Increasing burden of disease	X	X	?	X	8.5	5	6

• Intuitive and a "gut feeling." • Points to wider issues and not a visible trigger given the slow change in the COPD trajectory. • Polypharmacy/ repeat prescription screening. • "Poly-professionals being involved."							
Becoming housebound • "Absence" – not attending, they are 'invisible.' • GP – needing to visit; change from normal practice; becomes recurrent or 'the norm' to visit at home. • Quality Outcomes Framework (QOF) exemption reports - yearly reports but could pull off more frequently and match with COPD diagnosis (reporting systems are already in place for GPs). • Not necessarily helping with 'triggering' - professionals may be from different professional groups e.g. general practitioners or occupational therapists. • Residential home new patient initial assessment provides an opportunity to assess.	?	√	?	?	9	6	8
Failure to attend an appointment • People who were housebound would not make the appointment. • Degree of invisibility. • One-off non-attendance or multiple episodes. • Picking up the impact of other co-morbidities. • Good and bad days are the norm. • More opportunity if there is an elective booking system rather than a general practitioner system of urgent and quickly available appointments.	√	√	?	√	5.5	6.5	6

• Small proportion of people it would capture. • Is this group a subset of housebound patients?							
Shifting priorities of care • Difficult to make tangible; not very visible; quite nebulous. • Request for nutritional supplements from the general practitioner (patient not maintaining calorific intake and indicative of potentially deteriorating/low Body Mass Index, hence markers of disease severity also). • "Cooking what the patient likes and not eating it." • Frequency of reviews has changed, more or less (either side of the spectrum). • "Something has changed." • Patients may shift their priority of care.	X	X	√	?	7.5	6.5	6.5
Increasing carer burden • Not so much a trigger but more a 'marker' of disability; identifies a need for help and is there a receptiveness to offers of help? • Requests from formal carers for help/education; more regulatory Care Quality Commission (CQC) driven than genuine desire/interest) e.g. nebuliser or inhaler use/care. Carer consulting • 'Proxy' for the patient. • Is the carer consulting for their own needs or is it an opportunity to speak about the impact of their caring role i.e. the caring burden (vocal sounding board). • Change in roles e.g. walking the dog, doing the driving/shopping/gardening/paying bills. • 'Invisible' component and is difficult to make tangible and visible.	√	X	√	√	8	7.5	7.5

The attributes of a trigger

The multidisciplinary professionals, who came from a range of healthcare settings, debated the nature of triggers with initial opinions suggesting that features of advancing disease could prompt a call to action. This initially seemed more appropriate than specific interventions, such as home adaptations and requesting a disabled parking badge ('blue badge') which *"could happen at any time rather than at a transition point"* and *"may be suggested by the professional rather than the actual patient/ carer."*

However, after discussion on some specific candidate events, opinions changed and it was considered that features of advancing disease were difficult to fit into the concept of a trigger. For example, the candidate event relating to increasing burden of disease, was thought to be *"more intuitive"* and a *"gut feeling"* rather than a trigger. Similarly, increasing carer burden was seen more as a *"marker of disability rather than a trigger"* and whether it would constitute an effective *"call to action"* was debated. Carers could act *"as a proxy for the patient with COPD"* but this was also considered difficult as it could be influenced by their own health-related issues, as well as the increasing burden from the care-giving role.

There was general agreement that home adaptations might initially be very *"low level… items bought independently from mobility aid shops like a perching stool"* and therefore invisible to most professionals. However, more significant equipment requirements as the disease advanced, *"stair lift requests or needing to change the bath into a shower",* for example, would make a home adaptation request visible to professionals.

Visibility of candidate events as triggers within a patient arena

The group observed that a hospital admission was a very visible event within the disease trajectory for a minority of patients with COPD. This resulted in a debate about how applicable this event was as a trigger since it did not apply to the COPD population as a whole. Discussions focused on how equitable it was for a service delivery model to use a hospital admission as a trigger when

many 'exacerbating episodes' (even in people with more severe disease), were managed by *"intensive community care."*

Requesting a disabled parking badge ('blue badge') raised similar concerns, since it might not apply to all people with COPD. One professional felt it was *"middle class to have a car, 40%* [of their patients] *have no car or access to one",* though others observed that *"the patient may not be the driver"* so it might apply to more patients than at first thought. It was also observed that requesting a disabled parking badge *"points to wider mobility issues"* and thus could appropriately trigger further action.

Visibility of candidate events as triggers - a professional perspective

It became clear in the discussion about several of the candidate events that the professionals working within different health and social care settings were aware of the contrasting and varied arenas of patient care and the constraints they posed. For example, hospital admissions were more visible to some professionals than others e.g. general practitioners, community respiratory team, hospital respiratory team and hospital allied health professionals.

The potential of a change in appointment frequency to act as a trigger, either due to consultations that were missed or an increased frequency of attendance, caused much debate as appointment systems in the different settings (e.g. general practice, hospitals, hospice) had a varying ability to identify non-attendance or flag recurrent attendees. Professionals felt there was *"a degree of invisibility"* associated with this trigger and it had varying degrees of resonance, depending on the setting or system within which they worked. However, one professional felt that there might be a subset of housebound patients that could be captured within GP systems by *"exception reporting"* [coding applied by general practices to explain why some patients had not attended reviews as required by contract standards] (Standard General Medical Services Contract, Department of Health, England, 2013).

As the group moved towards recognising that contrasting events could be triggers for different professional groups to act, there was recognition that this would require clearly defined responsibilities and lines of communication to

ensure that a trigger observed by one professional, resulted in action that might be the responsibility of another. As one participant questioned, a trigger that was *"Visible and needing action"* ought to be *"… visible to different professionals"* and yet accountability was unclear *"… whose responsibility is it?"*

4.4 Discussion

4.4.1 Summary of the Findings

Of the eight candidate events, three achieved *a priori* consensus level of 75% agreement with ratings of eight or above; these were: hospital admissions, home adaptations and being housebound. An approach that utilises events to trigger a holistic assessment of needs (supportive and palliative) for COPD patients and their carers, was a novel concept for the members of the group to comprehend, but after discussion, it sparked discussion about how it could be used within a healthcare setting. The discussions and sequential ratings highlighted a shift in their understanding of the concept of triggers. This highlighted the lack of initial clarity in using the concept of triggers as an approach, with the group acknowledging that an event visible to at least one member of the team was potentially a more practical way of identifying patients and their carers who might benefit from a holistic assessment of their needs.

4.4.2 Strengths and Limitations

A nominal group technique was employed that required a representative sample of professionals involved in the care of COPD individuals. Unfortunately, consultant respiratory physicians and community nursing colleagues were not able to attend the group, though respiratory and palliative care specialist nursing teams were represented. This lack of representation amongst professionals is clearly important to acknowledge. Despite the challenges of gaining wider representation, this professional group had lively debate and discussions around the concept of triggers and the importance of clearly defining their attributes, as well as the need for visibility between professionals working in various care settings and within different healthcare

operating systems. In attempting to redress the lack of wider representation of care professionals, more involvement of professionals within the set-up phase would have been useful. Securing their participation in an ongoing, iterative review of this piece of work and canvassing the methodology that would best suit them (e.g. online formats, shorter but more frequent meetings within a wider geographical area or an ability to obtain their views virtually), could also have yielded additional information from a wider perspective.

Given the myriad of approaches employed in consensus methodology, the nominal group technique was favoured in terms of the ability to have discussions alongside the consensus process. Other methodologies have a more clear-cut, standardised, confirmatory approach (Day and Bobeva, 2005; Hasson and Keeney, 2011), but nominal group technique favoured the research objective here, of exploring the concept of triggers within a multi-professional arena.

Two of the professionals, whilst able to attend Round 1 and Round 2 ratings and be involved in the discussions, were not included in the analysis of achieving consensus.

4.4.3 Interpretation with Reference to Existing Literature

Triggers and 'red flags'

The approach of utilising candidate events from the illness trajectory and narrative accounts of COPD, to facilitate a holistic assessment of patients' and their carers' needs, did have some degree of resonance with professionals. The concept of using events as triggers requires professionals to have a clear understanding of the potential significance of such events and how this could be articulated within their workplace setting, and even within their specific professional arenas. An analogy can be made with the concept of 'red flags' that is widely applied in the context of diagnosis. Examples of symptoms or signs which have meaningful, predictive value for professionals include haemoptysis with suspected lung cancer (National Institute for Health and Care Excellence (NICE) Clinical Guideline 121: Lung cancer: the diagnosis and treatment of lung cancer (update) Evidence Review, Appendix

11, April 2011), photophobia associated with headache in bacterial meningitis (National Institute for Health and Care Excellence (NICE) Clinical Guideline 102: Bacterial meningitis and meningococcal septicaemia: Management of bacterial meningitis and meningococcal septicaemia in children and young people younger than 16 years in primary and secondary care, 2010a; updated 2014) or unexplained weight loss when suspecting undiagnosed cancers (National Institute for Health and Care Excellence (NICE) Clinical Guideline 27: Referral guidelines for suspected cancer. Developed by the National Collaborating Centre for Primary Care for the National Institute for Health and Care Excellence, 2005).

'Red flags' are intended to act as a warning signal for the professional to engage in an appropriate level of additional "due diligence" (Fox, 2011) and therefore have the potential to overcome the professional nihilism that can exist with the gradual, lifelong nature of COPD (Cawley *et al.*, 2014). The identification of events as triggers could have significant utility in terms of offering an alternative to the difficulty of trying to identify an elusive transition point to an end of life phase for individuals with severe COPD.

4.4.4 The Role of Triggers within Clinical Practice

Triggers not transition

The needs, both supportive and palliative, of people with severe COPD are well described in the literature (Gore, Brophy and Greenstone, 2000; Habraken *et al.*, 2007; Lanken, Terry and Delisser, 2008; Gardiner *et al.*, 2010; Pinnock *et al.*, 2011; Giacomini *et al.*, 2012; Boland *et al.*, 2013), but the dilemma and challenges for current models of care are whether they are sufficiently visible to alert professionals, in contrast to how the 'red flag' system is applied above, i.e. to more acute and visible conditions. Recognising events as triggers could facilitate concurrent provision of palliative and supportive care within the existing, on-going, routine management of the condition. This approach offers an opportunity to trigger an assessment of needs that can be paradoxically invisible to professionals because of the insidious, progressive nature of the condition. This would

affirm life within its multiple dimensions (physical, psychological, social and spiritual), centring on coordination and continuity of care, with the clear focus on the need identified, not on time, nor prognosis (Lanken, Terry and Delisser, 2008).

4.4.5 The Challenge of Triggers within a Professional Lens

Triggers and visibility

Visibility of potential triggers was regarded as fundamental to the success of this approach if it were to capture the needs of patients with severe COPD and their carers. Visibility, however, was not a static characteristic of the event; it varied depending on the health or social care professional involved, the health or social care setting, severity of the condition or impact of the event. Initially, this was seen as limiting the utility of candidate events (even those that reached consensus) until the group recognised that a single problem (e.g. the request for a disability parking badge ('blue badge') presented to one professional could trigger an assessment by a colleague who was able to assess the impact of the progressive mobility problems on the physical, psychological, social and spiritual aspects of the patient's life, and more importantly, stimulate appropriate interventions (e.g. such as providing a walking stick and/or other mobility aids). Therefore, integration of services with a whole-systems approach was seen as an integral step in the potential success of any new approach, in particular, that of events as triggers for holistic assessment.

4.5 Conclusions

Current models of palliative care fail people with very severe COPD, who silently and invisibly adapt to their gradually and increasing functional limitations. The concept of identifying events, such as hospital admissions, home adaptations and being housebound, to act as 'red flags' to trigger a further holistic assessment of needs, resonated for professionals in health and social care, representing a novel approach to improving care services for people with severe COPD and their carers. However, there is considerable debate with regards to the utility, feasibility and significance of this approach

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within current service delivery models and the professionals delivering this care.

4.6 Implications for the Next Stage of Research

The concept of using events as triggers in severe COPD has the potential to bypass the prognostic paralysis within the uncertainty of the disease trajectory. As mentioned previously in Chapter 3, the challenge of engaging services to support the ongoing and changing needs of patients and their carers will potentially conflict with existing service models, but afford an opportunity to strategically and clinically commission services that meet the oscillating visibility of need. The challenge is to offer an approach that is fiscally conscious of the economic constraints of the current service model, whilst offering additional benefits to the wider health economy. This approach has the opportunity to ensure patients and their carers have their needs assessed within a more holistic context (physical, psychological, social, spiritual). One application of this approach could be to establish proactive searching for triggers (for example, using structured reviews, protocols or templates).

Exploration of this concept from the perspectives of patients and carers is key to aid a holistic assessment of needs and as such, needs explicit discussion concerning its approach and usefulness.

4.7 Chapter Summary

This chapter has focused on the consensus methodology and qualitative discussion employed amongst professionals to explore the hypothesis that identifying events as triggers may be a better approach to facilitate a holistic assessment of need than using transition points. However, there was considerable debate on how the concept of triggers would transcend work settings since there was a degree of ambivalence towards the approach within different professional workplaces. The potential for such an approach to determine the need for supportive and palliative care services for individuals with severe COPD and their carers needs further exploration.

Chapter 5

Exploring the Concept of Candidate Events as Triggers with Stakeholders II: Patients and Carers

5.1 Introduction

In this chapter the concept of candidate events as triggers (outcome from Chapter 3, Section 3.4.1 Summary of Findings) will be explored and their ability to trigger a holistic assessment of need through the patient and carer lens (Figure 7).

Figure 7: Project Overview with Focus for Chapter 5
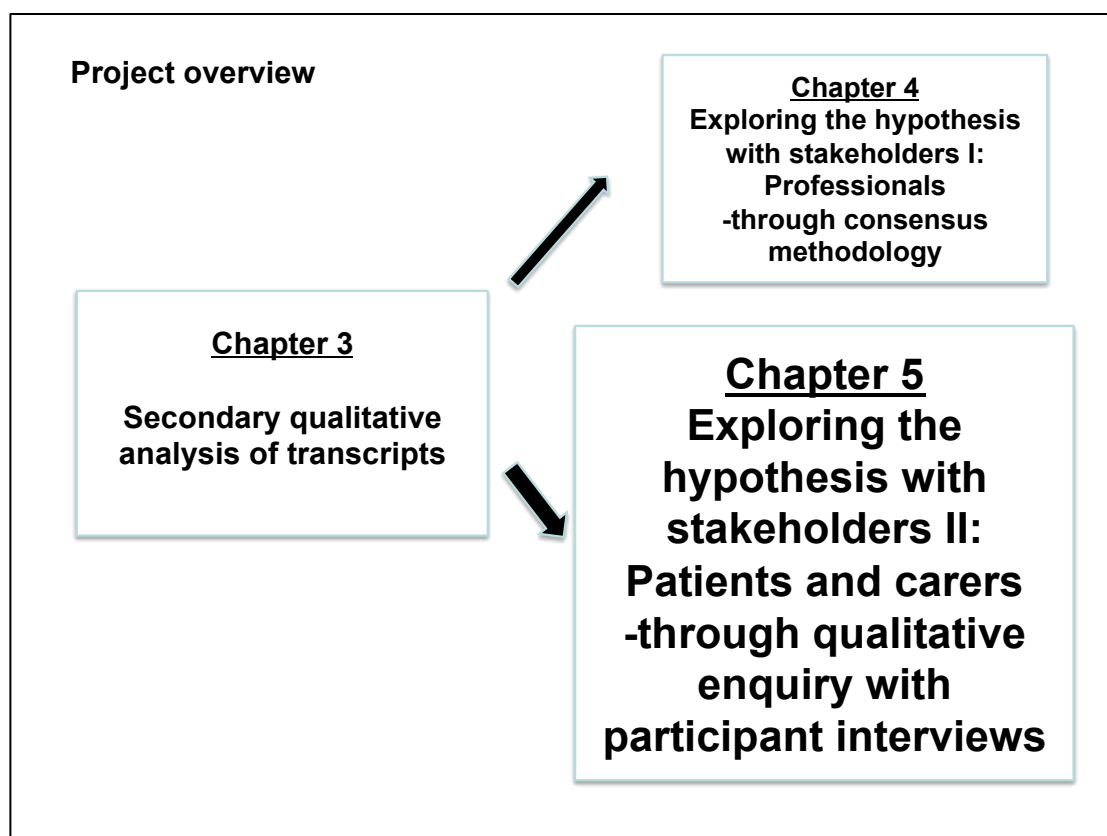
5.2 Methods

The variety of perspectives and perceptions within the delivery of COPD care and the different care settings, requires an approach to understand and hear each voice so that any meaningful outcome from the data can be grounded in the lived experience of illness, both in terms of those experiencing the

disease, but also of those delivering the care (Ritchie and Lewis, 2003; Braun and Clarke, 2006; Devlin and Appleby, 2010). Therefore, in this chapter, the development of the conceptual framework through its evolution from Chapters 3 and 4, will continue with the focus on individuals with severe COPD and their carers.

5.2.1 Conceptual Framework Development

To recap, the focus of the qualitative secondary data analysis was to identify events commonly occurring within the COPD disease trajectory that might have the ability to trigger a holistic needs assessment. The characteristics of a potential candidate event to act as a trigger were important to define, and as outlined in Chapter 3, were categorised according to the work of Hardin, Meyers and Louie (2008) and Lester and Campbell (2010) as previously discussed.

5.2.2 Rationale for this Approach

When analysing the complexity of a situation, according to Mason (2008), several concepts need to be considered. These include considering whether something more than, or separate from the part emerges, as well as looking for evidence of internal diversity, internal redundancy, neighbour interactions, decentralisation of control, randomness, coherence and feedback loops and stability, all of which can contribute to understanding social processes in action:

> New properties and behaviours emerge not only from the elements that constitute a system but from the myriad connections among them… to build effective dynamical models… institutions will need to know not just what people do, but why they do it, how they might imagine things being different, and what they would really want to do (Mason, 2008, pp. 45, 117).

By making links and comparisons between different perspectives (patient, carer and care professional), a list of potential events has been considered that could trigger the holistic assessment of needs in severe COPD (see

Chapter 3). The feasibility and clinical utility of such events in practice as potential candidates within the COPD trajectory has been explored from a professional perspective (see Chapter 4). The next step was to explore the perspectives of those experiencing and living with severe COPD and gain their understanding of potential event triggers.

5.2.3 Participant Selection and Recruitment

5.2.3.1 Participant recruitment

Participants were recruited from GP surgeries, community respiratory teams and hospital respiratory teams within the East Kent region, based on their diagnosis of COPD, as defined by FEV_1 spirometry measurements (www.goldcopd.org). Given the lack of correlation with disease severity and functional debility, as documented in previous studies (Coventry *et al.,* 2005; Giacomini *et al.,* 2012; Boland *et al.,* 2013)*,* a Medical Research Council (MRC) dyspnoea score of 3 or above (Walks slower than most people on the level, stops after a mile or so, or stops after 15 minutes walking at their own pace) (www.mrc.ac.uk), was used as a benchmark. Participants who had accessed hospice services were not included, given the literature supporting inequity of provision, but also the fact that patients perceive hospice services as professionals having given up on them (Giacomini *et al.,* 2012).

5.2.3.2 Sampling characteristics

Participants were purposively selected from the different providers of COPD care within East Kent. This purposive sampling, as described by Denzin and Lincoln, states that the researcher "explicitly and purposively chooses sampling methods to seek out groups, settings, and individuals where… the processes being studied are more likely to occur" (Denzin and Lincoln, 1994, p. 202). Therefore, patients were sought from a variety of settings, from different geographical areas and from different commissioning groups. East Kent has four different Clinical Commissioning Groups operating and they are charged with delivering care in line with national frameworks, but how they operationalise this care at an organisational and individual level with fiscal constraints will be different. Different organisations identified a link individual

who would act as a conduit to identify patients so the researcher had no contact with potential participants. Participants were contacted by post with an invitation letter co-signed by the researcher and the responsible organisation (Appendix I), with an accompanying reply slip (Appendix J) and stamped addressed envelope. Accompanied with this was the participant information sheet (see Appendix K (Patient and Carer version)). Potential participants had the opportunity to contact the researcher for further information, decline to take part in the study or reply stating their desire to participate. Only at this stage was the researcher able to make contact with the potential participants.

Patients were stratified into distinct subgroups (e.g. potential participants from the different organisations, different settings and different provider organisations), in advance of recruitment (Denzin and Lincoln, 1994; Silverman, 2005), in order to allow for a breadth of experiences across the health economy of all those providing COPD care, as well as looking at sex, presence of an informal carer (if recorded within electronic databases or paper records), and MRC score (Denzin and Lincoln, 1994; Silverman, 2005; Corbin and Strauss, 2008) (see Figure 8). As in previous studies seeking multiple perspectives, achieving a sample of 16-20 participant interviews was considered sufficient to reach saturation (Kendall *et al.,* 2009). In total, 350 recruitment packs were distributed to the different organisations and teams.

Figure 8: The Criteria for Patient Recruitment and Selection (*Denzin and Lincoln, 1994; Silverman, 2005; Corbin and Strauss, 2008*)

Inclusion criteria	1. Patients registered with a general practitioner within the East Kent region, within one of the four Clinical Commissioning Groups' jurisdiction.
	2. A diagnosis of severe COPD (FEV1 <30% predicted).
	3. An MRC score of 3 or more.
	4. Patients not known to hospice services.
	5. Patients known to community respiratory teams and hospital respiratory teams within the East Kent region.
Exclusion criteria	1. Patients cognitively unable to take part in the study.
	2. Patients with imminently life-threatening illnesses, such as acute exacerbation of COPD or advanced cancer.

5.2.3.3 Patient and carer interviews

Interview schedule development

In-depth interviews were conducted to generate data to gain patient and carer perspectives. The interviews were semi-structured with open questions and prompts to elicit detailed answers. The interview schedule (Appendix G) was constructed following identification of the research question and the data findings generated from the qualitative, secondary analysis and the professional discussion group work.

In addition, a systematic review and synthesis of the qualitative, empirical literature looking at the experiences of living and dying with COPD, informed the interview content (Giacomini *et al.*, 2012). This review identified the following key areas that the interviews aimed to explore:

- Adapting to life with COPD: A roller-coaster patter of up and downs; Increasing functional limitations isolating them from social contact but also from health care. This area was important to include (despite it having already been covered in the BOFA interviews), in order to set the context of the interviews, so as to establish participants' understanding and how they were recalling and describing their illness narrative (Kendall *et al.,* 2009).

- Holistic assessment: experience of asking about the physical, psychological, social and spiritual domains of illness and experience, if any of this had occurred.

- Transitions in COPD: transitions between settings of care create new levels of uncertainty from prognosis, their illness, care providers and available support. Carers' challenges often echo patients' challenges. The difficulty of identifying the beginning of 'the end of life'. The flux of needs in COPD calls for service continuity and flexibility to respond to the unpredictable but increasing demands of the disease over time.

The 2012 review by Giacomini *et al.* was relevant in that it enabled the identification of these initial questions, which were designed to elicit the

patient narrative, including specific examples about their day-to-day experience of living with COPD. These examples could then be probed in greater depth for understanding and interpretation of meaning with regards to exploration of the concept of triggers within their narrative assessment (Webster and Mertova, 2007; Riessman, 2008).

Exploration aimed to understand the participants' conceptualisations of what would constitute an event as a trigger, what their attributes were, their clinical significance and ultimately, their utility. This in turn, allowed identification of what was considered significant (or not), gaining both breadth and depth of understanding. Collecting personal narratives in relation to participants' experiences, told in relation to a holistic assessment of needs in COPD, allows interpretation of meaning from the storytellers' perspective and the identification of significant incidents (Denzin, 2002). Specific questions were asked about the feasibility, appropriateness and clinical utility of using triggers to aid an understanding of their relevance to clinical practice.

The interview schedule was initially piloted on three patient participants. However, the participants struggled to see how triggers would apply to their condition and questioned the relevance to their own needs as well as the significance and clinical utility of this approach. The initial ordering was designed to ask about the events identified as triggers and gain the views of participants about this approach. Participants felt the events had varying significance to them. Setting the scene with the context of how the participants recalled their everyday living with COPD, helped the discussion flow about how events as triggers for the holistic assessment of needs could have a role. In discussion with the research supervision team, the order of questioning was changed. This was also coupled with some minor modifications so that the interview schedule focused more on participants' experiences, exploring their perspectives and reflecting on emerging themes from previous interviews (Silverman, 2005; Corbin and Strauss, 2008). This again echoed the work of Mason (2008) since to analyse the complexity of the situation between COPD sufferers and their carers, the research team needed to understand the social processes in action, to know how people "imagine

things being different" but also "what they would really want to do" (Mason, 2008, pp. 45, 117).

5.2.4 Data Collection and Handling

Interviews were expected to take between 45-90 minutes, depending on whether they were single or joint interviews and according to the depth and breadth of discussions.

All patient participants were contacted prior to their interview and offered a location of their choice. If they had nominated a carer, they too were invited to participate in the interview, either with the patient in a joint interview or in a separate interview. Joint interviews, also known as conjoint, couple or dyadic interviews, have been used extensively in healthcare research. However, much health literature is constructed from the perspective of either carer or recipient, thus leading to services being directed at one or the other, rather than considering their common needs (Torgé, 2013). Here, joint interviews denote "interviews with two people who have a prior relationship, interviewed at the same time" (p. 103), while a dyadic approach refers to analysis that "utilises the interaction between the participants" (Polak and Green, 2016, p. 1639). Given the concept of candidate events as triggers facilitating holistic assessment, the merits of joint interviews were particularly suitable for this piece of work, since the shared views of participants were important to understand (Polak and Green, 2016) and the relationship between participants, socially defined (Morris, 2001).

Despite their usefulness, Torgé (2013) has identified certain criticisms of joint interviews, claiming that participants may be less candid and willing to talk about sensitive issues, especially if one partner is dominating the conversation. Thus, any potential conflict may be underplayed. It is also possible that only couples with good relationships will participate in joint interviews and as such, feel compelled to present a positive front (Morris, 2001). Joint interviews also run the risk of one partner inadvertently disclosing something to their partner that is potentially harmful (Morris, 2001), but as Polak and Green (2016) consider, a couple choosing to have separate

interviews implies that they have secrets, which could also cause conflict. In view of these issues, it was decided that offering individual or joint interviews would lend a "small degree of empowerment" (Morris, 2001, p. 556), to the participants, and so the research team employed this method.

Interviews ceased when no new significant findings were emerging from the data analysis, which occurred concurrently with interview data generation. This point of saturation does not only refer to when "no new ideas are coming out of the data", but also to the notion of a conceptually-dense, theoretical account of the field of interest (concept of triggers and holistic assessment), in which all categories have been fully accounted for, the variations within them explained, and all relationships between the categories established, tested and validated for a range of settings (Corbin and Strauss, 1990, pp. 181-93).

5.2.5 Data Analysis

5.2.5.1 Thematic content analysis

This qualitative approach is a method of textual investigation of the content of the data to categorise the recurrent or common themes (Silverman, 2005). This approach is commonly used in health-related, qualitative research and aids data interpretation when views from particular groups (such as patients, carers and professionals) are required (Green and Thorogood, 2004, pp. 176-177). The researcher examines the data (such as interview transcripts) and categorises respondents' accounts, summarising through a comparative process, the various narratives and then classifying them into themes that are common or recur in the data sources (Green and Thorogood, 2004, pp. 176-177). There are various methods by which this process can occur but, in this part of the study, interviews were digitally recorded, anonymised and checked for accuracy and then the transcribed interviews were subject to manual analysis initially. This was then assisted with NVivo10™ computer software (QSR International, 2012) to support this process. Coding schemes (a list of code names to apply to the data), were developed by reading through the early data to identify key themes that were then labelled, or coded (Green and Thorogood, 2004, pp. 176-177).

The crucial requirement using this strategy is that the categories are sufficiently precise to enable different coders to arrive at the same results when the same body of material is examined (Berelson, 1952). Therefore, thematic content analysis pays particular attention to the issue of transferability and auditability i.e. developing an audit trail of coding and analytical decisions that can be understood, ensuring that different researchers use them in the same way, as well as enhancing the credibility of the findings through the precise use of words and phrases (Guba and Lincoln, 1994, pp. 105-17). In this piece of work, a coding scheme was developed from the empirical data (interview transcripts), but elements were predetermined by the research question and others added as the data were analysed. The advantage of using this type of analysis is that it allows for the exploration of relationships between the themes that have emerged as well as the context of particular codes. This facilitates a deeper understanding of the social life of the respondents, so identifying what participants have said as well as providing a rich description of the setting studied. Again, this links with Mason's (2008) theoretical framework, as discussed earlier, since when analysing the complexity of a situation, several concepts need to be considered, all of which can contribute to understanding social processes in action (Mason, 2008, pp. 45, 117). This in turn provides a credible account of "what is going on" within the empirical data and the themes identified (Green and Thorogood, 2004, pp. 176-177).

5.2.5.2 Process of the analysis

All interviews were digitally recorded and transcribed verbatim. The handling of the data has been described in Chapter 2 under the methods section outlining thematic content analysis.

Transcripts were coded and then shared with the wider research supervision team (HP, JB, DO) to discuss emergent themes and to aid data synthesis and interpretation (Mays and Pope, 2000; Emslie *et al.*, 2005).

5.2.6 Reporting

The research process, in its systematic reporting, adhered to what respondents had discussed and required further exploration to gain greater depth and understanding of their experiences (Silverman, 2005; Corbin and Strauss, 2008). The transparency in the reporting of the study ensures no falsification, fabrication, suppression or misinterpretation of the data (RESPECT Report, 2004).

The consolidated criteria for reporting qualitative research (COREQ) checklist, as previously discussed and used in Chapter 3 (Section 3.2.5: Reporting) was again employed to ensure complete and transparent reporting (Appendix A: COREQ checklist).

5.2.7 Ethical Considerations

5.2.7.1 Ethical approval processes

This part of the study was approved by the University of Kent's Ethics Committee, South East Coast-Kent National Health Service, Local Research Ethics Committee (11/LO/1357) (Appendix H: LREC approval letter).

5.2.7.2 Consent

Participants were approached by their healthcare provider (a nominated person at each healthcare provider's organisation coordinated this process) initially, with an invitation letter co-signed by both the provider and the researcher (Appendix I: Invitation letter). The individuals were contacted by post with the invitation letter, participant information sheets (Appendix K) and reply slip (Appendix J), along with a self-addressed envelope that they returned to signify their willingness to take part in the study. Only then did contact with the participants occur. At this point, potential participants were offered the opportunity to ask any questions pertaining to the study before they agreed to participate. Patients, and if a carer was nominated, agreed a mutually convenient time for the interview to take place. This allowed participants the ability to not feel under coercion to take part in the study and enough time to process the required information. At the interview, written,

informed consent was obtained, detailing the issues of voluntary participation, so participants (patients and/or carers) were free to withdraw at any time from the study and this would have no impact on the regular, clinical care they were receiving (Appendix L: Consent forms for patients and carers). Also explicit in the discussion was how the data would be handled, so the interviews were to be recorded digitally, transcribed verbatim and anonymised so that any direct quotes used for publication could not be traced back to an individual participant. Participants were also informed of the data and research governance requirements that would underpin the conduct of the study. If patients so wished, their general practitioner and/or referring team were also informed of their participation in the study.

5.3 Results

5.3.1 Participants' Characteristics

Twenty-two patient participants were recruited and of them, eight identified carers who were also recruited. This recruitment was as a result of sending a total of 350 recruitment packs to the different organisations and teams. Of these eight participant-pairs, both parties identified themselves as a dyadic unit and as such, they all agreed to be interviewed together. The interviews took place in the patients' homes with their carers present throughout the entire interview. This was with the patients' explicit consent. Table 10 identifies the participants' characteristics, along with those of their carers.

Table 10: Patient and Carer Characteristics

Patient identifier (and carer)	Sex	Age	Marital status	Carer identified	Carer interviewed	MRC score	Oxygen dependent
I01	Female	69	Widow			3	
I02 (I02 daughter)	Female	82	Widow	Daughter	Yes	5	Yes
I03	Male	65	Married	Wife	No	4	
I04	Female	78	Widow			4	
I05 (I05 husband)	Female	74	Married	Husband	Yes	4	
I06 (I06 wife)	Male	84	Married	Wife	Yes	4	Yes
I07	Female	76	Married	Husband	No	4	
I08 (I08 husband)	Female	68	Married	Husband	Yes	4	
I09 (I09 sister)	Female	66	Single	Sister	Yes	4	
I10	Female	83	Single			4	
I11	Female	83	Single			5	
I12 (I12 wife)	Male	70	Married	Wife	Yes	4	
I13	Male	74	Married	Wife	No	5	
I14	Male	85	Single			5	Yes
I15	Female	75	Single			4	
I16	Female	70	Married	Husband	No	3	
I17	Female	73	Single			4	
I18 (I18 wife)	Male	77	Married	Wife	Yes	4	
I19	Male	65	Single			5	
I20	Male	68	Married	Wife	No	3	
I21	Female	80	Widow			4	
I22 (I22 wife)	Male	76	Married	Wife	Yes	4	
	F=13 M=9		M=11 S= 7 W= 4	Carer identified = 13	Interviewed = 8	3=3 4=14 5=5	N=3

5.3.2 Overview of Findings

The responses of patient participants and their carers were grouped into the following themes:

1) 'Living with the experience of COPD', with the subthemes of *understanding their condition*, *adaptation* and *resignation and resilience*; and

2) 'Perceptions of the concept of triggers', with the subthemes of *the personal visibility of triggers*, *views of professionally-constructed triggers* and *the relevance of a holistic assessment.*

Figure 9: Overarching Themes from Participants and their Carers

Chapter 5 Results
Overarching themes

Understanding of their condition

5.3.3 Living with the experience of COPD

Adaptation

Resignation and Resilience

Themes

Personal visibility of triggers

5.3.4 Perceptions of the concept of triggers

Views of professionally constructed triggers

Relevance of holistic assessment
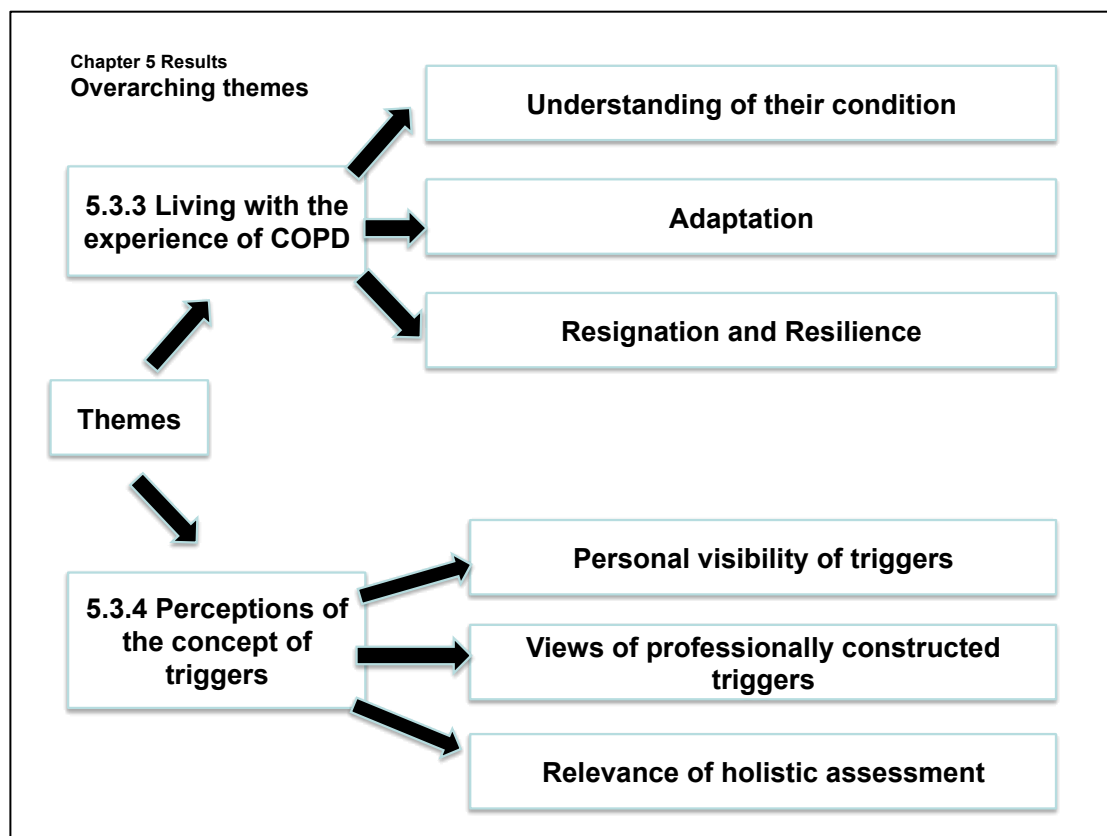
5.3.3 Living with the Experience of COPD

Understanding their condition

Some patients did not seem to fully understand what 'COPD' meant and were confused by the term when they heard it was their diagnosis:

> "*I saw my notes and it had got 'COPD' on them. Well I didn't know what that stood for and I asked... 'What's this? I've never heard of it. Nobody's ever told me I've got COPD.' But they wouldn't sort of explain anything to me. They just said, 'Oh it stands for Chronic something Pulmonary Disease. But chronic doesn't mean it's terrible, it just means it's long-lasting' and that's all they told me… but I feel nobody ever said... you know, explained to me what it was… It was almost sort of brushed aside.*" [I21 (patient)]

> "*I had a phone call from my clinic that I'd signed on with saying, 'Mrs [interviewee surname], because you've got COPD, would you like a flu jab?' And I said, 'I'm sorry? I don't know what COPD is' and I didn't. Oh right. Oh.*

Okay. And she said 'I think you'd better come and see the doctor.'" [I16 (patient)]

"… they don't seem to explain anything. I mean he said I'd got this... what was it? What is it? CPOD? Well I've not really had any dealings with it, really, to be quite honest." [I17 (patient)]

Participants suggested that the wider societal view was that COPD is associated with smoking and as such, patients felt as if they were to be blamed for the illness:

"I know there's a lot of public information about that particular disease (diabetes) and more so for Alzheimer's now and all the different type of cancers, but for COPD, it doesn't seem to be... you know... a lot of people would say 'What on earth is COPD? What does it even stand for?' it's not very self-explanatory, is it? And also, I think public... as soon as people... as soon as you say that mum's got lung disease, they associate it with it being a smoker." [I02 (daughter)]

Adaptation

Despite the very clear impact of breathlessness on daily functioning, patients had adapted to carrying out their daily chores. Individuals themselves had looked at alternative approaches to completing tasks so that professionals were not necessarily alerted to the fact that these issues were potentially problematic for patients:

"I couldn't do anything generally. I mean I could bend down and do my laces up and then I'd just sit up again and just go into a coughing fit and my chest would go... that's why I never use laces now. I use these Velcro." (I19 (patient)]

"Then I'll get up and do that room and then I will sit down. I do everything at my own pace… I suppose because I've had it such a long while... I know what I'm doing and what I'm not doing… I will try little things, but I know my limits – my limitations – and I don't go above that… I am the sort of person that I grin and bear it." [101 (patient)]

"*Every day is an effort… once I get started, I'm okay… I don't like the fact that I'm not coping properly… well I'm not coping because I'm not doing what I want to do, what I would like to do… I get satisfaction from when they're done.*" [I04 (patient)]

Patients were already adapting to their functional ability and struggled to delineate between the changes that were directly attributable to their COPD and those that were a result of multi-morbidity or indeed, just signs of getting older:

"*It's a combination of COPD and old age. Sure. But working out what the demarcation between the two is very difficult.*" [I18 (patient)]

"*I know a lot of people don't... don't like to face what their prospects are with different illnesses and ailments and so on and I know the prospect of COPD, the long-term prognosis is not good. It's not a nice way to finish your life but with my blood pressure I'll probably have a heart attack anyway so...! The lesser of two evils! It is a combination because even if my breathing was a hundred percent, I don't think I would be able to do the things I used to do.*" [I20 (patient)]

At times, participants appeared to exhibit a certain stoicism in managing their condition; plodding along rather than asking for help:

"*There's nothing I can do about it!*" [I11 (patient)]

"*Yeah, I mean you adjust! You will find a way!*" [I13 (patient)]

"*I know I'm getting older and there's nothing you can do about it; no creams or tonics or anything that's going to make any difference… the elixir of life, I haven't found it yet!*" [I22 (patient)]

Help, if it were sought, would generally be provided by family members or local support networks, especially for the day-to-day variations in general functioning. This could range from needing physical help with the garden or shopping, to more emotional help, so the person they could call upon if they were having a bad day:

"You just feel like you're fighting a losing battle [seeking help] *… my wife I can talk to her better than I can talk to anyone else… I'd sooner sort of run things through her before I went anywhere…"* [I03 (patient)]

"I don't want to be reliant on anybody coming in and doing anything… my partner does do a few things for me when she's down here and... she'll do the potatoes and the vegetables and things like that. She's very good. She's an ex-carer so she does know what's happening. So, she knows." [I19 (patient)]

Participants' experiences of asking for help from professionals, appears to have been disappointing and verged on the ambivalent at times. This resulted in a lack of consistency and assurance as to whether patients and carers would seek professional help at all. Some patients felt uncomfortable discussing certain aspects of their illness with their GPs, whilst others did not feel empowered to ask the right questions during a consultation. One participant also remarked that consultations with their doctor tended to focus on the physical side of their illness as opposed to the psychological and emotional, so that they usually ended up with a prescription for a pill they did not want nor need:

"Well I would bother the GP if I thought I was welcome to go and talk about problems, but you don't get that sort of impression. You know… it's not put over to you that way; you come here if you're sick. But of course, there's more ways of being sick than just sort of physical. You just... you bumble along, you know. I mean I would sooner have treatment that way where you're self-treated through, say therapy, just joining a club than medication. They give pills to horses – you talk to people." [I03 (patient)]

"It may be psychological more than physical medicine but nevertheless to them [the patients] *it is important and obviously aggravates their condition and I guess GPs generally are just so busy that they don't pick up on that."* [I06 (patient)]

"Because you're not told... we're not told much more, are you. You're only told if you ask. Yes, but a lot of people don't tend to ask, do they? And some people, they... they go and see a professional about something, they come out and think oh, I should have asked so-and-so. So, it ends up, you know... that's human nature, isn't it!" [I22 (patient)]

Resignation and resilience

However, it was very clear that some activities were becoming too much for individuals, despite their best efforts. There was a sense of "weary resignation" rather than of anger or frustration:

> "*You know, I get out of breath so easy because... I'm sixty-five. I don't really consider I'm that old… I'm just resigned now to making the best of what I've got. Yeah. So... I'm probably beyond wanting help.*" [I03 (patient)]

> "*I keep going whatever… Mind you, that's probably because I'm getting old and I can't do the things that I used to be able to do. I used to love running around. I think I get very tired. Very tired very quickly… We're not the sort of people to give in. We just battle through*" [I05 (patient)]

> "*Well… I wouldn't tell anybody… yeah. And I suppose it's back to that view is that I suppose you... get on with it! Well we're that age group, aren't we?*" [I16 (patient)]

Participants had a very strong sense that their breathlessness would not get in the way of them managing day-to-day and were determined to carry on fighting:

> Patient: "*I do everything at a slow pace anyway… if you say a disablement or whatever you like to call it and you... adapt accordingly... adjust to it… I keep pushing because I'm not going to let it beat me… If I sat on my backside I would go downhill rapidly…*

> Wife: *He's stubborn, you know, and I said… 'It takes you so long to get up those stairs.' He was crawling up the stairs, you know.*

> Patient: *No… No… No… my bed stays upstairs!*" [I08 (patient and wife)]

To this end, participants had recalibrated their expectations in terms of their level of activities and were realistic about what they could achieve day-by-day:

> "*Well, I don't let it get me right down because there's no point in that, is there, especially if you do live alone. I mean you're just going to be miserable, aren't you, so you try and... well, that's when I put the music on or do something*

else, you know… I'm sort of quite happy as I am jogging along… I mean... I've just got used to being comfortable with it." [I10 (patient)]

"But it's just the fact that I don't get them done… that's almost classing me as disabled and I'm not. I mean I know damn well that... I get out of breath. I know if I'm in the garden, if I empty the dustbins I'm puffing and blowing. But then, I forget about it, you know. Okay. I just push it to one side because I'd rather... do things… I mean... I managed... I struggled, mind you, but I did manage to get my potatoes put in this year, but nothing else. I'm so pleased when I've done the things and I'm so fed up with myself when I haven't been able to do the things… it is sometimes just the small things, yeah." [I04 (patient)]

"I'd just plod on, really. When you're on your own, you've got to get on with it." [I17 (patient)]

5.3.4 Perceptions of the Concept of Triggers

Personal visibility of triggers

The significance of triggers appeared questionable, especially when trying to distinguish between triggers that were COPD-related and those that were merely a result of old age:

"It's… confusing at our age... getting older if you... meet people who haven't got COPD who won't have a bath because they find it very difficult to get out of the bath because their back aches, their knees ache etc. So, whether you put it down to COPD or just getting older I don't know… it's then working out how much of it is down to the COPD and your incapacity… or your age!" [I18 (patient)]

Initially, when exploring participants' thoughts around the concept of triggers, it was apparent that it did not appear to resonate with them. It felt quite meaningless and rather abstract:

"Well I think that would be a good idea but I would wonder what other things that might happen... to let me think that way, so it's getting worse, you know… if anything got worse would that be a time to trigger off an MOT [a

holistic assessment] *but what I'd like to know is what do I look for that's going to get worse?"* [I14 (patient)]

"*What would trigger… an MOT* [a holistic assessment]? *That's a question. I don't know."* [I19 (patient)]

Patients experienced good and bad days and so felt they would struggle to distinguish between what was a day-to-day variation of their needs and an actual deterioration in their condition that would therefore trigger a holistic needs assessment:

"*I don't know how to sort of answer that. Whatever I do I can't stop anything coming on… I mean... I can plan the day, but it's just a moment-by-moment situation… I mean some days you can get up and you can be brilliant. And other days you can get up and you're not and anything in between. Planning something… carrying out a plan, sometimes I can't do.*" [I03 (patient)]

"*... I don't go and say 'Oh I've had a bad day today...' or... I just think 'Well it's just another day... it's just normal. Day-by-day, quiet day'. It's the way I'm going to be and that's the end of it."* [I22 (patient)]

"*One needs to distinguish between day-to-day variations and a measure of deterioration."* [I06 (patient)]

One patient felt that he had adapted to this new 'normal' of not being able to do activities by avoiding doing them. In this way, his debility would never be alerted to a professional's radar of concern, given the insidious and constant adaptation to his limitations:

"*You gear your life down to your breathing without noticing sort of how you are slowing up. Like a fail-safe system you automatically adopt; I don't like doing that so I shall avoid doing that in future. You just gauge your... gear your life to your problem, you know... but... and just hope it doesn't get any or much worse… so whether you put it down to COPD or just getting older I don't know… again, you just think 'Oh I don't enjoy that so I'll avoid having a bath and I'll have a shower instead'.... you've got restrictions on what you can now do... but progressively over the years you get accustomed to them and you adjust your life accordingly."* [I18 (patient)]

Participants struggled to endorse the suggested events as triggers unless they had experienced them personally for themselves, therefore questioning their significance.

Requesting a 'disabled' parking badge ('blue badge')

A disabled parking badge ('blue badge') echoed strong support, resonating with participants whom endorsed it as significant and very useful. Most participants had received their badge some time ago but refused to see this as a barometer of their deteriorating functional ability, resulting from their respiratory disease. Some participants however, identified that they would struggle to know when and how to apply for a badge:

> *"You've had your blue badge for a long time... and you have to actually speak to the doctor about that anyway. You have to have a report from the doctor and I would have thought that... possibly the doctor could trigger an assessment then. It might be... useful at that point because otherwise what we're doing is we're just leaving it until there's a crisis every time."* [I02 (carer)]

> *"I suppose it would help as well because I wouldn't know when I would be eligible for a blue badge."* [I01 (patient)]

> *"The blue badge... just never thought about getting one or trying for one."* [I12 (patient)]

Interestingly, only two patients perceived the 'blue badge' in a negative context, one claiming that the badge itself is open to abuse by individuals who take advantage of the system, and the other feeling that they were not sufficiently disabled to deserve it:

> *"I don't believe in blue badges, really! To be honest… I think some people take advantage of them."* [I17 (patient)]

> *"My wife... keeps saying, you know, "You really ought to get a blue badge," but I don't feel really that... I'm bad enough... to be absolutely honest I think*

I'd be a bit of a cheat if I... can walk the distance to get from a car park to the supermarket and not use a disabled bay." [I20 (patient)]

Overall, participants had a variety of responses in terms of their experience of the disabled parking badge, but the lack of discussion about the feasibility of its significance to act as a trigger for the holistic assessment of needs, was very evident.

Home adaptations

In terms of home adaptations, some patients had already begun this process and were not seeking professional advice on any changes or acquisitions they had made. Patients reported a change in their hygiene routine from having a bath to a shower, attributing this to a functional decline but not necessarily exclusively to their COPD:

"I took the bath right out because I couldn't get in and out of it and I've installed a large shower. A bubble shower so that when I'm in a bad way, my Mrs can get in the shower and sort of see to me in there, rather than sort of try and reach in." [I03 (patient)]

But I'm a person that would adapt my home myself! I went out and bought a bath seat. I've, you know, adapted things... I've done it… if someone comes in here... I mean if we hadn't have told you that we'd adapted them steps you wouldn't have known. You wouldn't have known." [I08 (patient)]

"I've got a thing over the bath to help me in the bath. I couldn't do it otherwise. I've got a bath-mate. And I've ordered a frame myself to buy… I've just had a new bed which is lower so I can get in and out of that okay. And it's an electronic bed; it goes up, you know." [I11 (patient)]

Participants had, through a variety of sources, different degrees of adaptations to their home. However, as with the blue badge, the lack of resonance with the patient participants as to whether these adaptations were considered a trigger for the holistic assessment of needs, was telling.

<u>*Hospital admission*</u>

Hospital admission as a candidate event received mixed responses from participants. Some individuals had never been in hospital and wanted to avoid it at all costs, whereas others felt it was very significant, but happened relatively infrequently:

> *"I don't want to go into hospital... we've got that agreement. We've spoke*[n] *about that long and hard. Okay. And we're not going. It's as simple as that. I'd sooner end my days here."* [I03 (patient)]

> *"Being brutally honest, I'm not sure it would happen... I have never been admitted."* [I06 (patient)]

> *"In the early days I was hospitalised a couple of times with it… that doesn't really apply to me at the moment. Yeah. So, it's difficult for me to give an opinion on that."* [I20 (patient)]

Others felt that hospitalisation was a response to an acute exacerbation of their illness and as such, did not address their longer-term needs:

> *"You go into hospital... well it was an emergency because I couldn't... just couldn't breathe but then they only just sort of treat you at that time. They don't say review your inhalers or anything like that. They just say 'What are you on?' and you just... well you take it with you and they see what you're on. I suppose that... they don't give any further treatment to what they think."* [I17 (patient)]

The varied responses to hospital admissions from participants within their experience of COPD, was in stark contrast to those reported by professionals (Chapter 4). This highlights the difficulty with either the selection process of the trigger events identified and presented to participants and/or more likely, the challenges that exist with the concept of a triggering process for the holistic assessment of needs.

<u>*Appointment frequency*</u>

Participants were adamant about keeping professional appointments, and would cancel in advance if for some reason they were unable to attend:

"Not unless I've been ill which I haven't been but no, I would never miss an appointment because I think it's abusing the system but people do." [I16 (patient)]

"Always go for appointments. Always. You know, never, ever... unless there's something then I'll phone up and change it but we never miss an appointment do we." [I22 (patient)]

However, participants suggested that a change in the pattern of their attendance, so for example, requesting more home visits rather than physically attending the surgery, might prompt further exploration, with the potential for a holistic assessment of needs:

"... 'I need a doctor but I can't get down there for the appointment' you would have thought that would automatically trigger with your doctor there's a problem. That is important, actually. You know, 'I'd better look into this a little bit more because they can't get down here, it's obviously a bit more than a sort of bad cold'. No, that is important. It's very important." [I18 (patient)]

"But if it happens a second time, then there's something... there's a problem there somewhere... that should flag up something... or as you say, trigger it to say 'Oooh, [patient's name] *been here a few times. What's the problem?'"* [I01 (patient)]

Housebound

Being housebound was acknowledged by one participant as significant but otherwise was not a situation that participants felt able to comment on. One patient remarked on how his wife was a driving force, ensuring that he did not acquiesce and confine himself to the house:

"Well I'm not housebound, no, because my wife has a big bearing on that because she makes me take her to work in the morning and she makes me pick her up in the afternoon. She makes me take her shopping. I can still drive the car, so I am... I've got mobility that way. Okay. And I've got incentive to get out of the four walls. Yeah, she is a big driving force." [I03 (patient)]

Daughter: *"If it got to the point where they couldn't get out of their house, it would it be useful to them to have a big assessment of their health at that*

point to see what... what assistance? Do you think that's right? Do you think that's a good idea?"

Patient: *"Yes. I think so. Yes, I do."* [I02 (patient and daughter)]

<u>*Patient and carer identified events as triggers*</u>

Patients and carers identified that they had modified certain activities to accommodate changes in functional ability and these ranged from taking holidays abroad and walking holidays, to restricted social activities and hobbies. The need to change was for most, a natural progression of their increasing functional debility and ageing. However, participants did not seem to identify these changes as significant and visible within their COPD illness, or indeed associate them as a trigger, highlighting deteriorating function and therefore prompting a holistic assessment of their needs:

> *"But you slow up generally and stop doing the things that obviously cause you distress whatever and then when people say to you, 'Oh what causes you distress?' you think 'Oh God, what does cause me distress?' because you haven't done them for so long because you've avoided them. So yeah, we don't go on holiday because of my COPD but we don't go on holiday for a host of other reasons. Yeah… it's age and COPD."* [I18 (patient)]

> *"Worst thing is I had to give up driving a car which I hate because I'm just dependent on my family or, you know, others taking me out. And then when I go out I can't walk far."* [121 (patient)]

One carer remarked on the issue of non-compliance with medications as potentially being a trigger point for a holistic assessment of needs:

> *"At the moment the thing that concerns me most is that mum doesn't take her medication regularly so if... you know, something needs to be looked at, at that point, if medication is not re-ordered, or some notification is given to the GP that medication's not being taken."* [I02 (daughter)]

Whilst another patient highlighted the significant volume of medications they were taking as a potential cause for concern:

> *"I've got seventeen different pills."* [I19 (patient)]

<u>*Relevance of holistic assessment*</u>

The majority of patients struggled with the concept of a holistic needs assessment in the context of triggers. This appeared quite an alien notion and as such left them quite challenged to articulate what their needs were:

> "*And I guess GPs generally are just so busy that they don't pick up on that… that would be good* [a holistic assessment]. *Generally, professionals – healthcare professionals – are so busy and they have such a... heavy schedule… they don't have the time to sit down and talk about where they* [the patients] *are emotionally, psychologically or... other elements of... their life, quality of life and how they're actually feeling in themselves… so it may be... psychological more than physical medicine but nevertheless to them* [the patient] *it is important and obviously aggravates their condition.*" [I06 (daughter)]

> "*So, in actual words, you're reversing the role of you... you're broadening the outlook of what else can be needed… they're* [the professionals] *not actually asking the person how they actually feel.*" [I01 (patient)]

> "*You're only told if you ask. Yes, but a lot of people don't tend to ask… no… no... and some people… they go and see a professional about something, they come out and think 'Oh, I should have asked so-and-so.' So, it ends up, you know... that's human nature, isn't it?*" [I02 (daughter)]

One patient remarked that if she was "prompted" she might divulge the impact of the breathlessness on her everyday life, but similarly if asked, how she was feeling, she would respond with "I'm feeling fine". This was echoed by other participants who were reluctant to willingly volunteer information about the more generalised, day-to-day impact of their breathlessness, unless they were explicitly asked:

> "*If somebody prompted me... you know, I'd sit there and say, 'Yeah, I'm having a bad day' or 'I'm having a good day' but if somebody* [asked] *'Well yeah, but how are you coping at home?' you know, 'Do you do this? Do you do that?' and I'd say 'Well no I don't' or 'Oh yeah...' I find that hard... if you're going every six months or, you know, then instead of you saying 'Oh yeah,*

everything's okay', you'd say 'Well... you know, I'm having a bit of trouble with whatever.'" [I06 (patient)]

"I think it is… it's sort of looking at the whole... it's not just dividing it up... yes… it's looking at the complete [picture]*... I mean if you're doing an assessment you want people who sort of got problems that you can help. Well I suppose… at the moment I've come to terms with my problems. So, the idea is that rather than you having to see ten people, that one person can actually get an overview… one doesn't always know what's available."* [I21 (patient)]

One carer likened the process of holistic assessment to their experience of attending their annual cardiology review and clearly, unless asked and probed, would not voluntarily talk about the wider impact of the condition on their everyday living:

"*Yeah so classic example is when... I go up every year for my ticker and* [named doctor] *always says to me, you know, 'Are you... short of breath?' I say 'No. I'm okay' you know. 'What about this? Any ankle swelling?' you know. He asks the questions that to me... it's a natural thing that he's going to ask me... it's something that'll... it's on his little book, but... you wouldn't say if your ankles were swelling… no, I wouldn't. No.*" [I08 (carer)]

The majority of participants seemed quite shocked that a health professional would be interested in their general wellbeing and concerned with subsequently exploring the possible remedies to the issues they identified:

 "*Well I would bother the GP if I thought I was welcome to go and talk about problems, but you don't get that sort of impression... you know, it's not put over to you that way, you come here if you're sick. But of course, there's more ways of being sick than just sort of physical."* [I03 (patient)]

Only three participants had experience of holistic assessment in previous situations. Two participants were involved in a research project exploring the effects of singing on their wellbeing and they were asked specific questions about their psychological health, as opposed to questions concerning the physical dimensions of their condition and its impact. Another participant had experienced holistic assessment in relation to her father, who, having had

mental health issues in the past that had a negative impact on his general health and wellbeing, had a structured, holistic needs assessment from the local mental health service, commonly known as a continuing healthcare needs assessment (CHC assessment (2012): https://www.continuing-healthcare.co.uk):

> *"With this singing trial... through the trial, I think two or three times… we have to complete a questionnaire about how it affects our day-to-day living, whether we got depressed or not and things like that. And, you know, that question kept recurring… 'Does it make you depressed?' And to some extent it does, you know... I don't like the way I am."* [I20 (patient)]

> *"I felt that when a mental health patient, i.e. dad, had a needs review assessment done in the* [Psychiatric unit], *I thought that was extremely thorough and very clear, very transparent in what was put there and that then went through to the NHS Continuing Care Fund panel and their way of measuring things and putting numbers against things was easy for me to understand… there was some sort of measurement that you could look at to assess where that person's need is at a that particular point. I thought that was really well done and I don't know whether you could do that in terms of respiratory and COPD."* [I02 (daughter)]

When participants were alerted through the interview process to the wider impact of breathlessness on their everyday living, they acknowledged the utility of professionals adopting a holistic assessment of their needs:

> "*I would like either a six-months or a year for you to go to a doctor's, or go somewhere and someone say to you 'Right, how have you been in this last year?'… Like being proactive… and it's following up and that because sometimes you can slip through the net…"* [I01 (patient)]

> *"But an objective view is always helpful… I guess that would helpful... it would be a measure of... where I am health-wise… rather than me needing to work them out for myself... or struggling on for a time before anybody says anything. So yes… I can see that. Even if he* [the GP] *said, 'Look, you're really not too bad. You're doing quite well. Don't worry about it. Go home and get on with life as best you can.' But... but we just don't get that sort of input."* [I06 (patient)]

Participants welcomed the idea that professionals could, at regular intervals, adopt this more proactive and holistic approach to assessing their needs. They felt this would act as a useful barometer of how they were doing from one time point to the next, as well as providing an opportunity for professionals to ascertain if they required any additional interventions:

> *"It's difficult to think of anything that can be done that isn't being done without knowing what the alternatives are that can be done… I think everything that happens - the various spirometry tests... and lung function tests and so on – they seem to fit the bill for the condition but if there's anything I don't know about then clearly, I don't know about it. If there's anything... any other options… some people just don't want to know what's happening to them. They just want to get the medication just sorted out... the professionals dealing with the individuals ought to recognise within that individual whether or not they can give them a bit more information and involve them more."* [I20 (patient)]

> *"I think it is… it's sort of looking at the whole... it's not just dividing it up sort of it's looking at the complete* [patient].*"* [121 (patient)]

Patients and carers consistently recalled the breathing test (spirometry) that they are required to attend annually and how this may be a good opportunity for professionals to perform a more holistic assessment of their needs:

> "*Every six months, I think it is... I always have a spirometry test done… I get that done beforehand so all the results are there when... he looks at it. And they tested my chest and whatever because it was COPD. That's the only thing... that's been done, really."* [I01 (patient)]

> "*I go once a year… she'll ask me how I'm getting on and how I'm coping and then… like this last time I went down I said that I thought my breathing was worse than it has been and she tested it and I'm down to thirty percent now. Yeah, I'd like… a copy of that just to watch the decline!"* [I08 (patient)]

In trying to understand a holistic needs assessment, participants likened it to a 'respiratory MOT'. They welcomed the idea of having a regular, yearly review that focused on their wellbeing and the more holistic enquiry into the multi-dimensional impact the condition was having on their lives. Using the analogy

of an MOT, participants remarked that an assessment could provide a benchmark for the next assessment. This would prove very useful as a progress report in "keeping a check on things":

> "*Yeah. MOT is appropriate, really… I think that would be a good idea!*" [I14 (patient)]

> "*An assessment… like an appraisal… a MOT sounds fine to me. I mean the reason why… MOT is that, you know, it's almost like a standard. Everybody knows what that means.*" [I22 (patient)]

> "*If you were to think about you go for your breathing test every year that it would be helpful to get a fuller picture by asking some of these questions to see how it's affecting you on a day-to-day basis and see if there's anything that... can be offered to try and help.*" [I21 (patient)]

5.4 Discussion

5.4.1 Summary of the Findings

The substantial and increasing burden of disease, whilst apparent and significant to patients and carers, was often rendered invisible because of the 'normalisation' of the slow, progressive nature of the disability, coupled with the day-to-day variation of symptoms and adapting to the restrictions it imposed. An approach that utilises events to trigger a holistic assessment of the supportive and palliative needs for patients with severe COPD and their carers, was a new concept for participants to consider. The previously identified candidate events had little resonance for participants in this study but the broader concept of having a more proactive and structured approach to assessing the holistic needs of patients and their carers was welcomed. Patients identified their yearly breathing assessment (spirometry) as a significant and visible interaction that could potentially have utility for themselves and the professionals involved in their care in terms of conducting a holistic assessment of needs (respiratory MOT).

5.4.2 Strengths and Limitations

This study evolved from work that developed the concept of using triggers within the severe COPD disease trajectory and events that had the potential to enable a more holistic assessment of need. The importance of checking the feasibility of any new approach with the individuals (patients and carers), who will be directly affected, is crucial so that the novel approach develops in a robust and sustainable way. As was discussed at the beginning of this chapter, in the theoretical framework of Mason (2008), in order to "build effective dynamic models, one needs to know not just what people do, but how they do it, [and] how they might imagine things being different" (Mason, 2008, pp. 45, 117). The findings here suggest that the concept of triggers has little resonance with patients and their carers. Indeed, they referred to augmenting their current provision, as opposed to favouring a new approach, thus highlighting that what may be a worthwhile concept for professionals, does not necessarily translate into the patient and carer arena.

Participants that were dyads in terms of a patient and carer unit, had joint interviews. This approach can be particularly suitable when the research question relates to a "phenomenon that is empirically a shared one" (Polak and Green, 2016, p. 1647), and as this study aimed to explore the concept of triggers within the severe COPD disease trajectory, joint interviews were deemed appropriate since both the patient and their carer were affected by the condition. The criticism that participants may be less candid in joint interviews or be unwilling to talk about sensitive issues did not seem to impede the discussions. However, the researcher was aware of some individuals dominating the conversation at times and conflict might have been underplayed (Torgé, 2013). Offering individual or joint interviews lends a "small degree of empowerment" (Morris 2001, p. 556), which both patient and carer participants were given in this study.

Although participants represented a broad range of demography, they may not have fully represented the diversity of people with severe COPD. All the interviews took place in East Kent, and as such, the findings might not be directly applicable to other geographical settings. Despite purposively

sampling participants from all care settings, those who were receiving predominately secondary care were not represented in this study. Participants were identified by the clinicians involved in their care and so they had the opportunity to screen patients whom they felt might not be able to complete the study, given the severity of their illness. However, these might be the very patients that research such as this needs to target, since understanding their perspectives on a holistic assessment of need is vital when investigating a novel concept of improving service delivery. However, the evolution of services that offer a palliative care approach should have a universal application to models of care delivery (Hall *et al.,* 2011; WHO definition of palliative care, 2013).

5.4.3 Interpretation with Reference to Existing Literature

The findings within this study echo the breadth of literature identifying the supportive and palliative care needs of patients and carers within the COPD disease trajectory (Gore, Brophy and Greenstone, 2000; Habraken *et al.*, 2007; Lanken, Terry and Delisser, 2008; Gardiner *et al.*, 2010; Pinnock *et al.*, 2011; Giacomini *et al.*, 2012; Boland *et al.*, 2013), as well as the description of needs, articulated in a much more functional language of interventions to manage the debility associated with advancing disease (Cawley *et al.*, 2014). In common with Habraken *et al.* (2008) and Giacomini *et al.* (2012), patients adapt to their debility and are often 'silent' about their situation, instead adjusting to the new norms imposed by their condition. Evidence from this study supported these findings since participants struggled to articulate their needs explicitly. Only when probed could participants see the utility of a holistic assessment process and the potential benefit to be gained from it, coupled with suggested interventions. Probing enabled participants to explore the feasibility and usefulness of the triggering approach, grounded in their own experience of living with COPD. Participants recalled their reluctance to ask for help, stemming from previous experiences that can only be described as professional nihilism; experiences that often resulted in *the prescription pad* when what people really needed was *time* and the clinician to *see the complete picture and person* and not just *their physical needs.* Kendall *et al.*

(2015) have described this anomaly from their extensive qualitative work in the field of illness narrative, in particular looking at COPD. They identified that in contrast to professionally-defined 'normative' needs, patients rarely perceived themselves as needy, accepting their 'felt' needs as the result of a disability to which they had now adapted (Kendall *et al.*, 2015). This understanding echoes the findings from this study and suggests that the perception of what constitutes a need differs greatly between professionals and patients. Therefore, greater exploration of the different and competing factors that can help articulate and visualise needs, for both professional and patient, is required. This will have important significance and utility in terms of holistic assessment and how this can be best achieved, given the prognostic uncertainty that permeates the severe COPD disease trajectory.

Events within the COPD disease trajectory as triggers for holistic assessment

The findings from this study, suggest that awareness of certain key events can have significant meaning beyond their specific significance as they point to wider, on-going, functional limitations within the narrative recall of people with COPD. Visibility of triggers is fundamental to the success of the approach but this study highlights that for the same event, such as a hospital admission, participants had very different experiences. This implies therefore, that the visibility of event triggers is not static, but instead appears as a continuum of triggering ability, ranging from none or minimal for some participants, to important or highly significant for others. Hence, from a patient perspective, the utility of this approach is limited, thus maintaining the invisibility of the insidious, progressive decline experienced within severe COPD. Furthermore, this also highlights the requirement for services to be integrated so that a whole-systems approach can be adopted to address the multi-dimensional (physical, psychological, social and spiritual) impact of advancing debility and to ensure that appropriate services identify and deliver care that is supportive and palliative in nature.

Patient identified triggers

Despite the lack of relevance of triggers to the participant group in general, patients did remark on the annual requirement for *breathing tests* (spirometry) as being an important event in their care. The approach of standardising the more holistic enquiry alongside this review, would seem an ideal opportunity. They felt this was highly visible to professionals and had significance in terms of benchmarking their functioning from the previous readings. However, more importantly was the potential utility of this assessment for clinicians to ask patients *how are you feeling?* Participants repeatedly felt this to be an important and punctuating event and likened the opportunity for a more holistic assessment of their needs to that of a respiratory MOT. They felt that this would be a standard approach, *a bit like an appraisal* and in a language that *everyone knows what it means.* Using the annual spirometry assessment, allows healthcare professionals to utilise existing processes within clinical practice to augment the systemic enquiry and have a more holistic lens on the disease, thus ensuring that patients with progressive disease are getting the supportive and palliative care approach that they require.

5.5 Conclusions

In previous chapters, events that punctuate and traverse the COPD disease trajectory were identified with the potential to trigger a holistic assessment of needs, both palliative and supportive in nature. The concept had some resonance with professionals from previous work (Chapter 4) but there was considerable debate about how feasible this approach would be across different disciplines and settings. The evidence in this chapter, clearly highlights the fact that patients and carers struggled with the concept of events as triggers, given the varying degrees of visibility, clinical significance and utility the events had within their everyday lives. The insidious nature of progressive, functional decline and the steely determination of participants to maintain their independence, may have contributed to this perceived lack of utility and significance. Visibility of candidate events (hospital admissions, becoming housebound, home adaptations, acquiring a disabled parking badge ('blue badge'), altered pattern of appointment frequency) had little

significance again with patients and carers. Therefore, the most significant finding from the study was that patients and their carers valued the holistic enquiry of their needs. They struggled to embrace the suggested events and the concept of triggers, whereas the opportunity to utilise existing routine reviews, such as the annual spirometry breathing tests as a means to facilitate holistic assessment of need, was welcomed.

5.6 Implications for the Next Stage of the Research

Within the delivery of care for patients with severe COPD and their carers, the concept of events as triggers for holistic assessment of needs, had little resonance with them. The events identified, as appraised by the participants in this study, had little significance to the day-to-day experience of living with severe COPD, which questioned the utility of exploring this approach further. In this piece of work, the existing review process of an annual spirometry (breathing test) assessment, was identified as a potential opportunity to adopt a more holistic assessment of needs (supportive and palliative), of individuals and their carers.

Greater understanding of individuals with severe COPD in how they perceive and express their needs warrants further exploration and understanding. An approach that is cognisant of how individuals with severe COPD view their needs, especially when professionals are trying to shift the goal of care to a more supportive and palliative approach to their disease, is a key area for enquiry.

5.7 Chapter Summary

In this chapter, the concept of triggers was explored, as well as holistic assessment and utilising events that traverse the severe COPD disease trajectory. The potential candidate events had little resonance for patients and carers, but the more pertinent event of a yearly spirometry assessment was more meaningful for individuals. Coupled with this, was the welcomed enquiry of the more holistic impact of severe COPD on an individual's day-to-day life. This had utility from a patient and carer perspective, rather than the actual events suggested as potential triggers.

Chapter 6

Conclusions from Triggers Facilitating a Holistic Assessment within Severe COPD

6.1 Introduction

This thesis is the result of theoretical and empirical work to explore the concept of triggers within the context of assessing the supportive and palliative needs for the care of individuals with severe COPD and their carers, and the involvement of their professionals. It is essential when a concept is identified as having the potential to aid care delivery within a certain area of clinical care that this involves the individuals who will be directly affected. The approach used mixed, qualitative methodologies through different data sources to capture the multiple perspectives of patients, carers and professionals. This approach has been an iterative process. The findings are discussed from the theoretical and empirical data perspectives in an attempt to develop a coherent message, which could lead to recommendations for clinical practice.

In this final chapter, the findings will be broadly summarised into key areas and how these can be understood within the clinical arena of severe COPD care. In addition, the methodological considerations with each of the components of this piece of work will be broadly discussed, with reference to their strengths and limitations. Finally, the role of the researcher as an instrument within the self-reflexive aspect that this plays throughout the research process, will be discussed.

6.1.1. Summary of the Principal Findings

The importance of exploring any novel concept to ameliorate the challenge of prognostic uncertainty within severe COPD, is grounded in the perspectives of the very individuals and professionals that will be immersed within that care and its delivery. These perspectives will have a dynamic impact on any potential model of care and will ensure that it is useful within the current service provision. This study has identified three specific findings that

together, provide further understanding of the challenges of holistic needs assessment within severe COPD.

6.1.1.1 Finding One: The Concept of Triggers

The concept of triggers was identified through the Literature Review (Chapter 2) and the qualitative, secondary analysis of interview transcripts identified candidate triggers (Chapter 3). The hypothesis was proposed with events spanning broadly two categories; events that signify increasing burden and those that correspond to interventions addressing the consequences of advancing disease (Table 5).

The potential of this approach of triggers as well as the actual identified events, was explored initially with health and social care professionals (Chapter 4) and then with patients and their carers (Chapter 5).

Professionals' perspectives were captured using a consensus methodology of nominal group technique, allowing the concept to be explored whilst attempting to gain consensus. There was considerable debate with different professionals from different settings, identifying the opportunities with this approach but struggling with how this could be achieved within the current service delivery model for COPD. The iterative process of the rounds of scoring and further discussion helped to crystallise the utility of the concept of triggers and then identified which events were more likely to trigger an assessment of need. The thematic analysis of the comments, from the discussion raised within the workshop, identified the possibility of how this approach could be implemented alongside existing structures and processes.

The approach of using these events as triggers had some resonance with health and social care professionals. It highlighted that everyday events seen within the COPD disease trajectory can have significance and meaning and alert professionals to facilitate a holistic assessment of needs (palliative and supportive). The aim of using a trigger approach was to explore processes within the healthcare system that would be less reliant on individual clinicians. A systems-led approach, despite initially being professionally-driven, could ultimately have tangible benefits for patients in terms of prompting a holistic

assessment of their needs. In this way, what might seem to be ordinary, everyday events to patients are seen as important and significant to clinicians, thus ensuring that a holistic assessment of needs (palliative and supportive) become less professionally-centred and more person-centred to those individuals with severe COPD and their carers.

Patients and carers perspectives are key in terms of their understanding with any potential new approach to their care. Therefore, in exploring the concept of triggers and the events that may facilitate their understanding and recognition, the qualitative interviews helped capture their views. However, patients and carers struggled to understand how the events identified could trigger an assessment of need. The concept was further challenged in that the identified events had different meaning and resonance for individuals and their families, compared to the professionals. For example, hospital admission was identified as a significant and meaningful event in terms of the COPD disease trajectory by the qualitative, secondary analysis of transcripts and by professionals. However, most patients tried to avoid hospital admission by self-managing their COPD and its exacerbations, and as such, they identified hospital admissions as something they would try to avoid.

Individuals and their carers identified the more practical issues of functional debility and the need for adaptions to the home environment as being significant and visible markers for changing function. In gaining an understanding of what was significant for the individuals with severe COPD and their carers, the more functional changes impacted by illness had the most resonance, such as the need for a stair lift or changing their bathing facilities to have a walk-in shower due to issues of mobility.

Therefore, the concept of triggers, with the identified eight events, had little traction with individuals with severe COPD as well as their carers. However, there was a consistent reference to the yearly breathing test (spirometry) assessment with the annual COPD review, which is mainly led by general practice specialist nurses. This was expressed as an important and significant event in terms of a yearly review and helped calibrate the patient's 'progress' from one year to the next. This also acted as a barometer to the preceding

month's health status. Individuals remarked that any deterioration in the breathing test (spirometry) readings echoed their own perceptions that their disease was progressing. This encounter facilitated a professional and patient meeting that allowed a joint understanding of current health status from comparative annual breathing test (spirometry) readings, to the more narrative, holistic enquiry of how the disease was affecting an individual on a day-to-day basis.

6.1.1.2 Finding Two: Holistic Assessment

The aim of the project was to identify an approach (events) and use a process (triggers) to facilitate a holistic assessment of palliative and supportive needs in severe COPD. The approach required the concept of triggers and the events to facilitate this assessment to resonate sufficiently with professionals, patients and carers. However, the approach did not resonate with patients and carers and thus had little clinical utility.

The most positive finding from the study was the holistic assessment of needs. This was welcomed by individuals and, in particular carers, to be the time when their needs could be discussed. Individuals remarked on the medical model of care when the professionals, at times, seemed more interested in their prescription pads than what an individual had to say. Others described the idea of a professional from any discipline or setting, asking "How are you doing?" as a very welcome and useful approach, since it allowed them to discuss their ways of coping with everyday living. Few individuals and carers had experience of a formalised, holistic assessment. They talked of their experience gained through family members rather than directly relating to the COPD illness, such as an assessment for continuing healthcare. Individuals could see the utility of a more holistic enquiry into the breadth of impact that COPD could have on their lives and that interventions could be suggested to help manage these difficulties.

This endorsement of a holistic assessment of needs was seen as an 'MOT' where it is possible, like the yearly breathing test (spirometry) assessment, to capture the issues and concerns with a more global lens, rather than that of a

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very clinically-focused model of disease management. This allowed individuals the opportunity if they wished, for targeted interventions, such as home adaptations, mobility interventions or psychological support or to simply raise awareness of the breadth of interventions available to help with their quality of life within the advancing trajectory of severe COPD.

6.1.1.3 Finding Three: Perspectives of Patients, Carers and Professionals

The multiple methodologies (qualitative, secondary analysis, nominal group technique and qualitative interviews) and the different participants (individuals with severe COPD and their carers and the health and social care professionals involved in their care), facilitated a breadth of perspectives and an in-depth understanding of the feasibility of events as triggers for the holistic assessment of needs (palliative and supportive), in severe COPD.

The importance of gaining perspectives from the very individuals (patients, carers and professionals) that are directly involved in care delivery, showed that before any novel intervention there are potential opportunities and challenges which question the entire concept and its clinical utility. Within the development of any new intervention, there can be a cycle through which a meaningful difference in care from a patient perspective can be achieved so that the derived outcome measure is a key for this change. The MRC framework for evaluating complex interventions identifies the cyclical processes within the iterative evaluation of any novel approach as a fundamental requirement, ensuring clinical utility from the outcomes of the research process (Craig *et al.*, 2008).

The professionals' perceptions of patient and carer needs, are reliant on the visibility of this need within their clinical radar, i.e. presenting for a consultation or actively seeking advice. However, patients and their carers do not see the day-to-day variability in their condition requiring clinical assessment, preferring to manage and cope within their current support systems, as they adapt their activities and use their family to help with their chores. The rate at which the illness of COPD progresses can be at such an insidious onset, that needs, such as requirement to have a walk-in shower as they cannot bend

down or lift legs into the bath, are seen as interventions that are related more to global health changes, such as ageing i.e. "*unsure which is COPD and which is just getting older*". This is a challenge for professionals as well as patients and carers, especially within the remit of multi-morbidity and an ageing population, as all attempt to decide what is specifically COPD disease-related. Therefore, the challenge for the wider health economy is for the delivery of services, which are specifically commissioned for COPD, when patients, carers and professionals lack clarity on the delineation of disease-specific needs and those of the ageing process. The opportunity within this challenge is that irrespective of what the disease-specific drivers are, when needs are identified, pooled budgets and teams within commissioning and service delivery providers, should work together to ensure that needs are met. This would then help avoid the challenge of identifying needs solely related to COPD and those solely related to the ageing process, instead focusing on facilitating patient-centred care.

6.2 Implications and Potential Recommendations

6.2.1. Implications for Clinical Practice

The findings within this study echo the breadth of literature identifying the supportive and palliative care needs of patients and carers within the COPD disease trajectory (Gore, Brophy and Greenstone, 2000; Habraken *et al.*, 2007; Lanken, Terry and Delisser, 2008; Gardiner *et al.*, 2010; Pinnock *et al.*, 2011; Giacomini *et al.*, 2012; Boland *et al.*, 2013). The literature also describes the issues regarding the description of needs, which may be articulated in a much more functional language and therefore interventions are a response to manage the debility associated with advancing disease (Cawley *et al.*, 2014). In common with Habraken *et al.* (2008) and Giacomini *et al.* (2012), patients adapt to their debility and are often 'silent' about their situation, instead adjusting to the new norms imposed by their condition.

Identification of needs within severe COPD

The evidence from this study supports the findings that participants struggle to articulate their needs explicitly. Only when probed could participants see the

utility of a holistic assessment process and the potential benefit to be gained from certain interventions. Participants recalled their reluctance to ask for help, stemming from previous experiences that can only be described as professional nihilism: experiences that often resulted in *the prescription pad* when what people really needed was *time* and the clinician to *see the complete picture and person* and not just *their physical needs.* Kendall *et al.* (2015) have described this anomaly from their extensive qualitative work in the field of illness narrative, in particular looking at COPD. They identified that, in contrast to professionally defined 'normative' needs, patients rarely perceived themselves as needy, accepting their 'felt' needs as the result of a disability to which they had now adapted (Kendall *et al.*, 2015). This understanding is echoed in the findings from this study and suggests that the perception of what constitutes a need differs greatly between professionals and patients.

Holistic assessment

Patient participants remarked on the annual requirement for *breathing tests* (spirometry) as being a significant event, "*a bit like an appraisal*" and in a language that "*everyone knows what it means*" (Patient transcript, I22). By adopting a more standardised approach, care professionals can use existing processes within clinical practice to augment the systematic enquiry and have a more holistic lens on the disease, thus ensuring that patients with progressive disease are able to obtain the supportive and palliative care approach that they require.

The process of assessment, and what is included within this, broadly falls into the physical, psychological, social and spiritual domains of support needs and is evidenced within the literature (Murray *et al.*, 2009; Ryan *et al.*, 2013). However, more recently, a systemic review of the literature, suggested that the needs identified were not exclusive to one domain, such as finance, work and housing, but included 13 broad categories of support need, with additional areas, including exercising safely, navigating services, and overcoming feelings of guilt (Gardener *et al.*, 2018). Therefore, there is a requirement for an assessment to be person-centred and interventions offered

that have clinical utility and resonance with patients and carers. The challenge for professionals in assessing the needs for patients with severe COPD is again, the process of assessment, its timing and the offer of meaningful interventions to meet both patients' and carers' needs.

Fringer, Hechinger and Schnepp (2018) identify that the key goal for individuals with severe COPD is maintaining normality in daily life, relating this to adaptations made by individuals and their families to unaccustomed and unprecedented life situations in the palliative context. They argue that health and social care professionals must be aware of this goal of maintaining normality and therefore target interventions, resources and strategies to help maintain this patient-focused goal (Fringer, Hechinger and Schnepp, 2018). The findings from this study would echo the need to immerse any potential approach in terms of assessing need to 'prescribing' an intervention (medications, psychological support, equipment needs, information resources) to be patient-centred and focused, but having professional visibility, enabling clinical utility for all parties.

Augmenting existing processes

The concept of a triggering system to prompt a holistic assessment of needs in severe COPD had some resonance with professionals but little traction with individuals and their carers. This study identified that a significant event, such as a hospital admission, was seen very differently by the participants and therefore has limited clinical utility. This implies that the concept of triggering events is not uniform, but instead appears as a continuum of triggering ability, ranging from none or minimal for some participants, to important or highly significant for others. The significance of the hospital admission and subsequent discharge was the focus of a study by Buckingham *et al.* (2015), which aimed to use this event as a trigger point for a holistic assessment of needs. However, this approach was not useful and the authors concluded that "integration of brief holistic care assessments in the routine primary management of COPD may be more appropriate" (Buckingham *et al.,* 2015). Thus, from a patient perspective, the utility of this approach is limited, in view

of the invisibility of the insidious, progressive decline experienced within severe COPD.

Within the delivery of care for severe COPD, involving patients and carers at an early stage in the development of any novel approach, increases the likelihood of a concept succeeding. In this piece of work, the annual breathing test (spirometry) assessment, provided an opportunity to standardise the process of a holistic assessment of needs, alongside existing processes and assessments, therefore streamlining and enabling a more useful approach to patients and their carers. This could also prompt better service integration, with the aim of moving away from a very disease-orientated approach to care, to a more needs-led, whole-systems focus.

6.2.2 Implications for Further Research

Exploring the concept of need within severe COPD

Greater understanding of the perspectives of individuals with severe COPD and how they perceive and express their needs, warrants further exploration and an approach that is cognisant with how individuals with severe COPD view their holistic needs and what prompts them to seek help. The interaction of patient and carer and how to utilise this unit to capture needs and provide support in terms of meaningful interventions, is a key area for further exploration. Rocker and colleagues are already involving carers in managing 'dyspnoea crises' so that not only are adverse patient outcomes avoided, in particular hospital admission and increased morbidity, but carers are enabled as partners in the delivery of care (Rocker and Cook, 2013 (INSPIRED programme)).

Gardener and colleagues have identified a comprehensive set of domains of support need for patients with COPD, using the perspectives of those best placed to identify them: the patients themselves, with a clear steer that further research must identify "an evidence base for an intervention to assess the support needs of patients using a person-centred approach" (Gardener *et al.*, 2018), that will have clinical utility whilst enabling professionals to shift the goal of care to a more supportive and palliative approach to their disease.

Exploring the clinical utility

This study highlights the daily variability that individuals with severe COPD and their carers experience whilst identifying the challenge of when and how to assess needs. Given the disparity between the professionals' and patients' perceptions of need and the meaningful interventions to help support those needs, further work looking at what patients and carers perceive as useful, would be key.

6.3 Methodological Issues

The strengths and limitations have been discussed in terms of the specific methodologies and the approaches within each of Chapters 3, 4 and 5, but below, more global considerations will be discussed.

6.3.1 Strengths and Limitations

Different perspectives

In capturing the multiple perspectives of those involved within the care of severe COPD, this study had a breadth of professionals from different settings and with different expertise. Patients and carers were represented from a variety of settings. However, not all professionals from all settings were represented, with secondary care professionals most notably missing from discussions, in particular at the consensus workshop event. This could have a direct impact on any findings, given the considerable component that secondary care contributes to the overall care in severe COPD.

Patient and carer participants were mostly recruited from general practice surgeries that were keen to support the study. The paucity of patient participants from secondary care may have an impact on the study findings and the experiences of care within the wider health economy. Therefore experiences, good or bad, may not have been totally captured by the study.

The lack of stakeholder / Patient and Public Involvement (PPI)

The lack of initial consultation and involvement of stakeholders has had a significant impact on the study in terms of the chronology of its methodological approach and outputs. The concept of triggers and the approach to facilitate a holistic assessment of needs could have been debated within patient and carer fora, to ascertain what *they* would define as a trigger in terms of characteristics, timing and utility. Stakeholders driving the quest for a better patient experience could have potentially facilitated the researcher to navigate their perspectives in a more authentic and coherent way throughout this piece of work. Such an approach could have given a clear platform to the discussions with professionals and driven more concrete outputs. This too may have changed the methodological approaches dependent on the questions needing to be asked. The clear reflection on the lack of PPI involvement within the very conceptual thinking and set-up stage of this piece of work, suggests that the outputs might have been very different and had more utility to all perspectives involved within the research, had this approach been used.

Geographical variations and fiscal constraints

The study participants were recruited from the East Kent area of the South East of England. Whilst this has the opportunity of exploring within this wider health economy the experiences of individuals with severe COPD and their related professionals, this may not be representative of the national, nor indeed, international landscape of COPD care delivery. The delivery of COPD is aided by NICE guidance and therefore should have some uniformity in delivery (NICE COPD, 2018), but there are four Clinical Commissioning Groups within the locality of East Kent, with competing fiscal drivers and there could be variability in the provision of care and adherence to guidelines across the area. The area may not be representative of practice nationally and there may be variations in the commissioning of health and social care services within the local health economy.

The NHS is an evolving platform in terms of care, embracing innovation and evidence-based practice, and during the time taken for this piece of work some areas of practice may already be implementing and addressing these issues for people with COPD.

6.3.2 Reflexivity

Reflexivity or self-reflexivity is an important aspect of qualitative work as it allows researchers to assess their own contextual position (Bunniss and Kelly, 2010). This enables transparency for readers to understand the evidence on which the author has based their arguments as a whole, whilst situated in a specific time and place. This occurs prior to abstraction of findings as the empirical data is considered with the theoretical and literature review in (Rees and Monrouxe, 2010). In this section, the researcher provides some personal reflections on their work.

In this section, personal reflections on the work carried out and the role of researcher sandwiched with medical doctor will be discussed. These reflections were not an afterthought to the work but integral and contemporaneous to all of the component parts of the research process and study.

Gaining an understanding of meaning

In an attempt to outline the thinking and ensure that the construction of meaning was itself interrogated and accounted for in this research, some considerations are discussed in this section,

Qualitative researchers primarily seek to understand meaning, but they do not assume that meanings are fixed and stable. They have no expectation that the truth is simply out there waiting to be discovered by asking the right questions. They do not assume that their questions are objective, nor do they assume that respondents' answers have straightforward, definitive meanings that mirror a singular reality (Ritchie and Lewis, 2003). Rather, they hold that all meanings are interactively and culturally constructed. Individual, social actors are variously located within social settings, structured by sex class,

race, age and other descriptive characteristics. Social actors' multiple, shifting social locations, shape the construction of meaning within any particular context (Rees and Monrouxe, 2010).

Qualitative researchers are interested in how meanings are produced and reproduced within particular social, cultural and relational contexts. They recognise the interview itself as one such context of interactive meaning-making (Webster and Mertova, 2007). Therefore, interpreting qualitative data requires reflection on the entire research context and involves making the research process itself a focus of inquiry, laying open pre-conceptions and becoming aware of situational dynamics in which the researcher and respondent are jointly involved in knowledge production (Corbin and Strauss, 2008). Therefore, findings do not emerge only at the last stage of the research, but rather there is a deepening of insight throughout the research process. Emergent findings from the different stages informed subsequent interviews and analyses. Reflexive practices provided the opportunity for revising questions and even re-framing the research topic as the project unfolded.

Often researchers undertake pilot interviews (as in this piece of work) to help identify the areas of greatest conceptual complexity. In early interviews, if questions did not seem to work, then questions were rebuffed because concepts were not understood or were seen to be insignificant. Ongoing analysis also entails examining the dynamics of the interview. Indeed, what was not said, can be as revealing as what was said. As the researcher comes to identify their assumptions and preconceptions, questions are revised for the next round of interviewing (Green and Thorogood, 2004).

The idea of 'insider versus outsider' research (Kvale and Brinkman, 2009)

I came to this piece of work as a medical doctor with a background in general medicine, general practice but as a specialist in Palliative Medicine. In my role as a consultant in Palliative Medicine I am challenged with optimising the quality of life for patients and their carers living with severe COPD whilst supporting professionals delivering this care, irrespective of setting.

My observations irrespective of my grade of training or my location of work (West of Scotland, North West England and South East England), have identified the same issues, namely the challenges of working across settings, the flow of communication, or the lack of it, the voices of the patient and carer, the challenges for professionals and the heterogeneity of service provision within different geographical areas and with increasing fiscal constraints. The challenge in delivering care that is patient-centred, needs-led and embedded within a local health economy for severe COPD, is where I have come to with this research question.

My own experiences inevitably have shaped my research interests. I was aware that I needed to listen to what the issues were from the different participants, why they may have occurred and, to listen attentively and acutely to where they envisaged potential solutions could be. This was useful for me as a researcher, to know the architecture of the health economy, whilst making a conscious effort with my questions, not to accept potential common assumptions or take issues at face value.

My role as a consultant in Palliative Medicine is difficult to compartmentalise from that of an independent, non-medical researcher. As I have taken up my role in East Kent from September 2009, I am not aware of the history or evolution of the service provision in its current configuration. Therefore, I am an outsider, in that I was employed as a joint appointment between Pilgrims Hospices in East Kent and the University of Kent and we are but a small provider in terms of severe COPD provision within the locality. I am also challenged within my clinical role to collaborate with professionals across settings to deliver seamless care for patients with severe COPD, to ensure they have optimum quality of care, irrespective of settings or provider. Therefore, I am an insider too in that I share the challenges and tasks of my colleagues, with the responsibility of delivering palliative care to individuals with end-stage COPD.

I chose to be open and explicit with participants about the research so they were aware of what I was looking for and able to make choices about the focus of their comments. This ensured the data generated was relevant and

reduced the risk of misinterpretation, although I am aware this means the research data must be considered as a work created in partnership with my participants. I guarded against becoming uncritical in several ways. Data were generated from participants (patients, carers, professionals) from different geographical locations and with different service provision, so it ensured interpretation was not solely based on a single group's perspective. Awareness, and later application of theoretical constructs, provided another means of interrogation for my interpretations (Kvale and Brinkman, 2009).

It has to be accepted that any research based on human interaction in its methodological approach will be to a degree influenced by the nature of the researcher. As this is inevitable, the more important issue is to consider the dynamics that might make a difference in any given situation, by considering the particular researcher position in relation to the participant groups. I believe that coming from a medical background and as a professional with responsibility in delivering palliative care to patients with severe COPD, this has been helpful in conducting the study. It has allowed the participants to identify with either my role as a clinician or as a professional colleague, and to include me more willingly than an outsider. I have remained diligent in my role as researcher, to remain neutral when an opinion has been sought and to continuously question and ask participants to explain from their responses any implied assumptions or hidden agendas.

Bourdieu and Wacquant (1992) outline three areas of potential bias: the social origins of the researcher, their position in the academic field and the intellectualist bias (viewing the world as a spectacle) (Bourdieu and Wacquant, 1992). All of these are important to reflect upon throughout the research process with particular importance placed on the individual, their perceptions, on meaning-making from experience, and on processing of experience in a particular health economy either as patient, carer or professional. Therefore, I am seeking to understand the theories of others in relation to their situation (Harrington, 2005). The development of an approach to identify the needs of patients and carers living with severe COPD, grounded within multiple perspectives of those that are involved within the

care delivery, would still need further exploration and testing in other contexts for applicability and generalisability.

6.3.3 The Researcher as an Instrument

The acceptance and acknowledgement of the 'researcher as the instrument' for qualitative data collection is widely published (Cassell, 2005; Rubin and Rubin, 2005; Turcato, 2005). Therefore, the attributes of the researcher have the potential to influence the collection of empirical materials with specific reference to the researcher as an active respondent in the research process (Hammersley and Atkinson, 1998). It is through the researcher's facilitative interaction that a conversational space is created, that is, an arena where respondents feel safe to share stories of their experiences and life worlds (Owens, 2006). The importance of 'how' a given interview is performed shapes the 'what' that is produced, and these are key steps in the analytical process (Holstein and Gubrium, 1995; Pillow, 2003).

The qualitative, secondary analysis was not conducted by the same person who completed the original qualitative interviews; and their position within the research process needed to be acknowledged. MK is an experienced qualitative researcher and along with HP the study author, has given a breadth and depth to the data collected and the multiple perspectives, therefore acknowledging the position of the researcher in relation to the participant groups.

The researcher (MK) has made every attempt to remain diligent in their role, to remain neutral when an opinion has been sought and to continuously question and ask participants to explain from their responses, any implied assumptions or hidden agendas facilitated through an open, conversational space whilst building rapport and mutual understanding. Pezalla, Pettigrew and Miller-Day (2012) argue that interviewers need to acknowledge how either end of the spectrum of self-disclosure to neutrality, can impact on the research process and how they can create different conversational spaces. This is echoed by Bordieu and Wacquant (1992) who identified three areas of potential bias: the social origins of the researcher, their position in the

academic field and the intellectualist bias (viewing the world as a spectacle). All of these are important to reflect upon throughout the research process, with particular importance given to the individual and the meanings they attribute to their perceived experiences and how they process their experiences in a particular health economy, either as patient, carer or professional. Therefore, the author is seeking to understand the theories of others in relation to their situation (Harrington, 2005). The development of candidate events as triggers for the holistic assessment within the severe COPD disease trajectory, was grounded within the multiple perspectives of those that are involved with care delivery.

6.3.4 Trustworthiness of the Data

Verisimilitude or truth-likeness is the "concept that distinguishes between the relative and apparent, or seemingly so, truth and falsity of assertions and hypotheses" (Tichy, 1974, p. 170). Popper (1959) proposes that closeness to the truth is a function of two factors; truth and content. The more truths that a theory entails (other things being equal), the closer it is to the truth (Tichy, 1974; Miller, 2000). Therefore, to produce verisimilitude, a logical, systematic approach is more important to adhere to than a particular set of methods (Kvale and Brinkman, 2009). To ensure credibility and transparency with the analysis and faith in its reliability, compassion and validity, multiple approaches to data generation and analysis were employed, so as to increase the trustworthiness of findings, by providing inbuilt checks and balances on interpretations through comparison of multiple perspectives.

During the process of this empirical work, I compared the data from each participant group and method of generation, looking at similarities and differences to gain maximum validity and interpretation of the multiple perspectives (Silverman, 2005). As the findings were integrated into the theoretical understanding of the needs and perceptions of illness, both common and so-called deviant cases can be accounted for.

The qualitative, secondary analysis of transcripts for this study was from primary, qualitative data focusing on understanding the perspectives of people

living and dying with severe COPD. It was a multi-perspective, longitudinal, qualitative study involving patients, carers and professionals within Scotland (Pinnock *et al.*, 2011). The study authors comprised one of the research supervisors and provided a first-hand account of the data generation and its analysis. Several meetings with the primary research interviewer (MK) who conducted the interviews, helped contextualise the data and gave a more informal account from their recollections and field notes of the data integrity (Silverman, 2005; Bryman, 2008).

Standard qualitative methods of achieving validity, such as checking that developing themes remain true to the primary sources, and presenting the verbatim text, have been used (Huberman and Miles, 2002). The analysis was also subject to checking by the research supervisors and all codes and transcripts were subject to back coding; that is, a return to the original transcripts and codes once the first round of coding with each participant group and each data source had been completed. The author reported emerging results to patient and carer networks, such as Breathe Easy groups and The British Lung Foundation, as well as to a wide variety of professional meetings (educational, managerial, research) in a variety of settings. Determining whether or not individuals identify with research findings, helps to provide a link from the field to the interpretative analysis and theoretical understanding, thereby assisting understanding of the potential, practical applications of the research findings and maintaining trustworthiness of the research process (Kvale and Brinkman, 2009).

6.4 Conclusions

The thesis aimed to explore the relatively uncharted area of events acting as triggers for a holistic assessment of needs (palliative and supportive) within severe COPD. Through trigger identification and stakeholder acceptability and feasibility with different methodologies, this approach was debated. The thesis concentrated on professionally-constructed events as triggers and then proceeded to explore the different stakeholder perspectives. Professionals could see utility in the approach with the product of this process being a

holistic assessment of needs. Patients and carers welcomed the holistic assessment but were less convinced about the events as triggers and the actual approach of triggers in general. Any attempts at improving the holistic assessment of needs in severe COPD, warrants a more standardised approach and the opportunity of the annual spirometry review to support this, needs further exploration.

6.5 Further Work

One of the findings in this study identifies that patients with severe COPD see utility in a holistic assessment of their palliative and supportive needs, which is echoed by their carers. How this should happen and by what means is unexplored. Patient participants identified the annual breathing test (spirometry) as significant and having sufficient utility in terms of a professional having a more holistic and systemic enquiry of their needs, much like a respiratory MOT. Exploring the standardising of the holistic assessment of needs alongside routine, annual reviews within severe COPD and the impact this has on the patient, carer and professional experience, as well as on their care, would be important to investigate further. This approach would interface the patient and the care professional, giving a shared response so that they can work together to ascertain what is needed. The interventions required may broaden from the more traditional clinical idea of inhalers and medications to the more supportive measures of acknowledging patient and carer needs, and utilising their own resources, signposting to external resources or making appropriate referrals. This piece of work could have a broader, less clinical focus on care, but as Gardener *et al.* (2018) state, this approach will use the perspectives of those best placed to identify what will help: the patients themselves (Gardener *et al.*, 2018).

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Appendices

Appendix A: COREQ checklist

Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups (Tong, Sainsbury and Craig, 2007)

Domain 1: Research team and reflexivity	Reference to this (Yes (Y) or No(N)

Personal characteristics
    1. Interviewer / Facilitator
    2. Credentials
    3. Occupation
    4. Gender
    5. Experience and setting
	Y
	Y
	Y
	Y
	Y

Relationship with participants
    6. Relationship established
    7. Participant knowledge of the interviewer
    8. Interviewer characteristics
	N
	Y
	
	(In a later chapter)

Domain 2: study design	
Theoretical framework 9. Methodological orientation and Theory	Y

Participant selection
    10. Sampling
    11. Method of approach
    12. Sample size
    13. Non-participation
	Y
	Y
	Y
	N

Setting
    14. Setting of data collection
    15. Presence of non-participants
    16. Description of sample
	Y
	Y
	Y

Data collection
    17. Interview guide
    18. Repeat Interviews
    19. Audio/visual recording
    20. Field notes
    21. Duration
    22. Data saturation
    23. Transcripts returned
	Y
	N
	Y
	Y
	Y
	Y
	N

Domain 3: analysis and findings	

Data analysis	
24. Number of data coders	Y
25. Description of the coding tree	Y
26. Derivation of codes	Y
27. Software	Y
28. Participant checking	N
Reporting	
29. Quotations presented	Y
30. Data and findings consistent	Y
31. Clarity of major themes	Y
32. Clarity of minor themes	Y

Appendix B: Email from the South-East Coast LREC

21st Jan 2011

Dear Declan

I've confirmed with the Chair of the REC that the first part of your study (involving anonymised transcripts and consensus meeting) does not require ethical approval.

As far as booking goes, the booking line is currently allocating slots in March, I believe. Once you have booked your space, the booking line will advise you that you have 4 days to print off your final application, get it signed by the relevant people and get that final, signed version to the coordinator of the REC you're booked in with.

Please do not hesitate to contact me if you have any further queries.

Best wishes

Dean

Dean Beattie | REC Co-ordinator

South East Research Ethics Committee

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Appendix C: Invitation email

I hope that the New Year is treating you well.

I am a PhD student with Hilary Pinnock, David Oliver and Jenny Billings as my research supervisors. I am sending you this email because I am organising a 'consensus meeting of experts' as part of my PhD project.

The focus of the meeting will be the data generated from the secondary analysis of Hilary Pinnock et al.'s work ' A Breath of Fresh Air (BOFA); improving care and services for patients living and dying with chronic obstructive pulmonary disease, and their carers' recently published in the BMJ. http://www.medscape.com/viewarticle/736720

The aim is to agree some of the potential triggers/milestones that will be practical for clinicians and meaningful for patients and carers while helping to identify their needs (supportive and palliative care) through holistic assessment.

Your expertise and experience would be invaluable and I would be grateful if you could make the meeting.

The date in question is 30th March 2011 running from 1100 to 1500 approximately with lunch provided. The location will be Pilgrims hospice in Canterbury (http://www.pilgrimshospices.org/).

We would of course pay your travelling expenses and if required can negotiate an honorarium.

I look forward to hearing from you and do hope that you can make it.

Regards

Declan Cawley

Dr Declan A Cawley

Consultant in Palliative Medicine

Research Fellow

Pilgrims Hospices

University of Kent

East Kent Hospitals University NHS Foundation Trust

Appendix D: Agenda for the Meeting

Consensus Meeting
30th March 2011

1030-1100	**Coffee**
1100	**Start** **Welcome** **Introductions**
1110	**Background to this meeting**
1125	**Initial scoring of potential candidate triggers**
1135	**Overview of the PhD project**
1145	**Candidate trigger discussion 1**
1200	**Candidate trigger discussion 2**
1215	**Candidate trigger discussion 3**
1230	**Candidate trigger discussion 4**
1245	**LUNCH**
1330	**Candidate trigger discussion 5**
1345	**Candidate trigger discussion 6**
1400	**Candidate trigger discussion 7**
1415	**Candidate trigger discussion 8**
1430	**Potential for additional discussion**
1500	**CLOSE**

Appendix E: Scoring Sheets

Round 1

Name			
Trigger	**Rating** **1-10** **(1=highest priority,** **10=not a priority)**	**Your score**	**Median score**
Blue badge			
Changing shift in the illness			
DNA or Failure to attend			
Home adaptations			
Hospital admission			
Housebound			
Increasing burden of disease			
Increasing carer burden			
Additional candidate trigger			
Additional candidate trigger			

Scoring sheet for Round 2 and 3 (E.g. Disabled parking (Blue) badge)

Name			
Trigger	Rating 1-10 (1=highest priority, 10=not a priority)	Your score	Median score
Blue badge			

Appendix F: CREDES checklist

Recommendations for the Conducting and Reporting of Delphi Studies (CREDES) (Junger *et al.,* 2017)

	Evidenced within the reporting Yes(Y) or NO(N)
Rationale on choice of Delphi technique 1. Justification	Y

Planning and design
    2. Planning and process
    3. Definition of consensus
	Y
	Y

Study conduct
    4. Informational input
    5. Prevention of bias
    6. Interpretation and processing of results
    7. External validation
	Y
	Y
	Y
	N

Reporting
    8. Purpose and rationale
    9. Expert panel
    10. Description of the methods
    11. Procedure
    12. Definition and attainment of consensus
    13. Results
    14. Discussion of limitations
    15. Adequacy of conclusions
    16. Publication and dissemination
	Y
	Y
	Y
	Y
	Y
	Y
	Y
	Y
	N

Appendix G: Interview Schedules

Interview schedule for Patient and Carer V1

Want to participate in other parts of study Y / N
GP

Interview schedule for Patient/Carer

Some work has highlighted the difficulties/challenges of living with COPD and we are looking at how we can work to address this by trying to understand better the 'events' 'time points' 'moments' when it might be helpful to make contact and assess/take stock if there are any current problems/issues/needs/concerns
What do you think of this idea?

We use the word 'trigger' as it would help to prompt/start/spearhead an holistic assessment of what the current issues are.
What do you think about this?

Things that we were thinking about (ask if these have happened / are happening for the interviewee)
- **Hospital admission**

- **Blue badge**

- **Home adaptations**

- **Housebound**

- **Increasing carer burden**

- **Increasing burden of disease**

- **Failure to attend appointments**

- **Shifting priorities**

Have you any thoughts on when you would think it helpful from your own experience?

What would be a 'trigger' for you?

What would you find helpful?
(needs to be things that can be clearly visible by other professionals/people)

When do you think that an assessment should be completed?

1

Want to participate in other parts of study Y / N
GP

What should we assess?

Is this something that you have had in the past, and was it helpful?

When did it occur and what did it entail?

Who do you think is best placed to ask/assess what are your problems?
GP/Practice Nurse/CNS/SW/OT/PT/CONS/Comm Resp Team

When would you think this assessment would be best completed?
At different 'time points/events/triggers', what are your thoughts on them asking you very similar Qs e.g. a doctor asking you about your benefits/ breathing/ housing and a social worker doing the same?

What would you like us to do with this information when we have made the assessment?

Who would you be happy for us to share it with?
GP/Practice Nurse/CNS/SW/OT/PT/CONS/Comm Resp Team

Would you want a copy of it?

Do you think this approach would be helpful?

If somebody is making a holistic assessment'of what are the problems, what should be asked about?

What things?

What sort of questions?

What would be important for you?
                            THANK YOU

2

Interview schedule for Patient and Carer V2

STUDY ID   MRC score   V2
Want to participate in other parts of study Y / N
GP

Interview schedule for Patient/Carer

Some work has highlighted the difficulties/challenges of living with COPD and we are looking at how we can work to address....

I would be really interested to hear what are the problems that your breathing is causing you at the moment?
-breathlessness; how does the affect you? What does it stop you doing? What do you do to manage it?
-general screen for symptoms

-Ask about how it affects their 'general wellbeing' and overall health?

-Does it ever affect how they think and feel? their mood?

-Have any special changes to the house or lifestyle happened as a result of the breathing (e.g. home adaptations, not going on hols, shower put in, downstairs living, not able to do leisure activities, stair lift)?

Any other problems have had an effect on the day-to-day living?

Has anybody every asked about the wider impact of COPD before?

Is this something that you have had in the past, what was it and was it helpful?

As we talked about the problems already and the 'approach' about asking about your general wellbeing, anything else you would want included and/or be important to be asked about?
What sort of questions or areas of interest would you want discussing?

What would be important for you?

Would you find it useful/helpful to have somebody ask an 'overview' of these sort of questions? What would be a trigger for you?

We use the word 'trigger' as it would help to prompt/start/spearhead an assessment of what the current issues are.
What do you think about this?

1

STUDY ID   MRC score   V2
Want to participate in other parts of study Y / N
GP
Who would you feel to be the right person to ask these sort of questions?
Who do you think is best placed to ask/assess what are your needs?
GP/Practice Nurse/CNS/SW/OT/PT/CONS/Comm Resp Team

What would you like us to do with this information when we have made the holistic assessment?

Do you think this approach would be helpful to be more proactive and seeking this information before problems arose?

When do you think it might be helpful to ask these sort of questions?
-    **can you think of any circumstances or situations that would have been useful for you?**
     (needs to be things that can be clearly visible by other professionals/people)

Things that we were thinking about (ask if these have happened / are happening for the interviewee)
- **Hospital admission**

- **Blue badge**

- **Home adaptations**

- **Housebound**

- **Increasing carer burden**

- **Increasing burden of disease**

- **Failure to attend appointments**

- **Shifting priorities**

THANK YOU

Appendix H: Ethics approval letter

NRES Committee South East Coast - Kent

South East Coast Strategic Health Authority
Preston Hall
Aylesford
Kent
ME20 7NJ

Telephone: 01622 713012
Facsimile: 01622 885966

04 October 2011

Dr Declan Anthony Cawley
Research Fellow / Consultant in Palliative Medicine
University of Kent
Centre for Professional Practice
Compass Centre South
Chatham Maritime
Kent
ME4 4YG

Dear Dr Cawley

Study title:	**What are the significant and appropriate triggers to assess the needs (supportive and palliative) of COPD (Chronic Obstructive Pulmonary Disease) patients and their carers' that can direct a model of care provision?**
REC reference:	**11/LO/1357**

Thank you for your letter of 29 September 2011, 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.

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.

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

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to

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<u>the start of the study at the site concerned.</u>

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System 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 approvals from host organisations

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).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter		05 August 2011
Evidence of insurance or indemnity		12 July 2011
GP/Consultant Information Sheets	1: GP/Consultant Letter of Participation	25 July 2011
Interview Schedules/Topic Guides	1: Interviews	25 July 2011
Interview Schedules/Topic Guides	1: Focus Groups	25 July 2011
Investigator CV	1: Dr Declan Cawley	25 July 2011
Letter of invitation to participant	1: End of Project Workshop	25 July 2011
Other: Academic Supervisor CV	Dr David Oliver	25 July 2011
Other: Student CV	Same as CI CV	25 July 2011
Other: Thank You for Participating Letter	1	25 July 2011
Other: Clinical Information from Medical Records	1	25 July 2011
Other: End of Project Workshop Flyer	1	25 July 2011
Participant Consent Form: Permission to Pass Contact Details	1	25 July 2011
Participant Consent Form: End of Project Workshop	1	25 July 2011
Participant Consent Form: Questionnaires (Patients)	2	24 September 2011
Participant Consent Form: Interviews (Patients)	2	24 September 2011
Participant Consent Form: Focus Groups (Patients)	2	24 September 2011
Participant Consent Form: Questionnaires (Carers)	1	24 September 2011
Participant Consent Form: Interviews (Carers)	1	24 September 2011
Participant Consent Form: Focus Groups (Carers)	1	24 September 2011
Participant Information Sheet: Focus Groups (Carers)	1	24 September 2011
Participant Information Sheet: Questionnaires (Carers)	2	24 September 2011
Participant Information Sheet: Interviews (Carers)	1	24 September 2011

Participant Information Sheet: Focus Groups (Patients)	2	24 September 2011
Participant Information Sheet: Interviews (Patients)	2	24 September 2011
Participant Information Sheet: Focus Groups (Professionals)	2	24 September 2011
Participant Information Sheet: Questionnaires (Patients)	2	24 September 2011
Protocol	1	25 July 2011
Questionnaire: St George's Hospital Respiratory Questionnaire		
Questionnaire: HAD Scale		
Questionnaire: Distress Thermometer		
Questionnaire: Zarit Burden Interview		
REC application		27 July 2011
Response to Request for Further Information		29 September 2011
Summary/Synopsis	1: Summary of Project Flow Chart	25 July 2011

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 NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

11/LO/1357	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Dr Ray Godfrey
Chair

Email: Sharon.Busbridge@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Ms Nicole Palmer*
                Ms Susan Kelly, East Kent University Hospitals NHS Foundations
                Trust

Appendix I: Invitation letter

Participants Name and Address

University of
Kent

Dear Participant Name,

We are currently involved in a project with the University of Kent in a study called 'Triggers to assess the needs of COPD patients and their carers'. This is designed to help us better understand and therefore plan services to meet your needs. We are writing to people with COPD who may be interested in taking part with this study. We have not given, and will not be giving, your name to the researchers at the University**. It is entirely your choice to respond to this invitation if you wish to volunteer.**

The enclosed information sheet provides detailed information about what will be involved. Please read it carefully. If you would like more information regarding this study please do not hesitate to contact the researcher.

Researcher: Declan Cawley   **Tel: 01634 888847**   **email: D.Cawley@kent.ac.uk**

If you decide that you would like to take part, please complete the contact details form, and return it to the researchers in the enclosed reply-paid envelope. The researcher, Declan Cawley, will then contact you to answer any questions about the study and, if you wish to take part, to arrange you first appointment.

Thank you for considering this invitation.

Yours Sincerely,

GP Name / Community Respiratory Team's name / Consultant Respiratory Physician
Dr Declan Cawley
Research Fellow
University of Kent

Please complete the contact details form or contact the researcher directly if you would like to take part in the study.

Appendix J: Reply Slip

University of
Kent

TRIGGERS FOR ASSESSING THE NEEDS OF COPD PATIENTS AND CARERS:

Name of Researcher: Dr Declan Cawley

Please initial box

I confirm that I have read and understand the information sheet (version 2: 24/09/2011) for the above study	
I understand that Dr Declan Cawley will contact me in the next few days to answer any questions about the study, and to enable me to decide whether, or not, I wish to participate	
I am happy for my contact details to be passed to the research team	

Signature _____ Date _____

Contact details

Name	
Address	
Telephone	
E-mail	
Are there any times of day when it would NOT be convenient for us to phone you?	

Appendix K: Participant Information Sheet (Patients)

<div style="border:1px solid black; text-align:center;">

PATIENT INFORMATION SHEET

</div>

University of **Kent**

Centre for Professional Practice, University of Kent, Compass Centre South, Chatham Maritime, ME4 4YG
Tel: tbc
Email: tbc

TRIGGERS FOR ASSESSING THE NEEDS OF COPD PATIENTS AND CARERS:

- Exploring the views of patients and their carers

This is an invitation to take part in a research study. Before you decide if you want to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

More and more people have chronic lung disease (emphysema, bronchitis, Chronic Obstructive Pulmonary Disease, COPD). We need to find out what services you and/or you carer require to help people with breathing problems. We need to identify specific 'triggers' that will help the professionals that look after you to make the most appropriate assessment of what you need and then organise how we can address these issues. We want to know your thoughts and experiences, good or bad, on what are the most appropriate 'triggers' and if this approach is worthwhile. This will ensure that when we complete an assessment, we will know the right questions to ask but also when to ask them. We would like your thoughts on some work we have already conducted and what your thoughts are, so that all the people (doctors, nurses, social workers, physiotherapists, occupational therapists etc) looking after people with breathing problems can better help people with these conditions.

Why have I been chosen?

You have been chosen either because your hospital doctor, general practitioner (GP) or community team knows you have a chest problem. We hope to speak to 20 patients with breathing problems and, if they agree, their relatives or carers. If you have a carer, we will ask if we may talk to them.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form.

Can I change my mind about taking part?

Yes. If you decide to take part you may change your mind at any time and without giving a reason. A decision to withdraw, or a decision not to take part, will not affect the standard of care you receive either now or in the future.

What will happen to me if I take part?

Meeting the study researcher

If you are still happy to help with the study, the researcher, Dr Declan Cawley, will contact you. It is important that the 20 people we recruit to the study come from different areas in Kent, and with different medical and social backgrounds. Dr Cawley will confirm whether you are suitable for this particular study.

The interview

The interview can be in your own home or in your doctor's surgery, hospital or community team's premises. We will pay your travel expenses if you choose to travel to see the researcher. The interview will be about how you are and your thoughts and experiences with our suggestions from some work looking at when and how to best assess what services you need. Interviews usually last for about 40 – 60 minutes, but you can break off at any time if you feel unwell. If you agree, the interviews will be recorded so that we can be sure that we remember and understand what you say correctly. The recording will not be heard by anyone other than the researchers and the study secretary and will be kept securely. You may listen to the recording, or read the transcript if you wish to do so. We may use some of the recordings as direct quotations in our reports but they will be completely anonymised and your identity will be protected at all times.

Relatives / carers

If there is someone who helps and supports you at home, a relative or a good friend, we will ask you if we can approach them and invite them to be interviewed as well. These interviews will also be recorded. We will ask them similar questions so that we can understand their point of view as well. We will not speak to anyone without your consent.

The interviews are part of a bigger project and will require more contact and information from patients with breathing problems and their carers in the future. If you would be interested in taking part again or would not want to be contacted then we will make a note of this. Whatever you decide to do, it will not affect the standard of care you receive either now or in the future.

Is there anything else you want to know about me?

We would also like your permission for the researcher to review your medical records. This helps us to understand the treatment you have had.

What are the possible benefits of taking part?

We cannot promise the study will help you but we will discuss our findings with health and social care providers. By helping us to understand your experiences and hear your suggestions, we hope that patients with chest problems and their families will get the best possible care in the future and help ensure the right services are in place to do this.

Are there any risks?

No. There are no foreseeable risks. Your treatment will not be affected: we are only asking you to tell us about your condition, the care you receive and your thoughts on suggestions for improving services in the future. There are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action. Any complaints or concerns about this study should be directed to Dr Cawley: Telephone: *tbc.* E-mail: *tbc.* The normal National Health Service complaints mechanisms are also available to you.

Will my taking part in the study be kept confidential?

Yes. Your name will not be known to anyone other than the researcher as we will use a code instead of your name so you will not be identified. No information will be given to anyone outside the research group. All documents will be stored securely for at least 5 years and then destroyed. At the end of the study, all the recordings will be destroyed. Occasionally monitors and inspectors may need to access to clinical notes as well as to study data, to check that the research is being conducted according to national regulations.

In the course of the discussion if any information was disclosed that may cause risk to yourself or others, then we would need to discuss the possibility of not being able to maintain confidentiality as the safety of yourself and others is paramount. We would work alongside your local teams to ensure that this process is sensitively handled and the local policies are followed.

Your consultant and GP will be informed that you are taking part in the study: this is to ensure that they are happy that you are well enough to take part. If at interview we discover something which we feel either the hospital doctor, your GP or community team should know about, we would discuss it with you and ask your permission to let them know. We will not pass on any information without your permission.

What will happen to the results of the research study?

The interviews are part of a larger study which ends in summer 2015. We will discuss our findings in a workshop of doctors, nurses, and health service managers where we will discuss ways in which we can improve the service provided for people with breathing problems. We will write a report at the end of the study which will be submitted to the University of Kent. We will offer everyone who takes part in the study a short summary of our findings. We will also publish our findings in medical journals in order to help other people to understand the needs of people with breathing problems. You will not be identifiable in any of these reports.

Who is organising and funding the study?

Dr Declan Cawley is leading the study with colleagues from the University of Kent. Dr Cawley will be carrying out all the interviews as it is part of his PhD thesis. The study is funded by the University of Kent and Pilgrims Hospices in East Kent. The study has been approved by the South East Coast - Kent Research Ethics Committee.

What if you have some questions about the study

If you would like to find out more about this study before deciding whether to take part, you can contact Dr Declan Cawley on Tel: *tbc* E-mail: *tbc*   You may have to leave a message on an answer phone but we will get back to you as soon as possible. If you have other concerns about taking part in this study, your GP or respiratory nurse may be able to answer them. (Please note that we can only answer questions about the study – you should discuss any concerns about your breathing problem with your general practitioner in the normal way).

What happens now?

- If you agree your GP, hospital doctor or community team will give your name and telephone number to Dr Cawley, the study researcher.

- In about 3-5 days-time Dr Cawley will phone to ask if you are interested in taking part in the study. He can answer any questions you may have.   If you are still interested in participating he will arrange to meet up at a time and place of your choosing. If you are not sure, he can answer any questions you may have, and can phone back another day.   If you have decided you do not want to take part, he will not try to persuade you and will make a note of this.

- Prior to the interview, Dr Cawley will explain more about the study, answer any further questions, and, if you decide to participate, he will ask you to sign a consent form.

Thank you for taking the time to read this information and please do not hesitate to ask for any more information if you need it.

Participant Information Sheet (Carers)

<div style="border:1px solid black; text-align:center;">

CARER INFORMATION SHEET

</div>

University of **Kent**

<div style="border:1px solid black;">

Centre for Professional Practice,
University of Kent,
Compass Centre South,
Chatham Maritime,
ME4 4YG
Tel: tbc
Email: tbc

</div>

TRIGGERS FOR ASSESSING THE NEEDS OF COPD PATIENTS AND CARERS:

- Exploring the views of patients and their carers

This is an invitation to take part in a research study. Before you decide if you want to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

More and more people have chronic lung disease (emphysema, bronchitis, Chronic Obstructive Pulmonary Disease, COPD). We need to find out what services you and/or you carer require to help people with breathing problems. We need to identify specific 'triggers' that will help the professionals that look after you to make the most appropriate assessment of what you need and then organise how we can address these issues. We want to know your thoughts and experiences, good or bad, on what are the most appropriate 'triggers' and if this approach is worthwhile. This will ensure that when we complete an assessment, we will know the right questions to ask but also when to ask them. We would like your thoughts on some work we have already conducted and what your thoughts are, so that all the people (doctors, nurses, social workers, physiotherapists, occupational therapists etc) looking after people with breathing problems can better help people with these conditions.

Why have I been chosen?

You have been chosen either because your hospital doctor, general practitioner (GP) or community team knows you are a carer for an individual with a chest problem. We hope to speak to 20 patients with breathing problems and, if they agree, their relatives or carers.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form.

Can I change my mind about taking part?

Yes. If you decide to take part you may change your mind at any time and without giving a reason.

What will happen to me if I take part?

Meeting the study researcher
If you are still happy to help with the study, the researcher, Dr Declan Cawley, will contact you.   It is important that the 20 people we recruit to the study come from different areas in Kent, and with different medical and social backgrounds. Dr Cawley will confirm whether you are suitable for this particular study.

The interview

The interview can be in your own home or in your doctor's surgery, hospital or community team's premises. We will pay your travel expenses if you choose to travel to see the researcher. The interview will be about how you are and your thoughts and experiences with our suggestions from some work looking at when and how to best assess what services you need. Interviews usually last for about 40 – 60 minutes. If you agree, the interviews will be recorded so that we can be sure that we remember and understand what you say correctly. The recording will not be heard by anyone other than the researchers and the study secretary and will be kept securely. You may listen to the recording, or read the transcript if you wish to do so. We may use some of the recordings as direct quotations in our reports but they will be completely anonymised and your identity will be protected at all times.

The interviews are part of a bigger project and will require more contact and information from patients with breathing problems and their carers in the future. If you would be interested in taking part again or would not want to be contacted then we will make a note of this. Whatever you decide to do, it will not affect the standard of care you receive either now or in the future.

What are the possible benefits of taking part?

We cannot promise the study will help you but we will discuss our findings with health and social care providers. By helping us to understand your experiences and hear your suggestions, we hope that patients with chest problems and their families will get the best possible care in the future and help ensure the right services are in place to do this.

Are there any risks?

No.There are no foreseeable risks. We are only asking you to tell us about your experience as a carer, your experiences within the care giving role and your thoughts on suggestions for improving services in the future. There are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action. Any complaints or concerns about this study should be directed to Dr Cawley: Telephone: *tbc.* E-mail: *tbc.*   The normal National Health Service complaints mechanisms are also available to you.

Will my taking part in the study be kept confidential?

Yes. Your name will not be known to anyone other than the researcher as we will use a code instead of your name so you will not be identified. No information will be given to anyone outside the research group. All documents will be stored securely for at least 5 years and then destroyed. At the end of the study, all the recordings will be destroyed. Occasionally monitors and inspectors may need to access to clinical notes as well as to study data, to check that the research is being conducted according to national regulations.

In the course of the discussion if any information was disclosed that may cause risk to yourself or others, then we would need to discuss the possibility of not being able to maintain confidentiality as the safety of yourself and others is paramount. We would work alongside your local teams to ensure that this process is sensitively handled and the local policies are followed.

If at interview we discover something which we feel the professionals involved should know about, we would discuss it with you and ask your permission to let them know. We will not pass on any information without your permission.

What will happen to the results of the research study?

The interviews are part of a larger study which ends in summer 2015. We will discuss our findings in a workshop of doctors, nurses, and health service managers where we will discuss ways in which we can improve the service provided for people with breathing problems. We will write a report at the end of the study which will be submitted to the University of Kent. We will offer everyone who takes part in the study a short summary of our findings. We will also publish our findings in medical journals in order to help other people to understand the needs of people with breathing problems. You will not be identifiable in any of these reports.

Who is organising and funding the study?

Dr Declan Cawley is leading the study with colleagues from the University of Kent. Dr Cawley will be carrying out all the interviews as it is part of his PhD thesis. The study is funded by the University of Kent and Pilgrims Hospices in East Kent. The study has been approved by the South East Coast - Kent Research Ethics Committee.

What if you have some questions about the study

If you would like to find out more about this study before deciding whether to take part, you can contact Dr Declan Cawley on Tel: *tbc* E-mail: *tbc* You may have to leave a message on an answer phone but we will get back to you as soon as possible. (Please note that we can only answer questions about the study – you should discuss any other concerns with your general practitioner in the normal way).

What happens now?

● If you agree, in about 3-5 days-time Dr Cawley will phone to ask if you are interested in taking part in the study. He can answer any questions you may have. If you are still interested in participating he will arrange to meet up at a time and place of your choosing. If you are not sure, he can answer any questions you may have, and can phone back another day. If you have decided you do not want to take part, he will not try to persuade you and will make a note of this.

● Prior to the interview, Dr Cawley will explain more about the study, answer any further questions, and, if you decide to participate, he will ask you to sign a consent form.

Thank you for taking the time to read this information and please do not hesitate to ask for any more information if you need it.

Appendix L: Consent forms (Patients)

PATIENT CONSENT FORM

University of Kent

Centre for Professional Practice, University of Kent, Compass Centre South, Chatham Maritime, ME4 4YG
Tel: 01634 888847
Email: D.Cawley@kent.ac.uk

TRIGGERS FOR ASSESSING THE NEEDS OF COPD PATIENTS AND CARERS:

Name of Researcher: Dr Declan Cawley

Please initial box

I confirm that I have read and understand the information sheet (version 2: 24/09/2011) for the above study and have had the opportunity to ask questions.	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my medical care or legal rights being affected.	
I understand that the study will involve an interview which will be audio-recorded for the purposes of accurate data transcription, analysis and anonymised quotations used for the published data report to the University of Kent and for publication in professional journals.	
I understand that sections of my medical notes may be looked at by the researcher from the University of Kent. I give permission for the researcher to have access to my medical records.	
I understand that relevant data collected during the study may be looked at by individuals from the University of Kent or regulatory authorities, for the purpose of audit or monitoring and where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
I would be willing to be contacted in the future regarding further contribution to the study.	
I understand that if in the discussions issues are raised that may put me or others at risk that disclosure of this information may be required in line with local policy.	

I would like to receive the results of the study when they are available or alternatively sent to: …………………………………… at the following address: …………..………………………………………………	
I agree to my GP/Consultant being informed of my participation in the study.	
I agree to take part in the above study.	

_____

Name of participant _____ _____
 Date   **Signature**

Dr Declan Cawley _____ _____
Researcher **Date**   **Signature**

Copies: 1 for patient; 1 for researcher: 1 to be kept with patient notes

Consent forms (Carers)

<div style="border:1px solid">

CARER CONSENT FORM

</div>

University of Kent

Centre for Professional Practice,
University of Kent,
Compass Centre South,
Chatham Maritime,
ME4 4YG
Tel: 01634 888847
Email: D.Cawley@kent.ac.uk

TRIGGERS FOR ASSESSING THE NEEDS OF COPD PATIENTS

AND CARERS:

Name of Researcher: Dr Declan Cawley
Please initial box

I confirm that I have read and understand the information sheet (version 1: 24/09/2011) for the above study and have had the opportunity to ask questions.	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my medical care or legal rights being affected.	
I understand that the study will involve an interview which will be audio-recorded for the purposes of accurate data transcription, analysis and anonymised quotations used for the published data report to the University of Kent and for publication in professional journals.	
I understand that relevant data collected during the study may be looked at by individuals from the University of Kent or regulatory authorities, for the purpose of audit or monitoring and where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
I understand that if in the discussions issues are raised that may put me or others at risk that disclosure of this information may be required in line with local policy.	
I would be willing to be contacted in the future regarding further contribution to the study.	

I would like to receive the results of the study when they are available or alternatively sent to: ……………………………… at the following address: ……………..……………………………………………..	
I agree to take part in the above study.	

_____   _____   _____
Name of participant   Date   Signature

Dr Declan Cawley   _____   _____
Researcher   Date   Signature

Copies: 1 for carer: 1 for researcher

Appendix M: Sample audio transcript (Participant I07)

<u>**Interview with participant I07**</u>

Okay, [interviewee name]. Thank you very much for being a part of the study...

That's all right.

... and one of the things as you know from the information leaflet we're trying to do is really to understand some of the problems that people with COPD breathing have.

Yes.

It would be helpful for me, if you don't mind, is just let me know some of the problems that your breathing causes you or how it interferes with... at the moment.

Right now?

Yeah.

Okay. Well it's some days I'm all right and other days I'm not. It... Going and walk out the town, right, I get breathless. And good job we've got a lift in... up the stairs, right, because I get breathless going upstairs if I go out with my daughter or something, I get breathless then.

Okay.

And sometimes I get a bit breathless in the night. Not very often but I do. I can't think of anything else at the minute.

Okay. So it sounds like you get breathless when you're... sometimes at night, sometimes when you're out going up the town.

Yeah.

But from a day-to-day point of view, things like in the house with your breathlessness so things like getting yourself dressed, having a shower?

That's all right. Hoovering; that makes me breathless.

Okay.

I have to sit down...

Okay.

...and have a rest and then I start again.

Okay.

And that's... that's it. Just day-to-day things indoors makes me breathless.

Okay. So just the basic getting yourself washed, dressed, hoovering, making dinner – those sort of things?

Yeah. Yeah. Getting out of bed I'm all right.

Okay.

It seems to be as soon as I come out here and I go to the bathroom, that's when I seem to get breathless; in the bathroom. I don't know why.

Okay.

But I do!

Okay. And what do you do to try and help that? So what are the things that you do to try and help things?

Well I take my puffers in the morning and if it keeps on I do, I take the blue one. Find it [looking through a bag]. 'Easy breathe'.

Okay. Yeah.

Yeah. I have a couple of puffs at that. That's in here somewhere [handbag] and I have a couple of puffs there. That seems to ease it then and I'm all right then.

Okay. Okay. And do you think in the house here and when you're doing things you take your time with it, you slow down a little bit?

Oh absolutely. I'm not what I used to be. I mean I used to rush about but of course I've had my hip replaced as well so I can't do that now.

Okay.

You know, so... Yeah.

Okay. And so you talked a little bit about the day-to-day bits that... that it affects but apart from the breathing problem and sort of the breathlessness that comes with that, any other problems with the... that your breathing causes in the house so generally?

No, I don't think so really. No.

Anything it's stopped you doing or things you can't do that you once did?

There's a lot of things I can't do now that I used to!

Can you give me some examples?

Well it's outside as well. I used to do a bit of gardening. I know I can't do that now but if I'm doing some standing up doing something then I get breathless and... and downstairs we have a... a bingo afternoon and if I have to move chairs about I get breathless then.

Okay.

And that's about it really. I mean I can't make beds anymore. Well I can make them but I can't change them.

Okay.

My daughter does that for me, both the beds.

Okay.

And... But I can pull... I can take the dirty things off but I just can't get to make them so...

Okay.

Too puffed out.

Okay. So it sounds like your... your daughter gives you a hand to do some of those things as well?

Yeah. Yeah. Yeah.

And are there other things that your husband has to help now with during the day that you had to do... you could do yourself previously?

What; he has to help me?

Yeah.

No. He's got dementia so he don't know what he's doing, so...

Okay.

Yeah.

Okay. Okay.

I mean I ask him to take his hanky out of his cardigan pocket and he's in his trousers, right, and I'm saying, "No, cardigan!" And he's still... he's going...

Oh dear.

Just things like that. Silly things, you know.

Okay.

Yeah.

Okay. And have you had any things in the house to be adapted, so have you had a bath aid or toilet seat raised or any of those sort of things?

No. We've had... I've had... It's only for my hip, this was, this raised.

Okay.

Toilet seat. I've had a toilet seat put on.

Okay.

This... this was all to do with my hip, see.

With your hip.

Yeah. And a thing to go round the toilet.

A frame, is it?

Yeah. And we've got a shower now. We've all got showers in this block now. We used to have a bath.

Okay. Was that changed?

Yeah. Everybody's got a shower now.

And was that...

Sorry?

Sorry. Was there any particular reason it was changed to the shower?

No. It's just the council; they wanted to... We had a new kitchen and a new bathroom and a new toilet and all the flats have got those.

Okay. So it... they were upgrading them then?

Yeah. Yeah.

Okay. Okay. And with your breathing and things changing, we know that that can affect how you think, how you feel. How do you feel about the things that your breathing stops you from doing?

Aggravated with myself. I get annoyed with myself. Yeah. I say, "I used to be able to do this years ago" but I can't do it now.

Do you ever feel down or...?

Not because of that I don't. No. No. My husband makes me down.

Oh. Okay.

Yeah. When he's away... He goes away... He goes to respite. He's just come back about a week ago from respite and I'm a lot calmer when he's not here.

Okay.

You know? And he was away for four weeks in February. And when I go up my granddaughter's or I go over my daughter's and I'm fine there.

Okay.

So I'm... I... I just blame it all on him. You know.

Okay.

Yeah.

Do you ever feel frustrated?

With him?

With your breathing.

With... Yeah. Yeah.

Okay.

Yeah. As I say, you can't do what you used to be able to do.

Okay. And how do you feel your overall sort of health and wellbeing is at the moment?

All right, I suppose. I mean I've got to go up the health centre tomorrow to have a heart thing, monitor thing.

Okay.

And I've been signed off for my hip so that's all right.

So you're not working at the moment?

No. I don't go to work. No.

Okay.

I've not worked for... Oh I don't know. About ten years I suppose now.

And for most of the problems you feel more that it's your hip than your breathing?

Well it was my hip because it was so painful at one time but of course that's all right now. But now it's my back.

Okay.

So...

So if you were to say your back or your breathing which is the one that causes you most problems at the moment would you say?

Breathing.

Your breathing.

Yeah.

Okay. Okay. I mean we've just talked about a little bit about how you're feeling, how your breathing affects, how it affects how you're feeling in yourself, but also things in the house – how it's affecting you and obviously things you can do outside or not.

Yes.

Has anybody ever sat down and actually talked you through what the problems are, what it's interfering with, what things you can do/can't do? Has that ever happened to you before?

No.

Okay. Do you feel it might be a good idea that if somebody was to sit down and actually get a more kind of a... more like an overview or picture of how things are and how...

Yeah.

...how things are generally?

Yeah.

Do you feel that would be a helpful idea to...?

Yeah. Yeah. Yeah.

And what we're trying to think about is... is actually knowing how it affects you, not just about your breathing or how good or bad it is but actually what is on a day-to-day basis are the things that it's impacting upon, like the toilet seat, like managing the shopping, like being able to go up the town but also things about what does the breathing affect you on a day-to-day basis of washing, dressing and also the other thing but how does it make you feel because obviously you said aggravated with it and frustrated?

Yes. Yeah. It's my husband that started. He was like that. Yes. Yeah. He's still got COPD but I mean he couldn't walk down the road. He couldn't walk from here across the road without his breathing right.

Okay.

And but he seems all right now.

Okay.

It's me. I've got it now.

Okay. Oh.

I have walked down the road and things like that but it is stairs gets me, you know.

Okay. So it's... it's anything that you'd go upstairs or... up hills, those sort of things?

Oh yeah. Yeah. That's... that as well. Yeah.

Okay. And I suppose with thinking about people getting this overview just generally how things are and it's obviously not happened to you, have you thought about when actually that might be helpful for people to actually think about asking you, so times when you found things difficult and awkward and you think *yeah, I... I think I would quite like if they asked me how I was generally doing?* Have things happened, or...?

People do do that here.

Okay.

They always ask how you are.

Well what about...

And of course you always say, "Oh I'm fine," like, you know. Even when you go up the doctors where you see somebody up there and they say, "How are you?" I say, "Oh I'm fine."

Okay.

But you're not really because you don't go up the doctor's if you're fine.

True.

Yeah.

Is it something that you would freely tell people if you were struggling or having difficulties?

Yeah. I mean I've got two good neighbours here. [clears throat] This is what it does to me. [clears throat]. Two good neighbours. I've got one upstairs and one round the corner and then especially when I had my hip done, they was always round and brought me shopping and doing things for me, like, you know. Then my daughter stayed here. She had to go to work, but she stayed all night.

Okay.

And yeah, so I mean I wasn't allowed to move. She said, "Don't you move. Don't you do that."

Okay.

But I was all right.

So it's your neighbours you find are the most helpful?

Yeah. They're... Yeah. Yeah.

And I mean what... How would you feel if... if somebody like your GP was to ask general sort of overview how things are – do you think that would helpful to get a sense of how things are and how...?

What; if I asked them?

No, no – they would ask you, so...

Oh yeah. Oh right. Our GP's really good though. Mmmm, I suppose so. Yeah.

Okay. You don't seem too sure about that. Are you...?

[pause] No. No. That's all right. Yeah. Fine. Yeah.

And what about if the practice nurse was to ask you the same sort of questions, so different people asking the same questions to see how you're doing – would that be...?

Yeah.

It would seem okay?

Yeah.

Other people would be like the respiratory team. I don't know if you've any contact with them at all?

Yeah. The asthma clinic – is that what you mean as well?

Well the nurses are in the clinic, yeah. That's... is that the breathing clinic you go to?

Yeah.

How often do you go to that?

Not very often.

And did they ask you how you're feeling and how you're...?

Yeah. And she said, "Well..." and I blow into that thing there. They've got a different thing now to what they used to have. I used to go red in the face, right, but... And the doctor does that sometimes and especially if I've got a cough, right, she does that to me. And I blow into that. I'm always… she puts a tube on the end.

So she'd look at spirometery which is the breathing...

Yeah, I've had spirometery. Yeah. That...

And there's a peak flow.

Peak flow. Yeah. And she's... When I went up there last, she said it's only a little tiny bit better. It just seems to stay the same.

Okay.

So...

Is that... So... If we take the same idea that if you're getting your peak flow done and they're doing it intermittently and seeing how does that compare, if we were to do an overview of how things are but to do it at different points, do you think that might be helpful to sort of almost give you some information on ourselves about how things are?

Yeah. Should think so. Yeah. Yeah.

Okay. And you feel it'd be okay for different people asking you the same questions?

Yeah. Don't matter to me.

Okay. And would you be happy if we were to do that that we then would share that information between different professionals to...

Yeah. That's all right. Yeah.

...give them the same information?

Yeah. Yeah.

I mean if we were to do this sort of overview, this assessment or progress report on how things are, would you want a copy of it? Would you want to...?

Yes I would like one, please. Yes.

You would want a copy. And how would you feel... Some of the examples that we are thinking about is... is trying to be more proactive so instead of just waiting for problems to happen, us maybe thinking about things that are happening already. So an example would be like when you're doing the blowing test...

Yeah.

...with the breathing test, how would you feel then if the nurse said, "Okay. So we'll sit down and tell me how things are at the moment. How..." and sort of almost make this... this as... this progress report, if you like, to use that as an opportunity to talk about how things are?

Yeah. Yeah.

How would you feel about that?

Yeah. That's right. Yeah.

And that idea again that it's happening alongside something else, would that be better than to take you down separately to try and do that so we sort of add on to what you're already having rather than trying to make a new appointment for something else and something different?

Just add it on I think.

Mmmm. Add it on.

Yeah.

Okay. And have you ever felt times when... So I'm talking about things that we... we can see already - the blowing test – but are there other times you've been down to the GP or things that have happened that you think might've been helpful to get an overview or people to ask further questions about how you're doing?

No, I don't think so.

No.

No.

Okay. Okay. Great. One of the things that we're thinking about are other things that happen or other things like you say... we'll use for an example to try and help is to think about the blowing test – breathing test - but we can add things on to the sort of general overview of how things are.

Yeah.

So that's what we're... the way we're thinking about this so what we're thinking about is this idea that something like that would trigger us to ask for something else and how you're doing.

Oh right. Yeah. Yeah.

So rather than just wait... *okay, well I've not seen [interviewee name] so she must be okay* **so… assess you...**

Yeah. Yeah. Yeah.

...we'd be much more proactive in asking how things are. How would you feel about that?

Yeah. That's right. Yeah.

Okay. So that idea of us trying to be more proactive and...

I must say this; when I... I used to go to the gym up the town... up the town, right, and I couldn't go no more when I had this done but I asked a consultant when I went up there and he just signed me off, right, and he said, "You can go back now," and I... I do aerobics – swimming aerobics, you know; water aerobics. He said I can do that. But I don't get out of breath up there.

Oh right.

In't that funny. I don't know what it is. I don't know… on the treadmill thing but I didn't get out of breath.

So actually it was...

My hip hurt me.

Okay.

That's why I had to stop, you know, when I was doing it.

But it wasn't the breathlessness stopped you?

Oh no. No, no. No.

So exercise was actually a bit helpful.

Yeah. Yeah. So I'm going back as soon as that room's finished then I'm going back up there.

Good.

Yeah.

Good, good. I mean we talked about some of the things that I was asking just to how things are generally and getting an overview. Do you think that there are other questions or other things that we should ask about, so I suggested something about how you're feeling about things, how are things in the sense of how are you managing the shopping, day-to-day stuff - are there other things that you think maybe should ask me about that or we should be including or asking how things are?

At the minute I can't think of anything.

No. Okay. Okay. Or anything that you think would be important to you for them to understand and know?   What about your husband, given the fact his... his condition and concerns?

We do have somebody come round. We have... I can't think of her name now. [named individual] I think. Something like that her name is. And she comes round or somebody else'll come round.

Do you know what she...? Is she a nurse?

She's a psychiatric nurse, yeah.

Okay.

Yeah. From St Martin's in Canterbury and she's very good and she'll come round and have a talk.

Okay. So do you think would it be helpful if we're asking questions about you that we actually ask about if your partner/husband how their health is, how their wellbeing is? Because thinking if you're saying to me that your husband has the problems with his memory – dementia – then it would be important for us to know that.

Yeah. Yeah. Well see he's got a short-term memory... A long-term memory/short-term memory.

It's the short-term memory, is it?

Is it short-term?   Yeah.   It's... he's watching the telly sometimes and he says, "Oh that's..." I mean I don't even know who it is, right – I've forgotten who it is. Something so... donkeys and donkeys years ago, like, you know.

Sure.

Yeah. Or if you ask him a question or say he's watching something, "Who's that then?" and he'll say it straight away. He's like... he's like that so he can remember things way back but he can't remember what I've just said to him.

Okay. So short-term memory wouldn't be very good but he's got recall of his long-term memory?

Yeah. Yeah.

Okay. So what we're thinking of is if we're more proactive, we ask the general overview of how things are but also thinking about the same people or sort of the same questions being asked by different people so even like a social worker who'd ask about your benefits asking, "Actually, [interviewee name] tell me about your breathing – how is that?" so whoever would see you that they can ask similar questions to see how things are.

Yeah.

And would you be happy that we would share that information and as you say, we could give you a copy of that progress report?

Yeah. Yeah.

Okay. And can I ask; do you have... do you have attendance allowance if you're having to look after...?

Yeah. Yeah.

Okay.   And what happened there?   Did you prompt that or did they prompt you to it?

No they did.

Okay.

Yeah.

And how did that happen, would you mind me asking?

Oh God. I can't remember now.

Is it attendance allowance for yourself or is that...?

Both. We get attendance allowance and the other one. I can't remember what it's called.

Disability living allowance?

Yeah. Something or other like that. And...

Can I ask who put you in contact with that or to get it?

I think it was the... Oh I know; it was the care manager, right, and she said about it. I mean she don't do it anymore but the person that... when she used to do it. That's right. She got all that in motion.

And how... who approached the care manager?

A doctor, I think.

A doctor.

I *think* she did. Yeah.

Okay. Good. Okay. That's helpful to know.

But we... we have a care manager but you don't know who it is.

Okay.

We used to have one. Just one, like, you know, but so many have left or they've been ill or something or other that you just phone up and somebody comes and you've never seen them before, like, you know.

Yeah. It's difficult to keep track, isn't it.

Yeah. Mmmm.

I suppose the other thing what I was thinking in my head as well is that if we were to do this assessment, take things on board and see how it's happened, anything else you'd like us to do with that information

so would you share it with different professionals involved, we'd give you a copy of this.

Yes.

Anything else you'd like us to do with it or... or where should it go or who should inform we've done it?

Just inform the people, that's all.

Okay.

Yeah.

So inform those who are...?

Yeah. Yeah.

So I hope you don't mind me taking an example of your husband and your own situation, so if I was to... you'd go down to the GP's surgery and they were to do an assessment or the practice nurse would do it, would you be happy that they would share that with the GP, the care manager?

Yeah.

Share that information?

I think so. Yeah.

Yeah. Okay. And would you be happy for that to be repeated over a different time points to... to see how the progress is?

Oh I see what you mean. Yes. Yes. Mmmm. Mmmm. Yeah.

And see... because it's the idea that the progress report would see if things have changed or if there's problems then they'd be able to offer potential things to try and help.

Yes. Yes. Mmmm.

So rather than you having to wait for things to happen then give you an opportunity to... to try and help.

Yes. I suppose.

Okay. So... Some of the things that we were thinking about, really sort of look for your opinion on these here which would be helpful is that we were thinking things that trigger – the things that sort of prompt or alert this process to happen – and obviously think about who would see it, so who would be... who would we be alerting to it? So like a hospital admission - have you had a hospital admission recently for your breathing at all?

No. No. I've never been in hospital for it.

Okay.

No.

And is that something that you try and avoid at all costs?

What; going to hospital?

Yeah.

No. Hospitals; I don't mind. Dentists; I don't like!

Oh right. Okay.

They can do anything to me in hospital.

Okay, but it's the dentist...

It's the dentist. No.

Okay. Do you think for people who have been in hospital and who have been unwell that it might be a helpful time just to when they come back out or at that... at that time is to think about what the problems are, again just to take stock to see if they can help with anything?

I don't exactly know what you mean.

So if you're thinking about when for us to trigger asking those questions that I did earlier on today, do you think if you were in hospital or just recently been in hospital that that might be a time to think _let's ask some more questions. Let's see how [interviewee_

name]'s coping generally and how things are at home **so that if things aren't so good we can potentially offer potential solutions to some of the problems.**

Yeah. Yeah. Yeah, that's a good idea. Yeah.

Okay. So the idea is that if things are happening, like a hospital admission so that would then prompt us or springboard us to think about *okay, we need to maybe ask [interviewee name] a bit more questions.*

Yeah. Yeah.

...*some more questions about how she's actually doing generally.*

Yes. Yes. Mmmm.

Does that seem like a sensible...? When we were thinking... One of the other things we were thinking about is if you were needing a blue badge so if things were difficult that that might prompt us to think *well okay, should we ask how is [interviewee name] getting on at home? How is she managing with...*

Yeah. Yeah.

...*bathing? How is she managing cooking meals?* **So we ask those wider questions.**

That's all right. I can manage all those things. [Clears throat]. Yeah, my husband used to have a blue badge but he doesn't got one now.

Okay.

Because I forgot to renew it.

Okay. And what about your children? You said your children take (*inaudible 00:24:39)

Yeah. My daughter. She lives up the road there. I mean if we have to go anywhere, like when he goes to respite in Faversham she'll take me over there, you know.

Okay. Do you drive yourself?

No, no. I wish I did. I should have learnt years ago. And yeah, there's always somebody [clears throat] to call on.

Okay.

[Clears throat]. Oh dear!

Are you all right?

Yeah. There's always somebody to call on or the people... Oh, I can't remember what they're called. The volunteer cars. We have those and they're really good. My friends haven't got cars anymore because one of them used to take me about if I wanted to go somewhere but she's just got rid of her car. But as I say, we have taxis so we do get extra money for things like that, like, you know.

Okay. But do you think if your daughter said, "Okay..." If you were talking to me and I said, "Okay. So you have difficulty getting out – well would it be helpful if your daughter had a blue badge to help you get closer to events or get closer to the hospital appointments..."?

Yeah. She did say that. She said, "You must bet a blue badge or even for dad, like. Get one for him, like." But sometimes like she takes him. We both go out somewhere with her, like, you know, to take us out. She said, "You must get a blue badge."

So that might be helpful to...?

Yeah. Yeah.

And you were saying to me about you having some of the things that... The raised toilet seat, the frame with your hip but if you had problems with your breathing that were causing those similar problems, do you think that might be a good time for us to think about how... how things are generally, thinking of this overview of how things are?

Like the... the frame is going back.

Oh right.

I've asked them to take it back and also the... I've got the walker... the walking frame as well, like, and I've asked them to take that back. And the toilet seat, you know; the raised one...

Yeah.

I've asked them to take that back because I'd bought one, right, so I knew they'd take that back.

Okay.

But then that broke the other day.

Oh.

So I had to go and get the other one out the shed so I'm going to phone them up and ask them if I can keep that one for now...

Okay.

...and just take two things back instead of three.

Okay.

Yeah.

And who... who got you that stuff? Was that...?

It was the hospital.

Hospital. Okay.

Yeah. Yeah.

Okay. Okay. So it sounds like from your point of view that's... that's something that's not particularly pertinent to you at the moment?

No. No.

No. Okay. What about if people weren't getting out and about, so people were sort of confined to the house – do you think that might be a good time for people to think *okay, we need to see how, you know, [interviewee name]'s doing. She's not getting out any more so...*?

Mmmm. Mmmm.

And who would see that? Who... who in your kind of circle would see that you wouldn't be getting out so if you're normally out and about?

Well my two friends here.

Okay.

My daughter. The two daughters that are closest.

Yes.

There's one lives in Whitstable and the other one lives in Beltinge but the others; one lives in Ashford and one lives in Wales and one lives in Cornwall so I mean they're farther away, see. But I mean the two that live closest, they're all right. Yeah. They'll be... They're all right.

Okay. Okay. And what about if things were just getting a bit more... You said about attendance allowance and you have it and that it's letting you get around. Because that would signify that things were becoming more difficult and you needing to get some money in to try and help look after each other I suppose. If at that point the care manager said, "Okay, [interviewee name]. How are you doing? How... how is your breathing? How is it affecting you?" you know, sort of again same questions but... would that be a helpful, useful time to try and ask how things are?

Yeah, I suppose so.

Okay. And generally if you felt that things were just more difficult so if you were feeling that your breathing was worse, do you feel that should be a sense of us trying to ask how that's impacting upon you, how that interferes with things?

Yes.

Okay. And what about appointments, [interviewee name]? Do you find it difficult to get to appointments at all, so...?

No.

No.

No. I get a taxi. I have to take my husband up there and get a taxi for him. Well he can't walk far so... He's getting too old.

Okay.

He said to me the other day... Because he'd been on respite for a week and when he come back he said, "Where are we going then?" I said, "I'm not. You are." "Where are we... Where am I going then?" I said, "You're going back to Age Concern." "I don't want to go there," he said, "with all them old fogies"! So he... he remembers things like that.

Sure.

You know, but I mean... No, he's all right really. I mean he gets on my nerves. I just walk away and he forgets about it, so...

Okay.

Yeah.

Okay. Okay. Thank you for that. So you've not missed any appointments so you normally make them and you don't... not able to attend them because of your breathing?

No, no, no, no. No. Even if I get a bad cold and a cough I do go to the doctor's as soon as it starts.

Okay.

Right? Because I know what'll happen if I don't and I will be in a bad state, like, you know, with my breathing so I do go up there.

Okay. Okay.

Mmmm.

So if people weren't able to go up to the... and when they've made appointments and they weren't able to attend because of their breathing being bad, do you think that might be a good time for people to... or a helpful time to ask about how things are generally?

Yeah. Yeah.

Okay. And the last thing we were thinking about is when things change, so when you've been out and about doing things and then actually you realise *no, actually I can't do that anymore* **so priorities change and think** *well actually I can't do this, I can't do that* **– might that be sort of time to think about** *okay, so let's look at what we can and can't do and see what things can be put in place to try and help that* **and what you said to me what you've felt better is when you went to the gym...**

Yeah.

...because actually you were exercising

Yeah. Yeah.

So actually thinking about the things that actually might help you get back to a stage where...

Yeah. Yeah.

...things aren't as problematic.

Yeah.

Do you think that might be helpful just to get an overview?

Mmmm.

Okay. And from just generally thinking about the research, do you think are there any things in particular that you think we should know about people with breathing problems and that might be helpful to try and help manage or I mean help better provide services for them so in your experience and what you've gone through so far? Any gaps you think that currently exist that we should be addressing?

I don't... I... I... I don't feel that I'm that bad really. I mean there is people I've seen worse, especially in here and I mean there's a man that lives here and he went out in the wind and the fog and I said, "You shouldn't do that! You mustn't go out in the fog and the wind and that," you know but he still does it, so... And his breathing is terrible.

Oh is it?

Yeah. But I mean I remember my... when my kids was little the health visitor said... Coz one of them I had to put outside *every* day. She was out there all day, right, in her pram – even the rain and that, you know - and she... and the health visitor used to come round then and she said... she said, "All right out there in all that weather. Don't matter if it's freezing..." not freezing cold, but "snow out there – it's all right as long as you don't put her out in the fog" for breathing, see.

Sure.

Yeah. So I don't go out in the fog.

Okay. That's interesting…

Yeah.

Good advice.

Yeah.

Okay, [interviewee name]. Thank you very much for taking part.

That's quite all right.

Anything else you want to ask? Anything else you think we should know from your point of view?

I don't think so.

Okay. I'm just going to stop the tape. Thank you again.

Appendix N: Evidence of Thematic Content Analysis

Samples from Qualitative Secondary Data Analysis (Chapter 3)