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WHAT IS THE ROLE OF HEALTHCARE PROFESSIONALS AND COMMUNITY SERVICES IN EMERGENCY ADMISSIONS OF PEOPLE WITH ADVANCED COPD AND LUNG CANCER? A SECONDARY ANALYSIS.

By

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ABSTRACT

Patients with Chronic Obstructive Pulmonary Disease (COPD) and lung cancer are often admitted to hospital at the end of life. This study offers insight into the role of community healthcare professionals involved in preventing emergency admissions. Secondary analysis was conducted of data from a qualitative study exploring emergency admissions of patients with advanced COPD and lung cancer. Data was retrieved from twenty eight original interviews, including fifteen healthcare professionals from one district hospital. Data was organised into themes and analysed using a constructivist case study approach. This study investigated the healthcare professional's roles in the admission process that had not been explored in depth in the primary study.

Understanding the role of healthcare professionals and community services in emergency admissions is complex and influenced by environmental factors. Patients admitted often experienced a change in normal support, gaps in service provision and being left with no alternative than hospital admission.

Absence of key healthcare professionals or community support increases the risk of emergency admission.

This study highlights the importance of consistency in care organisation within community settings. Strategies need to be implemented to manage patient expectations and promote understanding of community support.

DEDICATION

To my amazing Mum, I love the bones of you.

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LIST OF DEFINATIONS AND ABBREVATIONS

COPD – Chronic Obstructive Pulmonary Disease

SPCS – Specialist Palliative Care Services

NICE – National Institute of Clinical Excellence

NHS – National Health Service

DH – Department of Health

WHO – World Health Organisation

UK – United Kingdom

ED – Emergency Department

RICT – Respiratory Intermediate Care Team

EOL – End of Life

CCM – Community Case Manager

CRN – Community Respiratory Nurse

HRN – Hospital Respiratory Nurse

PCN – Palliative Care Nurse

RCNS – Respiratory Clinical Nurse Specialist

PT – Patient

GP – General Practitioner

LCNS – Lung Cancer Nurse Specialist

LTC – Long term condition

CNS – Clinical Nurse Specialist

CHAPTER ONE – INTRODUCTION

1.1 Chapter Overview

This chapter will introduce the subject selected for this study, discuss the reasons for choice and explain the relationship of the issue to current nursing practice.

1.2 Introduction

The increasing number of emergency admissions and attendances at emergency departments (ED) is a complex problem. There has been an enduring drive within the National Health System (NHS) to manage demand and to reduce unplanned emergency admissions. The National Audit Office (2013, p.5) defined emergency admissions to hospital as “admissions that are not planned and happen at short notice because of perceived clinical need”. Efforts have been made to control these numbers, however the number of emergency admissions continue to rise each year (Blunt et al., 2010, Purdy, 2010, Roland and Abel, 2012). Between 2012 and 2013, there were 5.3 million emergency admissions to hospitals, a 47% increase over the last 15 years, costing approximately £12.5 billion (National Audit Office, 2013). It is imperative that the National Health Service (NHS) manages these unplanned admissions, not only because of cost implications but also because of the effect they have on elective healthcare and the individuals admitted in each case (National Audit Office, 2013).

A large number of these emergency admissions involve patients with cancer and Coronary Obstructive Pulmonary Disease (COPD). There are currently around 160,000 emergency hospital admissions for patients who have lung cancer per year (Hospital Episode Statistics (HES), 2011). Similarly, there are 135,000 admissions to hospital for patients with COPD in the United Kingdom (UK) per year (Calderón-Larrañaga et al., 2011). Patients with life limiting conditions such as COPD and lung cancer access the Emergency Department (ED) for a variety of reasons at the end of life, including pain, exacerbation of symptoms, panic, anxiety and general deterioration. Gott et al. (2013) confirmed that patients with life limiting conditions experience a number of preventable hospital admissions in the last year of life. Since COPD and lung cancer patients are more likely to die in hospital than anywhere else (EoLCIN, 2011), addressing the issue of emergency admission for these patients is an important area for research.

All divisions of NHS England have a part to play in managing these emergency admissions, ensuring that patients are treated in the most appropriate settings. The National Office of Statistics (2013) suggests that primary healthcare settings such as community nursing and social care can help manage a patient’s long term condition better in the community thus preventing an emergency admission, estimating that “at least one fifth of admissions could be managed effectively in the community” (National Office of Statistics, 2013 p.8). When community and social care services are not working effectively, the burden is often taken by emergency departments. If patients are not accessing the relevant services in the community, or they are unavailable to them, they may attend the emergency department placing additional pressure on these already pressurised resources (National of Office Statistics, 2013).

NHS England (2013) announced a review of all emergency and urgent care services in England, setting out to address a wide range of issues including, patient experience, outcomes, sustainability, and access. It aimed to provide patients who have urgent non-life threatening needs with “highly responsive, effective and personalised services outside of hospital” (NHS England, 2013 p.5). It also acknowledged that “many people are struggling to navigate and access a confusing and inconsistent array of urgent care services provided outside of hospital, so they default to A&E" (NHS England, 2013 p.5). Community care for patients with COPD and lung cancer can impact on numbers of emergency admissions, highlighting the need to examine service provision for these patients to determine how effective community care can be at preventing an emergency admission.

Due to the needs of patients with COPD and lung cancer not always being met there is a possibility of dying in hospital. There is therefore a need to investigate, from their perspective, the reasons behind these emergency admissions. Between 56% and 66% of people in the United Kingdom (UK) die in hospital (Costello, 2006; Gomes and Higginson, 2008). It has been estimated that 90% of people will experience a hospital admission during the last two years of life (Office of National Statistics, 2008; Dixon et al., 2004). These end of life hospital admissions may be neither necessary nor appropriate. Research suggests that these patients are left with no alternatives (Quest et al., 2011). Gomes et al. (2011) predict that by 2030 only one in ten patients will die at home. Current research demonstrates that little attention is given to the supportive needs of the dying patient, resulting in lengthy admissions, problems associated with further treatments and unnecessary interventions (Bailey et al., 2010). The patient voice should be considered and addressed, in an attempt to reduce numbers of emergency admissions.

End-of-life care is defined as being "the total care of a person with an advanced incurable illness and does not just equate with dying. The end-of-life care phase may last for weeks, months or years" (NHS, 2011d p.1). This is the care relevant to those persons who have COPD or lung cancer. As end-of-life care is seen as a pioneering area of research (Chan, 2006) this project is appropriate to nursing clinical practice as it aims to discover what the roles of healthcare professionals and community palliative care services are amongst both patients with advanced COPD or lung cancer and their carers, who experience an emergency admission. The research question 'what is the role of healthcare professionals and community services in emergency admissions of people with advanced COPD and lung cancer' reflects this intention.

1.3 Background

Currently ten million people in the UK are over the age of 65, this is predicted to increase by five and a half million in twenty years' time (Parliament UK, 2010). Given the increasing ageing population in Europe and other developed countries, more and more of the elderly population live with one or multiple long term conditions. These people are far more likely to have chronic health problems meaning an increased need for urgent care or a hospital admission. They are more likely to make a visit to the emergency department and are more likely to be admitted once they are there (National Office of Statistics, 2013; World Health Organisation Europe (WHO), 2004; Costello, 2006).

People with COPD and lung cancer are increasingly regarded as having a long term condition. This is due partially to the approach to end of life care which now focuses on a longer period, consequently their care needs are similar to the increasing number of people with long term conditions (LTC). Long term conditions or chronic diseases are conditions for which currently there is no cure and are managed with drugs and other treatments (The Kings Fund, 2014b). The Department of Health (2012b) reveals there are currently 16.5 million people in England with one or more LTCs. The quality of end of life care in hospitals is a priority and responsiveness to individual need and circumstances is seen as integral to delivering this quality care (Oliviere and Monroe, 2004). Enhanced funding has been given to primary care trusts to ensure high quality provision of end of life care (DH, 2008a).*The National Health Service (NHS) National Institute for Health and Clinical Excellence* (NICE) (NHS, 2011a) published guidelines on quality standards for end-of-life care for adults which set markers of high quality care for all those approaching the end of life. They proposed that people at the end of their life should be identified at the right time, ensuring they receive appropriate care and that they should be communicated with and offered information in a sensitive way. They should be offered full assessments to ensure they are receiving the best care for their individual circumstances and these services should be offered at any time, day or night, whenever they need it. Care should be consistent, smoothly co-ordinated and delivered by staff who are aware of their medical condition (NHS, 2011a).

As the proportion of older people in the UK population grows, more people will experience a death which is drawn out and complex, requiring support from healthcare services for many months, if not years. The needs of a changing demographic must be met, people are less likely to die ‘before they should’ and most people will die after a long life. Higginson (2001) suggests that three quarters of UK deaths are predictable and will follow a period of chronic illness. Efforts need to be made to change the focus from trying to prolong life to improving the quality of our lives right to the very end. Leadbeater and Garber (2010, p.84) proposed that “the goal for the twenty-first century should be to improve quality of life, learning to live well, including at the very end of life: quality should become more important than further quantity; better years rather than more years”. Dame Cicely Saunders stated in 1968 that “you matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but to live until you die" (Saunders, 1968 p.1). This notion is still important today, the NHS suggested that continued work is required across healthcare to enable patients to receive end of life care in their own home. It comments that the system at present is complex, with multidisciplinary care limited (NHS, 2013a). Attention must be given to ensure end of life care within and outside the hospital environment is fully considered.

The NHS National Institute of Clinical Excellence suggests that people approaching the end of life should have access to high quality care regardless of their individual circumstances (NHS, 2011b). An idea which is not new to end of life care, the Department of Health's *End of Life Care Strategy* published in 2008 (DH, 2008b), suggests that high quality care at the end of life should be available to all. It seems however that end of life care may not be as equitable as proposed (DH, 2008b). Equity of access to end of life care services is a core goal which guides palliative care policy (Mathew et al., 2003). Ahmed et al. (2004) suggest that referral and access to palliative care services may not be accessible to all who could benefit from them. Although efforts are underway to improve end of life care, evidence grows to suggest that the most vulnerable patients are at risk of missing out (Krakauer et al., 2002).This equity of access, will often contribute to patients attending the emergency department, as the emergency department is accessible to all.

Palliative care is described by The World Health Organisation as an approach which improves the quality of life of individuals and their families facing the problems of life threatening illness, by encompassing physical, psychosocial and spiritual elements (WHO, 2013). Palliative care was traditionally believed only to apply to those who were dying. Recently the scope of palliative care has changed to encompass supportive care to patients in the earlier stages of disease trajectory (McIlfatrick, 2007). Specialist palliative care services (SPCS) address the needs of patients and caregivers, confronting a life limiting illness. The last two decades have seen palliative care and supportive services in the United Kingdom flourish (Ewing et al., 2009). Despite this Currow et al. (2008) argued that only half the patients who could benefit from SPCS are actually referred. Ahmed et al. (2004, p.526) remark that some patients have been seen to be “doubly disadvantaged not only because of their life threatening disease and the distress associated with that, but also by being excluded from the benefits of palliative care”. Patients should not be disadvantaged due to their condition at this critical stage of their care.

Despite recent recommendations and guidelines, inequalities in referral to SPCS exist; referrals are occurring late in the disease trajectory (Wentlandt et al., 2012). The majority of patients are referred to palliative care services within thirty to sixty days of death, with some patients being referred in the last days of life (Osta et al., 2008; Cheng et al., 2005; Earle et al., 2008 and Lamont and Christakis, 2002). A systematic review of studies examining barriers to access to palliative care services identified a lack of standardised referral guidelines, inequity of access, and health professionals lacking knowledge about palliative care as key concerns (Ahmed et al., 2004). Guidelines developed for cancer patients in the United Kingdom by the *National Institute for Clinical Excellence* (NICE, 2004) identified key areas to assist supporting patients and their families, ensuring they are well informed, cared for, supported and involved in decision making. Patients with advanced cancer should have access to a variety of services to help improve the quality of their lives and there should be support given for patients dying with cancer. Potentially these guidelines can be adapted to suit the provision of palliative care to patients with non-malignant diseases (McIlfatrick, 2007). Barriers in access to these services will have a knock on effect to emergency admission rates in the United Kingdom.

It has been demonstrated that there is a need to improve palliative care services for all those suffering from a life limiting condition. Due to this need and its complexity further research is required to investigate the role of community palliative care services, and its impact emergency admission numbers. This research will influence future policies and guidelines for patients with conditions such as COPD and lung cancer.

Chronic obstructive pulmonary disease (COPD) is a widespread condition associated closely with significant mortality rates (Gardiner et al., 2010). In the UK it is one of the most common respiratory diseases. The National Institute of Clinical Excellence (NICE, 2004) estimates that 1.5 million people in the UK are affected by this condition. Connors et al. (2006) showed that prognosis for patients with COPD is poor, showing that 50% of people with severe COPD die within two years of admission to hospital. Due to the nature of the disease, patients with COPD are more likely to live with their disease for a longer time than patients with lung cancer (Halpin et al., 2008). An early focus when managing COPD is to reduce symptoms and exacerbations. The COPD pathway was created in 2011 and included the shift of focus to palliative care as disease progressed, however, the timing of this shift is difficult to determine. It is hard to pinpoint when palliative care should be implemented as it is usually a gradual transition (Back and Curtis, 2001). As a patient with COPD is usually cared for in the community the onus falls on the community healthcare teams to work alongside the specialist palliative care teams to provide an integrated package of care (Halpin et al., 2008). When compared with lung cancer, patients with COPD have significantly more restrictions on their activities of daily living and they are more disadvantaged, physically, socially and emotionally than patients with lung cancer. They may also be diagnosed with clinically relevant depression and anxiety when compared to lung cancer patients (Gardiner et al., 2010).

Lung cancer is one of the most serious and common types of cancer (NHS, 2011c). NICE (2013b p.1) states “there are more than 39,000 new cases of lung cancer in the UK each year and more than 35,000 people die from the condition...lung cancer is now the leading cause of cancer death in women”. Only about 5.5% of all lung cancers are currently cured, a rate which is lower in the UK than Europe and America. Outcomes for lung cancer are worse in the UK but do vary with geographical location, this is thought to be explained by variations in standards of care and health inequalities in areas of deprivation (NICE, 2013b). The model of care for patients with lung cancer is completely different to those who have COPD. A cancer diagnosis ensures a comprehensive package of care: diagnosis, treatment and palliative care are all carefully considered and well developed (DH, 2000). Patients diagnosed with lung cancer receive better access to end of life care services and specialist palliative care teams in the community than those patients with a non-malignant disease such as COPD (Murray et al., 2002). Higginson and Addington-Hall (2002) argue that access to these specialist palliative care services should be based on patient need, not diagnosis.

When comparing the views of patients with COPD and lung cancer regarding hospital care, a marked difference in their experience and satisfaction was noted, despite sometimes receiving treatment in the same hospital, same ward and utilising the same facilities. Research undertaken by Gore et al. (2000) found that patients with COPD were dissatisfied with their hospital care; they experienced an increased length of stay or were readmitted unnecessarily. They often presented at the emergency department in distress when symptoms were acute. Rushed decisions had to be made about intubation, with little or no previous information about the patient’s quality of life, wishes or resuscitation status. In contrast patients with lung cancer were found to be enjoying a holistic package of care. Even though it has been noted that COPD patients are dissatisfied with care, especially in relation to emergency admissions, it appears that their concerns are not being heard, as there is evidence of disparity of care. It is imperative that COPD patient voices are heard and acted on (Bailey et al., 2011). While both these patient groups experience similar symptoms, have an equally poor health status, often get nursed side by side in the same hospital and have similar palliative needs, the individual needs of the COPD patient group are not being recognised or met.

As COPD progresses in a patient, lung function declines and the patient will experience an exacerbation of symptoms and an increased number of chest infections. At present COPD is thought to cause 1 in 8 emergency hospital admissions, with the average length of stay being 9.1 days (National Collaborating Centre for Chronic Conditions (NCCCC), 2004). The demand this condition puts on hospitals in the UK is predicted to increase as the number of COPD cases rise (Ward et al., 2005). To combat the increasing number of hospital admissions, exacerbations of COPD are increasingly being managed in the community by hospital-at-home schemes, where a respiratory nurse specialist in the community manages a patient’s condition, usually within their own home. Studies have shown the success of schemes which promote the self-management of the COPD patient preventing an emergency admission. By the patient developing an understanding of their condition and how it affects their lives they can develop skills allowing them to cope better with their symptoms better at home, averting an emergency admission (Purdy, 2010). Patients with long term conditions reported that self-management allowed them to live better lives by being in control of their condition (Corben and Rosen, 2005). Evidence suggests that self-management education for patients with COPD can reduce the risk of emergency admission by 36% compared to usual care (Effing et al., 2007).

Following an emergency admission with an exacerbation of COPD, approximately one third of patients have a further admission within ninety days (Price et al., 2006). Pulmonary rehabilitation, after a hospital admission, has been shown to reduce subsequent hospital admissions for further exacerbations of symptoms or hospital attendance over a three month period (Seymour et al., 2010). It has been shown that pulmonary rehabilitation in stable COPD can also improve survival, despite this there are still substantial geographical variations in the provision of the intervention (NHS England, 2014a). Similarly, 'hospital at home' schemes produces similar outcomes to inpatient care, at a similar cost when avoiding emergency admissions. A systematic review of trials comparing 'hospital at home' to inpatient care found 'hospital at home' services prevented certain patients requiring an emergency admission (Shepperd et al., 2009). Research has shown that these schemes are an economical and safe alternative to treating COPD in hospital, aiming to prevent unplanned emergency admissions (Gravil et al., 1998; Cotton et al., 2000; Davies et al., 2000; Skwarska et al. 2000).

However not all interventions have proved to be successful, the effectiveness of case management techniques in the community and in hospital have produced conflicting results. Case management involves identifying at risk individuals and success depends on how well the tool is used (Purdy, 2010). Case management of patients with COPD in the community usually takes the form of, nurse-led disease management programs, which include the assessment and monitoring of the disease process, pharmaceutical management, reducing risk factors and controlling exacerbations. Lu et al. (2007) tested the effectiveness of a case management program for patients with COPD and found that by implementing this program it improved patient disease related knowledge and patient satisfaction with nursing care and deemed case management programs an effective approach in the management of patients diagnosed with secondary COPD infections. However, by 2010 the success of case management was questioned (Purdy, 2010). A meta-analysis of health visitor home support for older people showed no significant reduction in emergency admission numbers (Elkan et al. 2001). Similarly, a systematic review of case management found weak evidence that its effect reduces admissions (Hutt et al 2004). A further review determining the effectiveness of post discharge nurse led case management, concluded, that there was conflicting evidence on whether it had a positive effect on re-admission rates (Latour et al., 2007). The community management for patients with COPD has changed a lot in recent years, with the introduction of these community based interventions. They have altered how patients with COPD are cared for in the community, however equity of access, and effectiveness should be considered.

For cancer patients a visit to the emergency department can be distressing and unnecessary, particularly near the end of life. These unplanned admissions are used as an indicator for poor quality cancer care (Barbera et al., 2006; Earle et al., 2003). Barbera (2010, p.563) states “ideally the symptoms of a patient near death would be adequately controlled and the patient would be cared for in the setting of his or her choice, rather than on an emergency basis”. Due to the high numbers of emergency admissions and the distress that comes with them there is a need to also reduce the number of cancer admissions to hospital. *The Cancer Reform Strategy* (DH, 2007) pushed for a shift towards caring for patients in a community environment rather than in hospital. Following the publication of this strategy the NHS showed its commitment by launching the *'Transforming Inpatient Care Programme for Cancer Patients'* (NHS Improvement, 2008). This focused on four main principles which aim to improve patient care and move care from hospital to community by testing and dispersing new models of care in primary and secondary care settings. The principles are:

1) Initial assessment of emergency patients prior to admittance, to make emergency admission the exception, not the norm.
2) All inpatients should be on a defined patient pathway based on their tumor type and reason for admittance.
3) Clinical decisions should be made on a daily basis to encourage pro-active case management.
4) Patients and their care givers need to be fully informed about their condition and symptoms to promote and encourage self-management and to know who to contact when needed (NHS Improvement, 2008).

The End of Life Care Strategy (DH, 2008b) stresses the importance of access to high quality end of life care for all people regardless of diagnosis. Research has shown that this is not the case; there are clear differences between the equity of and access to palliative care services between cancer patients and patients who have non-malignant conditions such as COPD (Au et al., 2006; Goodridge et al., 2008; Partridge et al., 2009). The latter groups of patients are more likely to die in a hospital than anywhere else (Gore et al., 2000). Palliative care should reach further than just cancer; however, there remains a lack of relevant research on the care needs of patients with life limiting conditions such as COPD (Gardiner et al., 2010). In particular very little high quality research, exploring the experience of patients admitted to the ED who have COPD or end stage lung cancer, has been undertaken. Further research in this crucial area is necessary in order to ensure the patients' voice is heard.

There is a need for community palliative care services to become more patient centered to reduce the numbers of emergency admissions. The Department of Health *Equity and Excellence: Liberating the NHS* (DH, 2012a) suggested that patients should be central to all care decisions. Patients should be fully involved with decision making in partnership with their healthcare providers "no decision about me, without me" (DH, 2012a p.1). However, despite the recommendations for end of life care, it is still not clear to what extent the patient's voice is actually being heard. There is a clear need for this, the reasons behind the emergency admission need to be investigated from the patient's perspective in order to determine if the services available to this patient group prevent an emergency admission. The aim of this study was to listen to this vulnerable group and their carers at an appropriate time and to understand the patient experience behind the emergency admission. This research will explore the role of healthcare professionals and community services in emergency admissions to gain this lost patient view. Are there barriers which prevent patients managing their condition at home? Do patients and healthcare professionals have different understandings of diagnosis and services provided in the community and is communication effective? Research undertaken in this area may help the implementation of NHS strategies aimed at preventing emergency admissions. Exploring the experiences of emergency admissions for patients with COPD and lung cancer, may help inform the understanding of individual issues relating to each patient group, thus aiding the development of future services. A literature review will be undertaken to identify relevant research which could contribute to answering these questions.

1.4 Aim

The study aimed to examine the experiences of healthcare professionals, patients with advanced COPD and lung cancer and their carers, in the process of admission to the Emergency Department.

Study design was a sequential two phased project;

- A literature review systematically explored and identified relevant research to discover how patients with advanced COPD and lung cancer experienced their condition in the community.
- Secondary analysis was performed on an existing qualitative data set, to discover the role of healthcare professionals and community services on offer to patients diagnosed with advanced COPD or lung cancer.

1.5 Objectives

- What are the perceived barriers to managing advanced COPD and lung cancer at home thus preventing an emergency admission?
- Is there a difference in understanding between patients and healthcare professionals of community service provision, which if in place, could prevent an emergency admission?

CHAPTER TWO – LITERATURE REVIEW

2.1 Chapter Overview

This chapter explores how a comprehensive approach was developed and used to search relevant evidenced based literature relating to community services for patients with advanced COPD and lung cancer and their experience of an emergency admission to hospital.

2.2 Literature Review

A literature review was performed to identify gaps in knowledge which require further research. Booth et al. (2012 p.3) suggest that it can “give us a sense of the strength of the available evidence and the quality of the studies”. A search of the literature was conducted in a systematic way.

2.3 Literature Review Aim

The aim of this literature review was to explore how patients with advanced COPD and lung cancer experience care in the community for their condition.

2.4 Literature Review Objectives

- How do the conditions affect the patient’s lifestyle in the community?
- What is the patients understanding of their illness and how do they communicate with their community healthcare professionals?
- Are patients utilising their community facilities appropriately?
- Why do these patients have frequent attendances at the emergency department and admissions to hospital?

2.5 Literature Review Methods

Constraints due to time frame and resource limitations meant that this did not form a comprehensive systematic review, for example, analysis of non-English language studies would prove too time consuming for this project. Retrieval of all relevant articles was attempted. The databases searched were Medline, CINAHL, Science Citation Index and PsycINFO, from the beginning of 1990 to the second week in May 2013. Since 1990 major changes to end of life care and emergency services have been introduced, therefore this period was chosen (DH, 2001b). They were searched using the strategy found in Appendix One.

Table One – Initial Keywords

Population	**Exposure**	**Outcomes**	**Context**
COPD	End of life*	View*	Death
Lung cancer*	EOL	Attitude*	Dying
Respiratory* disease	End of life care	Opinion*	Dignity
COPD patient*	Palliative care	Perception*	Community
Lung cancer patient*	Critical care	Beliefs*	Emergency department
Respiratory patient*	Terminal care	Equality*	Accident and emergency
Terminally ill patient*	Palliative care service*		A&E
Critically ill patient*			
Emergency patient*			

The keywords listed in the above table were combined with Boolean logic commands ‘AND’ or ‘OR’ in different combinations to return studies on the subject. ‘Wild cards’ at the end of appropriate word endings were used where relevant to ensure a thorough search was completed. The keywords were refined further (Table Three) to retrieve more relevant results. The search strategy shown below (Table Four) was completed.

Table Two – Refined Keywords

Search	Keyword
1	COPD
2	Lung cancer
3	Palliative care
4	End of life care
5	Community
6	Emergency Department

Table Three – Search Strategy

Search	Keyword combinations
1	COPD
2	Lung cancer
3	Palliative care
4	End of life care
5	Community
6	Emergency Department
7	COPD **AND** Lung cancer **AND** Palliative care **AND** End of life care **AND** Community **AND** Emergency Department
8	COPD **AND** Lung cancer **AND** Palliative care **AND** End of life care **AND** Community
9	COPD **AND** Palliative care **AND** Community
10	COPD **AND** End of life care **AND** Community
11	Lung cancer **AND** Palliative care **AND** Community
12	Lung cancer **AND** End of life care **AND** Community
13	COPD **AND** Palliative care **AND** Emergency Department
14	COPD **AND** End of life care **AND** Emergency Department
15	Lung cancer **AND** Palliative care **AND** Emergency Department
16	Lung cancer **AND** End of life care **AND** Emergency Department

In order for studies to be included for review the following inclusion / exclusion criteria had to be met.

Table Four – Literature Review Inclusion Criteria

Inclusion criteria	**Rationale**
To be written in the English Language	Only studies written in English will be included, due to the difficulties of analysing papers in a language not understood (Aveyard, 2010).
To be published after 1990	As major changes have been made to end of life care services since 1990, only studies published after this date will be included. Studies published before this date would probably have limited relevance to current practices.
To describe empirical data	Only studies presenting empirical data related to how patients with advanced COPD and lung cancer experienced their condition in the community will be included to ensure the results are current and relative to the literature review aim.
To refer specifically to patients with COPD or Lung cancer which was described as severe, end stage or advanced.	Due to the numbers of patients with either COPD or lung cancer, only those whose condition was described as severe, end stage or advanced will be considered, due to the vast amount of data.
To be of quantitative or qualitative design.	Both qualitative and quantitative study design will be considered if it relates to the literature review aim.

Table Five – Literature Review Exclusion Criteria

Exclusion criteria	**Rationale**
Unpublished literature	Due to limited resources and time restrictions the ability to access unpublished literature is compromised and therefore will be excluded (Song et al., 2000).
Research that uses children or adolescents as participants	As the research question focuses on patients with advanced COPD and lung cancer, only adult participants will be considered.
Research that is related to any other long term condition.	Only patients who have advanced COPD or lung cancer will be considered as these patient groups relate directly to the literature review aim.
Research that investigates advanced COPD or lung cancer patients not in the community	Studies will be excluded if they relate to patients experiencing advanced COPD or lung cancer anywhere other than the community environment.

Abstracts were reviewed and evaluated for inclusion within this search.

2.3 Results

Using the methods previously mentioned, five hundred and ninety one papers were initially chosen for inclusion, five hundred and sixty one papers were then excluded as they did not meet the inclusion / exclusion criteria set or were duplicates, leaving thirty papers for inclusion in the review.

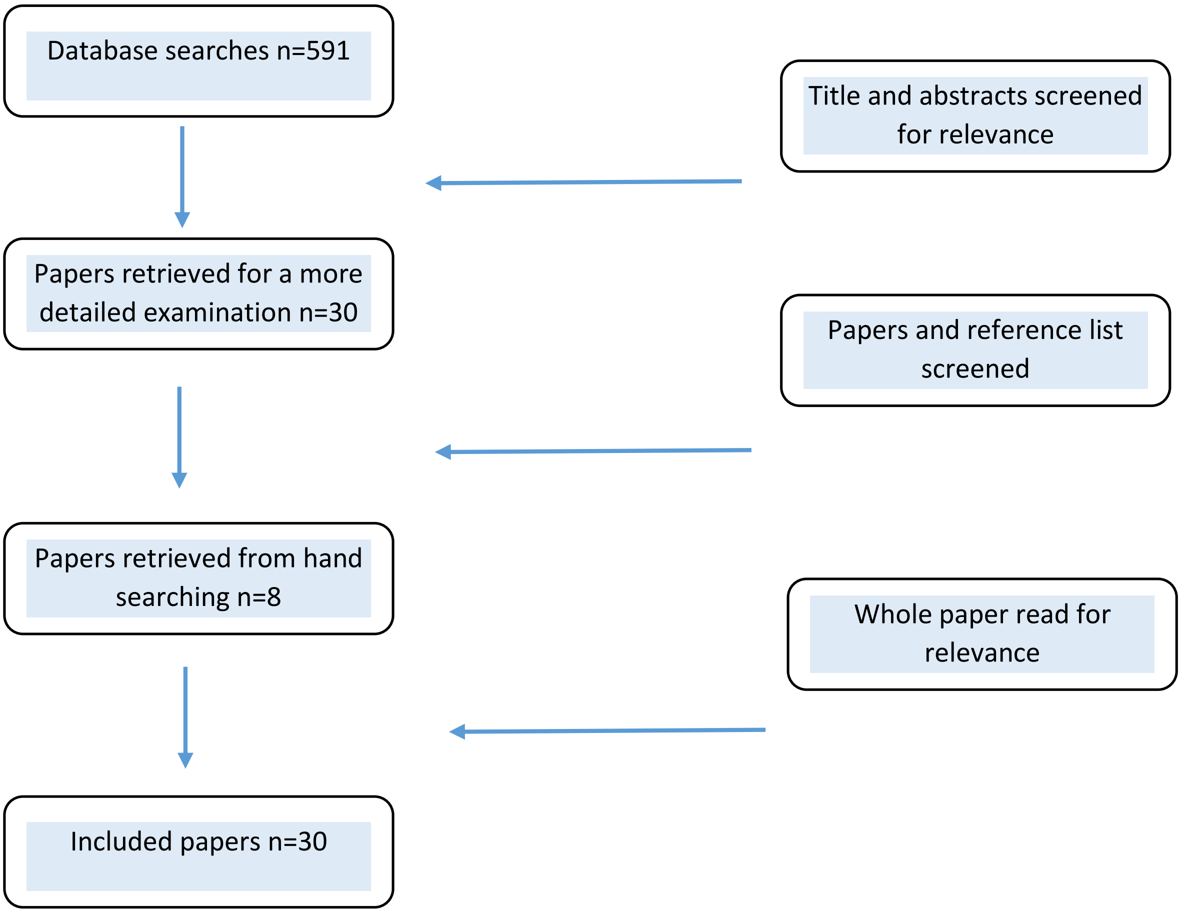
2.4 Hand Searching

Selected article reference lists were further scrutinised for relevant papers. Time constraints limited the undertaking of hand searching specific journals individually. A basic internet search was completed to ensure all appropriate studies were retrieved. Relevant studies are often identified by chance so electronic searches should not be the only component to a literature review (Montorio et al., 2004; Conn et al., 2003). Eight further papers were retrieved in this way, providing thirty eight papers initially relevant to the research question.

2.5 Results and Data Extraction

Of the thirty eight papers initially identified as relevant, a further eight were excluded as they did not meet the inclusion criteria when the whole paper was read, leaving a total of thirty papers to be included in the review. The papers were selected for relevance to the literature review aim and objectives, to determine what was already written on how patients with advanced COPD and lung cancer experienced their condition in the community. The papers finally selected formed a diverse selection. Overall the breadth of issues covered in them meant that the conclusions drawn from the literature review were valuable, relevant and useable.

Illustration One - Flowchart of Literature Search Results



2.6 Critical Appraisal

The selected papers were assessed systematically and considered according to their validity and relevance (Parkes et al., 2001). The critical appraisal tool developed by Woolliams et al. (2009) was chosen as it is deemed suitable for both qualitative and quantitative research. Critical appraisal “is the process of carefully and systematically examining research to judge its trustworthiness, and its value and relevance in a particular context” (Burls, 2009 p.1). The Wolliams et al. (2009) tool permitted such an examination, by investigating purpose, methods, results, relevancy and size of studies. This tool was however, adapted with aspects of Cronin et al. (2009) which allowed self-reported limitations and recommendations for further research from the study to be considered ensuring a thorough critical appraisal was completed. Combining the best aspects from both tools aimed for a rigorous synthesis. The adapted model with completed appraisal can be found in Appendix Two.

2.7 Ethical Considerations

Clinical research aims to improve the care patients receive across the broad spectrum of the NHS. NHS patients benefit from past research and continue to benefit from research that is currently being carried out (NHS Choices, 2013). Research with palliative care patients raises ethical concerns (Keeley, 2008). Care must be taken when using participants who are at the end of life, or patients with a high risk of dying. Debate about whether these patients should even participate in research exists (Gysels et al., 2012) , with little agreement on outcome (Addington-Hall, 2002; Duke and Bennett, 2010). However, excluding this patient group for ethical reasons may violate the principle of justice, denying these patients a valid opportunity to make an important contribution to future healthcare. Advances to clinical knowledge about the care of these patients would be difficult without their participation (Henry and Scales, 2012). The culture surrounding palliative care research needs to change, leading to new ways of thinking about research and opening up new ways of exploring this area (Gysels et al., 2013). This is taken into consideration when executing this literature review.

2.8 Thematic Analysis

The findings from this completed appraisal were synthesised through a process of thematic analysis (Joffe and Yardley, 2003), producing a new interpretation of the results (Finfgeld, 2003). The main findings from each study were assigned codes and collected together according to relevance, thus creating themes. The four themes stated below emerged:

- Symptom management and psychological aspects for patients with COPD or lung cancer
- Communication between patients and healthcare professionals
- Appropriate use of community resources
- Acute exacerbations and Emergency Department admissions

These four emerging themes will be discussed in detail below.

2.9 Symptom Management for Patients with COPD

Patients with COPD reported a high symptom burden which was poorly controlled (Gardiner et al., 2010), with the most dominant symptom being breathlessness (Elkington et al., 2004; White et al., 2011). Jones et al. (2004) studied the requirements of 16 patients dying from COPD, finding that breathlessness had a major effect on lifestyle activities. However, this study can be criticised, the sample size was small and not generalizable due to patients being recruited for the study by the own GP. Due to patient condition it was hard for researchers to determine which patients were dying, as the research question aimed to discover the needs of patients dying of chronic obstructive pulmonary disease in the community, this may or may not have been achieved meaning results could be seen as untrustworthy. White et al., (2011) reported that some patients described the breathlessness they experienced as completely disabling. This was retrieved from patients who responded to the questionnaires they were sent. The response rate for patients was not as high as hoped (61%). Researchers found however, that the respondents were at least as severely affected as non-responders and were no different in demographic characteristics and deprivation, helping to reduce the bias of participants involved in the study. Elkington et al. (2004) explored the experience of the last year of life in COPD from the carer perspective, looking at symptoms and services. Interviews completed with carers showed the profound effect breathlessness had on patients in terms of life style restrictions and physical function. Breathlessness, such as this, could prevent a patient accessing their local healthcare centre due to its effect on impaired physical ability, patients may not be able to walk far thus preventing them from attendance. The study's results should be viewed with caution however, as interviews which sought to retrieve the experiences of patients and how their symptoms affected the last year of their life, were completed with the carer, as the patient had since died in the previous three to ten months, questioning the reliability of results.

2.10 Symptom Management for Patients with Lung Cancer

Patients with lung cancer reported a different prevalence of symptoms. Edmonds et al. (2001) undertook a comparison study of the symptoms experienced by patients dying from COPD and lung cancer. They found that patients with lung cancer experienced breathlessness less often than COPD patients in their final year of life (78% lung cancer vs. 94% COPD). Comparisons between the COPD and lung cancer group of patients should be made with caution. There were far more participants recruited for the lung cancer group than the chronic lung disease group 449 and 87 respectively. Claessens et al. (2000) showed that breathlessness was reported more frequently in patients with COPD but lung cancer patients reported higher levels of pain.

2.11 Psychological Symptoms

Breathlessness in some patients was linked to anxiety and panic. Elkington et al. (2004) reported that the feeling of breathlessness in the patient triggered a panic attack, exacerbating their symptoms. Patients may be reluctant to leave their homes due to the fear of breathlessness, again restricting their attendance to their healthcare centre. This indicates why community home care services are crucial to patients with COPD and lung cancer. The burden of symptoms in both conditions can restrict a patient's ability to not only leave the house, but also increase the fear of doing so. Without the support of specialist palliative home care services this group of patients may miss out on the care they need and deserve.

2.12 Communication between Patients and Healthcare Professionals

There are often patient misconceptions regarding COPD and its future implications. Jones et al. (2004) observed that although patients knew the name of their condition, over half questioned wanted further information regarding managing their lives with COPD. They found that over half of the patients studied knew their disease was progressive but it was unclear whether they understood their prognosis. Planning for the future is an area which is often neglected for patients with COPD (Wilson et al., 2008). Pinnock et al. (2011) discovered that for patients with COPD death was not considered an imminent threat. They reported however that their sample of participants may not be representational to the diversity of people with very severe COPD. In particular, none of the participants were from an ethnic minority background. A study by Gore et al. (2000), showed that patients disclosed a lack of diagnostic information, prognosis awareness, and future management and that knowledge gained was attributed to conversations taken place during emergency admissions rather than from the community healthcare professionals. Elkinton et al. (2004) reported that only 63% of patients with COPD believed they had a life limiting illness despite being housebound, having high symptom prevalence and experiencing recent hospital admissions. Crawford et al. (2012) agreed, suggesting the lack of communication between patients with COPD and health service providers was highlighted as a major issue in their study.

There appears to be a difference regarding communication with lung cancer and COPD patients. Murray et al. (2002) reported that patients with lung cancer had access to written information and most of the patients questioned understood their illness and its causes. Patients appreciated the healthcare professionals' honesty and treatment options were discussed openly. Exley et al. (2005) showed that patients with cancer gained information from their GP with the majority referring to clarity about diagnosis, prognosis and information regarding treatment or lack of it. However this has been critiqued the study was small in scale and only completed in two GP practises in the East Midlands, results may not be generalisable to other areas of the UK and may not be replicated if done on a larger scale.

Metastatic cancer for most patients and health care professionals is a diagnosis that will imply death, however a diagnosis of COPD is viewed less ominously (Steinhauser et al., 2011). This study was limited by the cross-sectional nature of data. Mahtani-Chugani et al. (2010) studied patients with non- oncological diseases and the barriers faced in accessing palliative care. They showed that the difficulty of determining prognosis in non-metastatic conditions was listed as one of the barriers identified by healthcare professionals. Health care professionals are unsure on when to approach the subject of dying with patients with COPD and lung cancer (Murray et al., 2002). This reluctance will ultimately prevent a patient's referral to specialist palliative care teams. Despite the disease trajectory, poor prognosis and prevalence of symptoms, it is worrying that there is a lack of information provision (Gardiner et al., 2010). Patients should be fully aware of their condition and how best to manage it in order to make informed decisions regarding their care. Communication between patients with COPD and lung cancer and their health care professionals needs to be improved. Guidelines and strategies should be put in place to help facilitate this clear need.

2.13 Appropriate Use of Community Resources

Due to the high number of people in the UK living with a long-term condition (Department of Health, 2012b), the government has set out a strategy to improve the outcomes for this group with the introduction of the community matron (CM) role (DH, 2004). The community management for patients with COPD in the community has changed since this implementation.There is, unsurprisingly, a high level of contact with health services for patients with COPD and lung cancer, due partially to their high symptom levels. The majority of contact with healthcare professionals occurs outside the patient’s home. Specialist services such as specialist palliative care teams, specialist respiratory nurses, district nurses and community matron teams are often not available for patients with COPD (Elkington et al., 2004; Elkington et al., 2005; Goodridge et al., 2008). Patients with lung cancer receive a more holistic package of care. Gore et al. (2000) showed that lung cancer patients received good access to specialist palliative care teams; alternatively the COPD patients had no equivalent package of care and their palliative care needs went unrecognised. Cooke and Thackray (2012) reported that equity of access to services was an important issue for patients and healthcare professionals alike but both groups had different views. The health care professionals expressed a concern that the patients were not utilising provided services, “people don’t tend to come forward so health beliefs prevent communication” (Cooke and Thackray, 2012 p.1527). The patients however believed there was no consistency in the referral process and felt they were being moved around healthcare services, GP to chest clinic to physiotherapist. The study can be criticised however as the sample population is biased, both patients and professionals recruited to the study were not ethnically representative of the city population and included a range of volunteer clinicians and self-selected patients with their carers who provided or used the COPD services. Goodridge et al. (2010) showed that location had an influence on service provision, finding that the likelihood of receiving specialist palliative care services was significantly reduced in rural or remote areas. However, the data represented one Canadian province only and regional variation in practice may affect the generalisability of the findings. The data analysis did not allow for assessment of the quality of life, or the appropriateness and adequacy of care for those who died with respiratory illness. Researchers declared that using an administrative database could cause inaccuracy of coding and lack of contextual detail.

Patients with COPD can be accepting of their condition. Pinnock et al. (2011 p.4) described COPD as becoming ‘a way of life’, suggesting “it was something that had to be coped with ‘as best as you can’”, meaning patients did not actively seek out help. A study by Currow et al. (2008) explored the views of caregivers for patients with end stage lung disease. They reported that caregivers felt they had unmet needs in regard to support with physical care and symptom control and lacked knowledge about illness course and service provision. They admitted that assessment on patients who are near death was problematic. Patients may under report symptoms to avoid distressing their carers. When participants are interviewed after a life changing event (death) their recall of events could be compromised, questioning the reliability of the data. As only people who were living in remote settings were used for this study, not all cultural backgrounds were represented.

People who lived alone, or whose caregiver subsequently died were not represented. Participants whose first language was not English were also under-represented in the data, meaning participant bias affected this study. Edmonds et al. (2001) showed that none of the patients who had chronic lung disease in their study received care from a Macmillan or hospice nurse, whereas almost a third of patients with lung cancer received help from a Marie Curie nurse. Seamark et al. (2004) explored patient perceptions of living with COPD finding that relationships with healthcare professionals provided benefits such as being given a diagnosis and having confidence in the doctor, normally the GP. However, negative aspects such as confusion over the role of hospital clinics, specialist respiratory nurses and a perceived lack of follow up or surveillance of the disease were also apparent. This study is limited due to the results not being generalisable.

Some studies have reported positive attitudes towards healthcare services, Murray et al., (2002) showed that patients with lung cancer were happy with their care and appreciated the support of a hospital based lung specialist cancer nurse during treatment. Disler and Jones (2010) showed that patients with a malignant disease such as lung cancer were looked after well by district nurses in the community. They found however there were restrictions when engaging with COPD patients, even though their symptoms were severe and the patients were mainly housebound. The study's results however cannot be generalisable due to the sample size of the survey (44% of population). Exley et al. (2005) showed that patients with cancer were more likely to receive care from a district nurse than those with end stage lung disease. Evidence demonstrates that clear discrepancies between specialist services for COPD and lung cancer exist. This warrants further investigation.

2.14 Acute Exacerbations and Emergency Department Admissions

Towards the end of life, patients with COPD and lung cancer experience higher symptom prevalence and increased exacerbations, often leading to emergency admission. There is a call to reduce the hospital admissions for this group of patients, thus sharpening the increasing need for palliative care (Kelly, 2011). Gyseles and Higgingson (2009) found that when a patient's breathlessness became acute, carers felt unsure of the right moment to seek emergency care. Panic usually lead to a call for an ambulance. Carers described that panic was the hardest symptom to cope with at home. They also reported that each exacerbation was a learning process and they felt better prepared to handle the incident the more they experienced it. They also found that patients with COPD had difficulties accessing emergency care, experiencing a traumatic emergency admission. Exley et al. (2005) showed in their study that the care of patients with COPD seemed to be managed by the hospital specialists, normally in response to an emergency admission, rather than by a GP in the community. Barbera et al. (2010) showed that patients with lung cancer were often admitted to hospital during the last two weeks of life. Ideally patients would want to avoid this emergency admission, suggesting the quality of care they received in the community was not sufficient to address their needs. They suggested that "with comprehensive and coordinated palliative care, individual patients could be managed in clinics, at home and in palliative care units or residential hospices without the need for a visit to the emergency department" (Barbera et al., 2010 p.566). The study however relies upon administrative data so the risk of bias was high.

If patient conditions can be managed in the community the increasing demand on emergency services can potentially be reduced. Ward et al., (2005) reported on the efficiency of a respiratory intermediate care team (RICT) set up in Oxford, to enable patients with chronic respiratory diseases, predominately COPD, to remain at home during an acute exacerbation in an attempt to prevent a hospital admission. They showed that patients referred to the RICT required an average of 12.2 days support and four home visits. Identifying patients earlier during an exacerbation helped the patient and carers manage the condition at home, preventing an emergency admission. Without this kind of support and service patients with COPD remain 'socially invisible' until an acute phase of illness requires an emergency admission (Guthrie et al., 2001).

2.15 Conclusion to Literature Review

Regardless of the increasing number of hospital admissions for patients at the end of life, few studies primarily explored the reason behind these admissions or considered the way in which the roles of healthcare professionals and community service providers influenced these emergency admissions. However, they did suggest that these admissions were complex in nature and were made more complex due to disease progression, and complications relating to service provision, access and social issues. The literature suggested there is a clear need for improved palliative care services for patients with respiratory disease and that there is an increasing demand for palliative care to be extended to all who require it. The recognition of the unpredictable nature of advanced non-oncological diseases, such as COPD, needs to be an equally important consideration for healthcare professionals. As none of the studies explored the specific reasons behind a patient's admission, nor did they consider the role of healthcare professionals and community services in the patient's admission.

This review has provided an overview of current literature to ascertain how patients with advanced COPD and lung cancer experienced their condition in the community. It was discovered that the experiences of community healthcare professionals and community services in relation to emergency admissions of people with advanced COPD and lung cancer was under investigated, thus justifying an examination into this area of research. The next chapter will discuss the methodology of this study.

CHAPTER THREE - METHODOLOGY

3.1 Chapter Overview

This chapter will present the framework for both the primary study and secondary analysis. Justifying the methodology used in each case, ensuring an ethical approach was undertaken. Study designs will be discussed and presented.

3.2 Primary Study- Methodology

A huge amount of qualitative data was generated from an existing study which explored the perceptions of patients with advanced COPD and lung cancer, who had experienced an emergency admission to hospital (Munday et al., 2013). The study followed a Critical Incident Case Study approach (Yin, 2009). The critical incident was the emergency admission of patients with COPD and lung cancer to hospital and the ‘case’ encompassed the wider context, exploring the admission processes and relevant factors. Semi-structured interviews were conducted with the patient, one of their carers and key healthcare professionals who had been closely involved with the patient at the time of their admission, both in the community and in the hospital (Munday et al, 2013).

Three hospitals within the Midlands participated in the study. Patients were recruited as soon after admission as possible, the study aimed to recruit forty five patients across the three sites. For each patient the study aimed to also interview an informal carer, a community health professional and a hospital health professional. Patients recruited for the study had to meet the following inclusion / exclusion criteria.

3.3 Primary Study Inclusion Criteria

- Patients with a previously diagnosed non-operable lung cancer and admitted as an emergency
- Patients with pulmonary mesothelioma
- Patients with COPD on home oxygen admitted as an emergency
- Patients of 18 years of age or over

3.4 Primary Study Exclusion Criteria

- Lung cancer patients which was not advanced (e.g. patients who had had previous surgery and had not been diagnosed with a recurrence)
- Patients who had undergone major surgery within the past 2 months
- Patients whose admission was as a result of pure trauma – e.g. Road Traffic Collision, where there was little likelihood that the trauma was related to their disease

The recruitment procedure differed slightly depending on site but utilised research nurses based at the hospital and COPD and lung cancer clinical nurse specialists (CNS). The initial approach was made as soon as possible after the patient had been identified for recruitment, and only if they were considered well enough to take part. Carers and health professionals were chosen by patients and discussed with the researcher during interview. The research team followed up these health professionals by emails, letters or telephone calls to make contact.

A semi-structured interview schedule was used by the researchers over approximately a one year period. Each patient was interviewed twice, when possible. A short interview was conducted, as soon as possible, while the patient was still an inpatient; and a longer follow-up interview was conducted following discharge from hospital. In some cases the second interview was not possible because of rapid deterioration or death. The follow-up interviews were conducted in the patients' homes. All the interviews were audio recorded and transcribed verbatim.

Up to two health professionals, chosen by the patient, were interviewed by the researchers to explore the reasons for admission from their perspective, to obtain further information about the patient's circumstances and to explore the specific factors which contributed to the emergency admission. The interviews were undertaken as soon as possible after patient admission and were conducted face to face with a small number by telephone or email.

Table Six - Participants in Primary Study

	Interviews	**Sex**	**Mean Age**
Lung cancer patients	24	14M/10F	72.5 (range 55 – 90)
COPD patients	15	9M/6F	72 (range 62 -89)
Carers	20		
Hospital HCP	27		
Community HCP	23		
Total Interviews	109		

Ethical approval was granted from the NRES Committee West Midlands (The Black Country) Ref 11/H1202/. Required approvals according to NHS Research Governance regulations were also granted for access to eleven sites. Audio-recordings of interviews were transcribed verbatim, anonymised and entered into NVivo. Confidentiality was maintained at all times.

The data recorded in the patient/carer and healthcare professionals interviews concerning each emergency admission were analysed concurrently. Analysis took a realist approach (Robson, 2011) and used a theoretical approach from complexity theory (Holt, 2004, Byrne, 1998), to explore the complex mechanisms evident in the decision making of patients and their carers which led to emergency admission.

The analysis was conducted in two stages, first a chronology of events table was developed from the accounts provided by the patients and carers, and secondly thematic analysis of the data was undertaken. During the second phase of analysis the transcripts were read and re-read. Codes were assigned to segments of data and grouped together into emergent themes. This process was undertaken to capture the detail of the experience of patients, carers and health care professional as reported in the interviews.

A template approach was used for thematic analysis (King, 2004). A template was initially developed which derived from preliminary interviews with clinicians and was added to following repeated readings of the transcripts and discussions amongst the research team. The final template was agreed by research team members and the codes identified in the full dataset of transcripts were identified and recorded using NVivo10.

3.5 Primary Study Findings

Findings suggested that the patient progressed through three distinct phases leading up to emergency admission; complex self-management, negotiated decision making and letting go. Each phase was triggered by physical and psychological changes which combined to create a situation where the patient or their carer perceived a hospital admission to be unavoidable or they accepted the advice of a healthcare professional who recommended admission (Munday et al., 2013).

Patients reported a positive experience of the initial emergency admission. However, when the emergency situation was stabilised, there appeared to be lack of attention to the wider more complex needs associated with lung cancer and COPD. Care given beyond the emergency department was reported as poor with particular concern expressed about communication, attention to individual needs, lack of awareness of the expert family, and a lack of continuity in care. The connection between the patients and their community services appeared to be limited, often as a result of poor communication, difficulties in access, and a severe lack of understanding of community roles on the part of the patient. A lack of connection between primary and secondary care services led to patient confusion regarding their care plan. Community healthcare professionals voiced concerns over a lack of communication with hospital professionals, suggesting that patients' admissions were not appropriate and were complex in nature. It also identified a lack of adequate 24/7 service provision in the community and a lack of quality care for patients following hospital admission.

3.6 Primary Study Limitations

The similarity in patients' experiences across the three sites were variable, the methods used were mostly quantitative and therefore did not seek generalisability, however the findings did have substance in a wider context providing a framework for understanding the processes involved in the emergency admission of patients with COPD and advanced lung cancer. No comparative data was attained from the patients who were unable to participate in the study.

Due to patients' condition at the time of admission, the recollection of their pre-admission period was not clear, often relying on their relatives during the interviews to supplement their accounts. Therefore a number of the interviews were collaborative between the patient and carer. Healthcare professional data was not fully analysed in the primary study. Involving the healthcare professionals view in the secondary analysis provided a fuller picture of the pre-admission period, which the primary study did not examine, thus justifying an exploration into this area. Not all patients and carers had a follow up interview, either because they were too unwell, declined a second interview, or had died. Reusing this valuable data with secondary analysis ensured the significance of the original data was not lost even if the patient had since died (Corti and Thompson, 2006). Secondary analysis provided greater context to many of the issues discovered in the primary study, and further contributed to ideas about where future policies and research should focus.

The number of community and hospital clinicians interviewed was not as planned. A comprehensive picture of the health care professionals' perspective on the admission was not achieved. Patients were able to identify a healthcare professional involved in their care, however contact details could not always be retrieved. Lack of response was noted from some professionals who were contacted, others replied that they did not know the patient or only knew them very slightly and suggested they would have nothing to contribute. Some health care professionals did not attend for arranged interviews. Professionals working within the hospital proved easier to contact. Staff rotas, however, often meant that it was sometime before they could be interviewed, by which time recollection of patient admission proved difficult. No comparative data was gained from patients who experienced similar symptoms but were not admitted and able to stay at home.

A gap in the analysis showed that further investigations could be made from the healthcare professional data as the primary study focused on the patient. By taking a smaller section of the produced data and performing secondary analysis new insights may be derived.

3.7 Secondary Analysis - Methods

Secondary analysis is "the analysis of data originally collected by another set of researchers" (Seale, 2011 p.347). Hinds et al. (1997) defines secondary analysis as, using existing qualitative data to answer different questions to the original research. Existing data taken from the primary study was retrieved and reused (Munday et al., 2013), often from patients who have since died. Long-Sutehall et al. (2010) suggest that utilising existing data in this way can readdress a topic within a sensitive area of research, without causing unnecessary stress to patients at the end of life. Secondary analysis can also facilitate access to an elusive research population, allowing the palliative patients previous contribution to research to not end with their death or completion of first project (Long-Sutehall et al., 2010). Hinds et al. (1997) suggest this is a suitable method for those who wish to pursue additional analysis of an original data set, to apply a different perspective to the original research question (Heaton, 1998). The primary study aimed to discover and understand patients' experiences of the period leading to hospital admission, the admission process itself and the immediate period following admission (Munday et al., 2013). However, this project is focussed on addressing the existing data to examine the roles of healthcare professionals and the perceptions of community services for patients with advanced COPD and lung cancer, preceding their hospital admission.

Secondary analysis should also be viewed with caution, particularly when the researcher was not part of the original research team. The secondary analysts do not possess the contextual knowledge about the circumstances of the data collection found by the primary researcher, knowledge which is deemed necessary for the qualitative work to proceed (Seale, 2011). The difficulties of secondary analysis in an independent capacity have been noted (Thorne, 1994). However, in this study in depth knowledge of context is not required and using secondary analysis as a method was deemed as a major strength because of the sensitive nature of the dataset utilised. Vulnerable patients at the end of life did not have to give their valuable time to aid future nursing research. By using data already in existence an ethically sound method was reflected. Maximising the use of existing data in a new way meant that data not capitalised could be readdressed to explore new issues which could inform nursing practice.

3.8 Secondary Analysis Ethical Considerations

Informed consent was obtained in the original study. As the data is of a sensitive nature, consent cannot be presumed for secondary analysis. It was not feasible to seek additional consent as most of the participants had since died. Discussions were carried out with supervisory team members from the primary study, they confirmed that patient consent was secured for reanalysis of the data. It was therefore established that a reuse of the data did not violate the original contract made between the participants and primary researchers (Hinds et al., 1997).

3.9 Secondary Analysis Study Design

The secondary analysis followed a broadly constructivist case study style approach. A case study is defined as being “an empirical inquiry that investigates a contemporary phenomenon in depth and within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident" (Yin, 2009 p.5). This case study approach was based within the constructivist paradigm, which is a way of understanding reality from the perspective of those experiencing the phenomena, so meaning can be constructed (Polit and Beck, 2008). This constructivist 'collective case study' approach allowed understanding and insights to be gained on the roles of health care professionals and community services in the emergency admissions of people with advanced COPD and lung cancer. It permitted the phenomenon to be looked at from different perspectives and within the context it was set, how the phenomenon occurs in a given situation, exploring what triggered the patient's admission to hospital and how the roles of health care professionals and community services affected that. By using this approach an empirical investigation could be ensured in that it involved the collection and analysis of the data. By using several different sources of data; interviews from patients, carers, and healthcare professionals, the research findings were strengthened as the evidence was triangulated. Triangulation is an important concept in case study research because it allows an investigation of the phenomenon from different perspectives. It provides a solid foundation for the findings and supported arguments (Yin, 2009). The aim of this secondary study was to explore and gain understanding of the role of healthcare professionals and community services in the emergency admission of people with advanced COPD and lung cancer through multiple perspectives, therefore a constructivist 'collective case study' approach was deemed justified.

3.10 Secondary Analysis Data Management

Knowledge of the local context from which data was collected is an advantage to researchers (Seale, 2011), therefore, from the three hospitals across the Midlands used in the primary study, the Birmingham data set was selected for the secondary analysis. An integral part of qualitative appraisal is to ensure depth (Higgins and Green, 2011), therefore choosing the Birmingham data set would facilitate this as it was familiar to the researcher. The chosen dataset was completed in a large hospital trust, accessing a variety of opinions and experiences from the patients. The hospital trust from which this data was collected was specific to the area where the researcher lives and works. It is not untypical to a city centre hospital. The chosen dataset consisted of thirteen patient sets which involved thirty four interviews across patients, healthcare professionals and carers. Three patient interview sets were rejected as they had no accompanying healthcare professional interview, as required by the research question (see Appendix Three for rejected patient sets). This left a total of ten patient interview sets, which consisted of twenty eight interviews, given by patient's, carers and associated health care professionals (see Appendix Four).

Table Seven - Participants Included in Secondary Analysis Study

	Interviews	**Sex**	**Mean Age**
Lung cancer (LC) patients	6	5M/1F	86
COPD patients	4	2M/2F	74
LC patients post discharge interview	0		
COPD post discharge interview	2	1M/1F	
Carers	1 (*4 other carers formed part of a patients interview)		
Hospital HCP	9		
Community HCP	6		
Total Interviews	28		

3.11 Secondary Analysis Data Analysis

The secondary analysis took a thematic analytical approach, a method which allows identification, analysis and the reporting of patterns or themes within data (Braun and Clarke, 2006). The analysis was conducted in three stages, first, in order to familiarise and fully understand the data set, each patient interview was initially read and an illustrative schematic was created. As interviews were originally undertaken by another, this allowed the researcher to become fully immersed in the data, which forms the first step of thematic analysis (Grbich, 1999; Braun and Clarke, 2006). Data was managed initially by creating patient schematics, detailing three specific aspects related to the patient; patient profile, timeline of events and support networks. Initially a patient profile was compiled, detailing age, gender, cohabitation status and health conditions. The patients' characteristics were all retrieved from patient, carer or healthcare professional interviews. Secondly, schematics then illustrated the patients' timeline of events preceding admission to hospital, what triggered the admission to hospital, who made the decision to call 999 and what happened to the patients once they attended the ED. Finally the schematic illustrated the patients support network. Family, friends and healthcare professionals involved in their care were identified. Each time such a person was mentioned in an interview it was included in the patient schematic. All this helped build a picture of who the patient was, their medical condition and gave an idea of the involvement the patient had with community services by looking at disclosed healthcare professionals. Patient schematics can be found in Appendix Five.

Secondly, accompanying carer and healthcare professional interviews were then read and reread along with patient interviews and a patient transcript table was produced to explore and explain the whole data set. The patient transcript table posed questions such as; what was the perception of the reason behind admittance to hospital, why were community resources not utilised in an emergency, had referral to appropriate community resources been made and was the patient accessing these facilities which enabled the data to be managed thoroughly? Creating this patient transcript table enabled a greater depth of familiarisation with the data, allowing the search for patterns and similarities to be picked out from each individual interview thus laying the groundwork for coding to continue from later in the analysis. Full details of this patient transcript table can be found in Appendix Six. As this data management stage was initially completed by hand before being typed up into a table a photograph can be found in Appendix Seven to illustrate this process. Managing data rigorously to create patient schematics and patient transcript tables was completed in this way as it allowed the researcher to see the whole dataset as one, allowing ideas about what the data consists of and why this is important along with initial patterns to emerge.

Once data had become familiar to the researcher, the third stage of analysis, involved the production of initial codes. Codes identified certain features of the data, which appeared interesting based on the literature review and the results from the primary study and referred to “the most basic segment or element of the raw data or information that can be assessed in a meaningful way regarding the phenomena” (Boyatziz, 1998 p.63). Lader (2013) refers to this as the essential step in analysis. As the coding was completed by hand the researcher utilised paper and coloured pencils. Transcripts were read line by line and assigned a code, this piece of text was then highlighted with a certain colour, if another line of transcript referred to the same code this line was coloured using the same colour. If the sentence referred to a new code a different coloured pencil was used to highlight the sentence. This was completed to all twenty eight patient, carers and healthcare professional interviews. Some codes occurred often and some less frequently. Colour coding patient transcripts this way enabled the researcher to not only see individual codes assigned but also how often these codes appeared by looking for specific colours within the transcript thus ensured a rigorous data management technique was being used. A photograph is included for evidence of this process (see Appendix Eight). See Figure One for an example of codes applied to a short segment of data taken from the interview of lung cancer patient number 03.

Table Eight - Data Extract with Codes Applied

Data Extract	**Coded for**
And she said ‘the oxygen is putting you back’ and that’s where I’ve been going wrong so, so I said ‘well fair enough, I don’t want no more oxygen’ she said ‘you don’t’ but then when they do it’s given me a tablet that relaxes you under the tongue [ahh] and keeps me off the oxygen [right].	3. Confusion in medication 4. Co-morbidities
It’s ever so strange, over these past two weeks I’ve been getting up of a morning, feeling okay, go to the toilet, come back, collapsing [ahh], can’t breathe and it’s all down I think to this oxygen	5. Patient trying to cope 14.Breathlessness
I mean I was fit as a fiddle [mmm] when I went in the army when I was 18. I done two years in the Warwick’s, I done three years as a paratrooper, I couldn’t jump over a stick now, but I’m hoping	1. Patient decline (deterioration) 21. Hope
I’m getting a bit more confidence because RNS’s giving me the confidence and I thought ‘if she can sort this…	2. Faith in Healthcare Professional (praise)
She’s going to get me a little green inhaler which I can use, see where I’ve reaching for the oxygen I should have been reaching for this inhaler [yes yes] and you know that’s what it’s all about really.	3. Confusion in medication

One hundred twenty individual codes were assigned to the data. All the codes were then collected together to form a list (see Appendix Nine), the analysis was then refocused at the broader level of themes rather than just codes (Braun and Clarke, 2006) by identifying similar codes together and grouping them together to enabling relationships within the data to be examined and to identifying potential themes (Green, 2013). Alsop and Saks (2013) suggested that thematic analysis is a useful technique of managing mass data by condensing it into an amount of interconnected themes, creating a credible structure for analysis, justifying the use as an analysis tool in this project. A visual representation was developed to help sort different codes into themes. Individual codes were cut from a piece of paper and rearranged into theme piles. Braun and Clarke (2006) suggest this method can be helpful when searching for themes. A photograph of this method can be found in Appendix Eight.

Sub themes were then reviewed by assessing the extracts of data coded in relation to them. Fifteen sub themes then emerged as seen in Figure Two below. These sub themes were then refined to become themes. Some of the sub themes collapsed into one collective theme and some remained as a standalone theme.

Table Nine – Thematic Analysis – Sub Themes and Themes

Sub Theme	**Theme**
• The idea that hospital was the right place to be	Hospital – ‘the right place to be’
• No other alternative to hospital • Hospital pathways	Experience of access
• Patient decline • Patient death • Caregiver burden • Gender	Patient particulars
• Lack of services • Absence of key carer • Confusion • Dissatisfaction	Absence
• Disengagement • Disconnection	Disengagement and Disconnection
• Positive perception (confidence)	Confidence
• Cope	Cope

Themes were then refined further. “Identifying the essence of what each theme is about and determining what aspect of the data each theme captures” (Braun and Clarke, 2006 p.22) is a key requirement when defining and naming themes. Initial data was revisited to ensure a comprehensive idea of final named themes. They were considered in relation to the research question and then in relation to each other to ensure there was no overlap of the themes (Braun and Clarke, 2006). The seven actual themes were further refined into three overarching themes.

Table Ten – Themes and Final Themes

Themes	**Final Themes**
• Absence • Disengagement and Disconnection	A Change in Normal Support
• Experience of Access • Absence	Service Provision Gaps
• Hospital – ‘the right place to be’ • Cope • Confidence	‘Knowing’ What to Do In an Emergency

Using a case study approach to the analysis, allowed for multiple perspectives of community services to be examined, both preceding admission and the admission process itself (Tritter, 2013). The findings from this process will be discussed below.

CHAPTER FOUR – FINDINGS

4.1 Chapter Overview

This chapter will present the data and findings discovered from the analysis process.

4.2 Findings

This study aimed to provide an exploration of what is the role of healthcare professionals and community services in emergency admissions of people with advanced COPD and lung cancer. After coding all twenty eight interviews a total of one hundred and twenty individual codes had been assigned. To extract themes from these codes a process of thematic analysis was undertaken (Green, 2013). Codes were collected together according to relevance and similarity, thus, creating themes. Three themes emerged relevant to the research question, as a result of the data analysis process and they are discussed below.

4.3 Emergency Admissions – Confirming EURECA Findings

Analysis revealed that patients and their carers reported positive perceptions regarding the healthcare professionals involved in their care and the services available to them. This positive perception emerged throughout all patient and carer interviews, confirming the findings of EURECA (Munday et al., 2013). However, as the focus of this study was on the healthcare professionals, this will not be considered further here. The secondary analysis also found that the majority of healthcare professionals, patients and family members believed hospital admission was required, this is an issue which will be returned to later in the discussion.

4.4 Theme One – A Change in Normal Support

Thematic analysis showed that an admission was more likely when there had been a change in the patient’s normal support, for example, an absence of a particular individual, carer or healthcare professional potentially leading to a hospital admission. Regardless of the previously mentioned positive perception of community services, it appeared that if the patient was experiencing an episode of ‘absence’, for example, patient 09’s community matron was on annual leave, all the faith in community services could be dismantled as the ‘absence’ appeared influential in precipitating a hospital admission.

The notion of ‘absence’ was raised by patients as they discussed their emergency admission. Six of the ten patients interviewed revealed that an ‘absence’ of an individual during their care influenced their admission to hospital. All four of the COPD patients reveled this ‘absence’, ranging from informal carers such as family members to key healthcare professionals. Patient 09, who called 999 before seeking community help, disclosed he did this as his community matron was absent during the time of his deterioration. Despite the hospital respiratory nurse making patient 09 aware of alternative access to community services, this still resulted in this patient being admitted to hospital. The community nurse expressed her frustration, she understood a solid relationship was required in order for patients to access services, however she was concerned that a reliance on this relationship could ultimately lead to a dependence on her. The nurse explained that if she was on annual leave, patients refused to liaise with colleagues in an emergency, alternatively, they called 999. Patients knew they could rely on the ambulance service and hospital staff.

“Even though I say to them, look just because I’m on annual leave the service doesn’t stop, I’m not that important. You know, there are other people that cover, I think they get so used to people that they gain confidence in people and then they’re just like ‘oh I don’t want strangers’ so they end up going in then [hospital]…I do question my own

involvement in it, and I think do I make them dependent on me? And I honestly I don't think I do, I do always say to them look, I'm going on holiday, but the service doesn't stop, please phone, we'd rather you phone and get checked out and be okay than you ending up in hospital. And they go yeah, yeah, yeah, but I can name a few on my caseload that just don't. And it frustrates me then because I come back and I'm like why didn't you phone?" (CCM [patient 09 - COPD]).

The quote above demonstrates the impact an 'absence' can have on a patient and how it can often lead to a hospital admission. Regardless of all the groundwork completed by patient 09's clinical case manager, if his deterioration occurred during a period of annual leave, the result was often a hospital admission. Likewise, the absence of a family member and a healthcare professional can lead to a similar scenario. In Patient 08's case the healthcare professional and the informal carers had gone away. Her daughter and son had both gone away together, she lived alone and the only person around during her period of decline was her neighbour. Several community healthcare professionals acknowledged this problem, expressing concern that their annual leave had led to a patient's hospital admission.

"Maybe you should have rang me or somebody else, somebody else would have come out and seen you, if I wasn't on duty that day" (CCM [patient 08 - COPD]).

Ideally patients would be handed over to colleagues during a period of annual leave, in an attempt to avoid a hospital admission. However, this alone could cause complications.

"It's alright when you're on duty, but if somebody else is on duty and they're getting a call to say I've just started my rescue medications, it may not go down so well…they may not know the patient" (CCM [patient 08 - COPD]).

When the community case manager went on annual leave, she would hand the caseload over to other members of the team, however, this handing over during a time of annual leave did not appear successful. Similarly, the 'absence effect' and its contribution to a hospital admission is also displayed by patient 08. Here we see the patient did seek appropriate alternative community help, however, due to an absence this contact was not made. The patient then explained, he would now call 999 if he deteriorated further. Again, despite the groundwork of the community case manager, an absence may have precipitated an admission.

"I phoned up once when I was in trouble but [community matron] was on leave and the lady who took the call said 'I can't get round because I'm finished in ten minutes. So I thought that's fair enough, I'll see how I go and I'll call somebody [referring to 999]. But I seemed to pull myself together, knowing full well that nobody was going to come anyway and I settled down, you can panic a bit you can't help it. She's a lovely person but she always seems to be on leave" (patient 08 - COPD [post discharge interview]).

Despite the absence of patient 08's community case manager, he had received input from other members of the team. The community care manger described the care this patient received prior to admittance.

"Ah yes, I was away, my colleague [name] spent an hour with him on the 3rd August, and then 15 minutes calling on him on the 4th August, and then on the 6th August intermediate care saw him on the 5th and 6th of August. Then on the 9th of August I picked up contact there…He's had a lot of input from my colleagues, yeah when I was off" (CCM [patient 08-COPD]).

Patient 08 was supported by community services during his episode of deterioration, despite his community case manager being on annual leave. Regardless of this input, he was still admitted to hospital. The 'absence effect' may have influenced his admission. Likewise, patient 10 received community support before admission. Measures put in place to avoid a hospital admission, such as other members of the team being aware of and actively supporting patient 10, had been put place as her community respiratory nurse was on annual leave.

"Well actually I was on annual leave, the health care assistant… she went out to see [patient] and gave advice on the phone" (CRN [patient 10 - COPD]).

Again, despite the involvement of community services with patient 10, she was still admitted to hospital. Patient 01 disclosed that his GP was on annual leave at the time of his admittance to hospital.

"Well he's gone on holiday now and he said 'oh I'm going on holiday' he said 'so it will be about a fortnight', I said 'hey you can't go on holiday' [laughs], 'not while I'm all crook" (patient 01 lung cancer).

It was found that the absence of a key family member could also influence an admission to hospital. Patient 28's daughter was absent at the time of admission, she displayed an attitude of not knowing who else to call in an emergency, so she called 999. The district nurses only became involved with this patient after the admission to hospital, so in this case patient 28 did not have specialist community support she could rely on as a backup when her key carer was absent.

"'I was on me own, and I had these terrible pains in the chest…I rung for an ambulance…Now boss [daughter] is back from her honeymoon" (Patient 28 lung cancer).

On occasion, patients found that it was not the absence of an individual healthcare professional which led to a hospital admission, it was that services were not available. This may have been due to the lack of appropriate services, for example, patients had been told to contact community services when unwell, however, if this happened on a weekend or their regular nurses were unavailable, this could precipitate emergency admission. In addition, healthcare professionals did not refer patients to particular services as they had previous knowledge of patients with certain conditions having no entitlement.

4.5 Theme Two – Service Provision Gaps

Some patients reported that they had difficulty accessing community resources. The lack of these services often meant an admission to hospital was likely. Some nurses felt that this problem, was due to the patient's diagnosis. An example of this was disclosed by both the hospital and the community respiratory nurses.

"The things that were quite frustrating to the community matron, they had twice referred him for respite with the hospice, and for – she's never got to the bottom of it, but she feels that, on one occasion she was told that they didn't have the staff to facilitate his respite admission…she had tried a couple of times…nothing ever materialised" (HRN [patient 09 COPD]).

"People don't do much with these patients because COPD is not very sexy" (CCM [patient 09 COPD]).

"People with lung cancer have a lot in place and they are much more likely to have had conversations about palliative care with service providers. Services are just not there for patients with other respiratory conditions…With cancer, you've had a diagnosis of cancer, and they have got time to get used to it. Everybody knows that if you had a diagnosis of cancer that the outcome might not always be one of survival" (CRN [patient 10 COPD]).

"I think if you have a cancer diagnosis, then I think you're very well supported. But I think people have a little bit more difficulty with palliative patients that have a non-cancer diagnosis, but is a deteriorating condition, long term, and especially when they reach that end of life, and of course with COPD patients, they have the same type of symptoms that cancer patients have in terms of their breathing, pain, anxiety, the emotional side. BUT

the resources aren't available to address that…it's also about the clinicians identifying that and initiating discussions and having the support available, I think that's where are gaps are, for someone as end stage as this gentleman" (HRN [patient 09 COPD]).

The perception held by the nurses, was that patients with lung cancer could be referred to and have access to more services than those with COPD, for example, with patient 09, respite care was not available as this patient had COPD, meaning that the patients in need of this required a hospital admission. The community matron for patient 09, felt that, her attempts failed to secure access to respite services, in her words, due to patient 09 having COPD.

The palliative care nurses expressed that a lack of practical community facilities, for example, blood taking or IV administration, could trigger an admission to hospital. The evidence suggests that these patients were admitted to hospital due to a lack of services provided in the community.

"Unless she was able to have IV antibiotics in the community I think that would have been the only way to prevent her coming into hospital…if they had oxygen and IV antibiotics at home they mightn't need to come in at all" (PCN [patient 28 – lung cancer]).

"Trying to get bloods done quickly as well can be difficult…if you miss the morning slot to get them up to hospital on time…They've got to be done in the morning then get to the GP so they can be sent off in the afternoon" (PCN [patient 28 – lung cancer]).

"it was probably the best place for him to be honest, there was no way he was going to have bloods done in the community at that time of day, so it was the best place for him really, it was appropriate for him to be admitted" (PCN [patient 22 – lung cancer]

If these services were available to patients in the community, hospital admissions could potentially have been avoided. Similarly, in patients 08's case a community facility was required. This patient required a home visit from the community respiratory nurse specialists which patient 08’s daughter had tried to arrange. They did not attend as they had made a home visit the previous day and everything appeared normal, a decision which had dramatic consequences

"If the COPD operation had of come out, they'd have known her oxygen was dangerous, and they'd have admitted her straight away…Instead, we had to administer CPR on her and everything, while we were waiting for the ambulance"(Daughter [patient 08, COPD).

Similarly, Patient 22 required a home visit from the GP. Patient 22’s wife had called community palliative care nurses due to her husband being unwell, they then requested a home visit from the GP which was not carried out and patient 22’s wife therefore needed to call 999.

“I had a call from his wife on the 27th to say that he was poorly and increasingly confused and then I spoke to the GP...and suggested he needed a medical review, which didn't happen, then I went to visit him on Saturday morning, but he had actually been admitted to hospital the night before, so the GP didn't go out to review him” (PCN [patient 22 lung cancer]).

Not only service provision gaps were discovered, patients were unable to access services due to the telephone number being engaged. Patient 03’s hospital respiratory nurse explained that difficulty in making contact with community matrons could contribute to difficulties accessing services. The telephone number for the community matrons and the district nurse was the same, and this number was often engaged due to the high demand. As a consequence, patients would seek help from 999, knowing that the response would be immediate, and this in turn would often cause a hospital admission.

“They don’t have a direct line telephone number, and we do know that the single number that everyone uses is also the referral line, it’s used for both District Nurses and

Community Matrons, and we get many patients that will ring us and say 'can you get hold of such and such a matron, because I've been trying to get hold of them all day and can't get through'…whether there should be a separate number…that might be more ideal '" (RCNS [patient 03 - COPD]).

The respiratory clinical nurse specialist felt that patients were unable to access services due to the telephone number being engaged. Patient 09's hospital respiratory nurse eluded that avoiding an emergency admission was all down to the patient.

"It's down to the patients appropriately using the service, either ringing the community matron, rather than 999..." (HRN [patient 09 COPD]).

However if, in an emergency this number was engaged, patients may have been left with no alternative but to call 999. As with accessibility, a reduction of out of hours or weekend services was reported by some. The influence this outside office hours restriction had on patients often meant a hospital admission was necessary. Healthcare professionals, unknown to the patients, would often see them in distressing circumstances, breathless and anxious. Not knowing this patient's normal symptoms could often mean an admission to hospital was deemed necessary. The community respiratory nurses described the accessibility restrictions that patients faced when requiring support out of hours.

"*Things like our service anyway, works Monday to Friday, nine till five, and the number of patients I've got with anxiety element, it always seems to be out of those hours…We are a safety net…I'll now say to my patients, I'll say 'look, if you start to feel unwell, don't leave it until four o'clock, phone me in the morning' at least then I can get out and visit you. Because there's certain things that we can put in to prevent admission"* (CRN [patient 10 - COPD]).

“Most COPD admissions come in overnight and over a weekend. I would love to see a telephone service with even potentially, if money was no object of course, a carer or somebody able to, not necessarily a night sitter, but a bit of response, that either they could talk them through their breathless episode or somebody that could just nip out and ‘are you okay?’…But the number of admissions we have are high and most of them call during the night” (RCNS [patient 03 - COPD]).

Patient 33’s community palliative care nurse disclosed the implications of falling ill at the weekend, suggesting that when patients access the community help available to them they would often be diverted to hospital. Local to recruited patients was an out of hours doctors clinic, the ‘Badger service’, where, when patients sought advice they were often be told to call 999.

“One of my lung cancer patients was very breathless and was having a panic attack,… he always, always said he didn't want to go to hospital, doesn't want to go back to hospital and his wife knew that, so she rang Badger, and Badger doctor said dial 999 and quite often Badger advise that, and she said to the Badger doctor 'no my husband doesn’t want to go to hospital, I want a doctor here' so they sent out a Badger doctor, but it was only because she was very firm in what she said and I think sometimes as well, and I know at the weekends, when we’re doing on call, Badger doctors quite often will say 'oh well just dial 999 and get the paramedics out" (PCN [patient 33 lung cancer]).

The connection patients had with community services was sometimes limited due to availability, accessibility and time restrictions. The complexity of community service provision, resulted in misleading advice. Patients were advised to contact community services during a crisis to prevent an emergency admission, however, this is only applicable Monday to Friday, nine to five. Out of these hours, an alternative pathway is required; a patient deteriorating through the night or at the weekend could result in an emergency admission, due to the absence of services which would negate a hospital admission.

4.6 Theme Three – 'Knowing' What to Do In an Emergency

Thematic analysis revealed that hospital was deemed as the last resort for most patients and their healthcare professionals. However, in a crisis there became a point where the patient or their carers believed that they were left with no alternative to hospital. Some patients felt that despite the positive depiction of healthcare professionals and their effective management techniques, enabling patients to stay at home, they still required a hospital admission. A number of patients demonstrated this, revealing that there became a point where they were left with no alternative. This confirms the findings from the main study (Munday et al., 2013).

This behaviour was displayed by patient 10, who, when feeling unwell, called the specialist respiratory nurses the day preceding admission. Her usual nurse was on annual leave so a colleague made a home visit. The following day she felt worse, but did not access the respiratory team and called for an ambulance. The paramedics attended the patient's house and gave her the option of staying at home or being admitted to hospital. The patient decided the care she needed could only be delivered in hospital, despite her previous intentions of staying at home. The palliative care nurse for patient 33 also commented on paramedics offering her the choice of a hospital admission.

"They can do more for me here [hospital,]… I needed to come in, because, although you've got district nurses and that there, they can't do everything" (patient 10 - COPD).

"Lots of people will say, 'Yes, I want to be at home, yes we're going to do it at home, and we're going to stick it out' and then when it comes to the crisis point or they're very anxious they will just pick up the phone and dial 999…And I think the paramedics are also, will usually would say to the person 'Is this what you want to do? Do you want to go to hospital?'...I think if people are asking for hospital admissions the paramedics wouldn't force them to stay at home" (PCN [patient 33 – lung cancer]).

The paramedics also believed that home was the right place for these patients, but as they had been called, they had a duty of care, and offered patients the option of admission to hospital or care at home. Patient 10 and patient 33 had asked for help during a period of distress by calling the paramedics. End of life care within the home is promoted by current policies, guidelines and government initiatives, giving patients the autonomy to make an informed decision about their care in the place of their choosing. However this choice was given to the patients during a period where they may not have been able to make an informed choice, because the symptoms were so distressing to them, patients decided that a hospital admission was required. The respiratory nurses shared the views of the paramedics and a hospital admission should be seen as a final choice when all other alternatives had been exhausted.

"Hospital is the last resort really. So it's about education, and it's about the type of patients as well…the aim is educating patients how to use services to their advantage and avoid admission, and if their symptoms change, to alert the team to ask for advice, do not wait" (CRN [patient 10 - COPD]).

Although patient 10's respiratory nurse discussed the importance of avoiding a hospital admission, she stressed how important it was that the patient stayed at home, but at the same time instructed patients not to wait in a crisis. Patients demonstrated an understanding that the right thing to do was to avoid a hospital admission, but if one was needed, they were often chastised for leaving it too late.

“"I was pushing off the inevitable" (patient 31 lung cancer).

"They hold on and hold on, and they think they'll be okay" (CCM [patient 09 COPD]).

"Yes, we often think, well you know, when I phone up the ambulance, is this really necessary, But you know, it has been so...basically [husband] or I will make a decision, if you understand what I mean...so we say hold on, hold on, hold on and then... "They don't like to if it's not necessary, if you know what I mean?" (Wife [patient 33 lung cancer]).

"It's me own fault, because I didn't call her…. I've got to stop getting to the point where I'm so desperate I've got to call an ambulance" (patient 03 COPD)

"*Now the patient has a community matron, but instead of contacting her when he starts to become ill, he waits for a few days, will become worse and then ring for an ambulance"* (RCNS2 [patient 03 COPD]).

Patient 03's community case manager had been trying to prevent the patients admission by teaching him to cope with his condition at home, however, she also commented on the idea that Patient 03 feels safe in hospital, he considers hospital the safe alternative.

"A big part of Mr [name's] care, from my input has been anxiety management and trying to help him cope with his condition and recognise early deterioration a bit sooner" (CCM [patient 03 COPD]).

"He's the highest hospital admission patient by a long way that I know... and I think he's had a pattern of behaviour for so long where he would go into hospital, that that's reassuring for him, because he feels then he knows the staff and things like that. So it's very much a battle, to try and break that routine with him" (CCM [patient 03 COPD]).

Despite this familiarity and feeling of safeness within the hospital. Patients and their carers normally do everything to avoid a hospital admission. Healthcare professionals acknowledged that often patients know best if they require an admission to hospital.

"Giving them the education and that independence really and nine times out of ten they're right" (CCM [patient 09 - COPD]).

The idea that patients know their conditions best was discovered through the analysis and EURECA highlighted the importance of the expert patient (Munday et al., 2013). When asked if the hospital admission was required it was affirmed by most of the patients.

"Oh yes. Yes. Oh yeah. Yeah. I might not have been here if I hadn't have come into be honest with you" (Patient 08 COPD).

"Oh yes, yes, I really did. Well I just couldn't get my breath at all, and of course you don't know what to do…I thought 'well I can't go to bed like this', I just couldn't breathe at all" (Patient 10 COPD)

"Oh well, I needed to come in, because, although you've got district nurses and that there, they can't do everything" (Patient 16 lung cancer).

"Oh yes, yes" (patient 33 lung cancer).

"She said [the Dr] 'just in time' he did it just in time, she said 'yes we did the right thing'" (Wife [patient 33 lung cancer]).

In answering the research question 'what is the role of healthcare professionals and community services in emergency admissions of people with advanced COPD and lung cancer?', it was found they were extremely complex and often influenced by environmental factors such as absence, service provision gaps and knowing what to do in an emergency. These findings will be further examined in the discussion.

CHAPTER FIVE – DISCUSSION

5.1 Chapter Overview

This chapter will consider the findings from this study in relation to existing policies and research.

5.2 Discussion

Findings suggest that the role of healthcare professionals and community services in emergency admissions of people with advanced COPD and lung cancer are extremely complex and are often influenced by environmental factors. The role of healthcare professionals and community services identified the importance of relationships between patients and their community providers.

Analysis revealed three themes relating to the research question; a change in normal support, service provision gaps and 'knowing' what to do in an emergency. The relationship between patient and community providers emerged as a fundamental factor in recognising the reasons for the decision to access the emergency department. Two major implications encapsulated the findings from this study; 'implications of absence and inaccessibility to healthcare' and 'home – the right place to be?'

5.3 Implications of Absence and Inaccessibility to Healthcare

Healthcare professionals are encouraged to manage COPD exacerbations and lung cancer patients in the community in an attempt to reduce the number of hospital admissions. Research has shown that this is a safe and cost effective management technique (Gravil et al., 1998; Cotton et al., 2000; Davies et al., 2000; Skwarska et al 2000). NHS England (2013 p.5) suggest that patients must be provided with "highly responsive, effective and personalised services outside hospitals…delivering care in or as close to people's homes as possible" However, the study identified that the absence of a key healthcare professional, such as the community respiratory nurse, could often influence a hospital admission, despite having plans in place to manage this patient effectively in the community. There was no comparison group however to determine if an emergency admission would still have occurred if a health care professional was on duty at the time. The Roy Castle Lung Cancer Foundation and the National Lung Cancer Forum for Nurses (2013) recently published a report exploring the value of lung cancer nurse specialists. They recommended that “NHS commissioners and/or providers should ensure that there are sufficient numbers of Lung Cancer Specialist Nurses (LCNSs) in place, taking into account the need for appropriately skilled nursing cover during periods of planned and unplanned LCNS absences” (The Roy Castle Lung Cancer Foundation and the Nation Lung Cancer Forum for Nurses, 2013 p.4). The study showed that frustration was often felt by healthcare professionals when they returned from their annual leave to discover their patient had been admitted to hospital during their absence.

The importance of a good nurse relationship in end of life care has been well documented (Mok and Chiu, 2004; Bailey, 2011; Stajduhar et al., 2011). It is an integral part of nursing care and fundamental to nursing practice (Ramos, 1992; Tanner et al., 1993; Taylor, 1998). When patient 09’s community nurse reflected on her involvement in her nurse-patient relationship, she expressed a development of a good relationship but questioned it when she was temporarily absent; concerned that she had built up such an effective and one-to-one relationship with her patient and that she was ultimately creating a dependence, the nurse was clearly upset. It does not seem appropriate that healthcare professionals feel that the building of good nurse-patient relationships is a problem. New initiatives are required regarding therapeutic relationships in end of life care. Even though cover had been put in place for her period of leave, her patient had developed such a strong bond with her, that he did not wish to seek help from a colleague and preferred to be admitted to hospital instead. Costello (2006) confirms that there is an increasing number of hospital admissions for patients at the end of life. The absence of key healthcare professionals leading to an admission was not isolated to this one case.

It appeared that patients had built up these effective nurse-patient relationships with one key community nurse, who they allowed freely into their homes and trusted, considering them almost as an extension of their family. Similar findings were discovered by Mok and Chiu (2004) who explored the nurse-patient relationship within palliative care showed that these relationships evolved into a trusting and connected friendship, with the nurse becoming part of the patient's extended family. This will have an implications on the role of community case managers when considering their nurse patient relationships and in turn will be helpful to inform future policies.

Organisational change will have to be implemented to ensure absences of any kind do not affect the patient. Alternatives are required before the absence occurs, for example, having more than one nurse with whom the patient can trust and allow to enter their home .However, the implementation of change in complex environments such as healthcare can prove difficult. Greenhalgh et al. (2005) showed that it is the interaction of the intervention with the particular social context in which it is embedded that determines outcomes. What is successful in one environment may not achieve such success in another, it may not be generalisable. For each patient to be cared for by a number of community nurses rather than one key nurse, an increase in their already extended patient list is required. This may not be accepted well, community nurses will need to liaise with colleagues to avoid gaps in service provision. Sharing caseloads may not be straightforward, and what works in one community healthcare facility may not work as efficiently in another.

Findings showed that community services were often restricted to office hours, with normal services running Monday to Friday, nine till five. Out of these hours patients often had to access the on call team, consisting of nurses and doctors who were unfamiliar to them. Equally, Gysels and Higgingson (2009) found that patients with COPD often had difficulties accessing care in an emergency which often led to an emergency admission. Although patients become ill, not just between the hours of 9-5 Monday to Friday, the current drive towards a seven day working week in secondary care is not matched by community services. The National Audit Office (2013 p.8) suggest this "compromises efforts to avoid out-of-hours hospital admissions and prolongs the length of stay for inpatients unable to access pathways out of hospital seven days a week, disrupting the capacity to manage new admissions" Would seven day working patterns improve the community service available? The NHS Seven Days a Week Forum believe that "patients in every community in England should be able to access urgent and emergency care services, and their supporting diagnostic services, delivered in a way that meets the clinical standards we have developed, seven days a week" (NHS, 2013b p.7). If patients are to experience genuine seven day care transformational change will be required in primary and community health services. The NHS Forum will announce proposals in autumn 2014 for the creation of a fully integrated service delivering high quality treatment and care seven days a week (NHS England, 2014b). The NHS England's A Call to Action, confirmed these goals, promoting a united approach to fundamentally change how healthcare is delivered and used (NHS England, 2013b). Patients need the

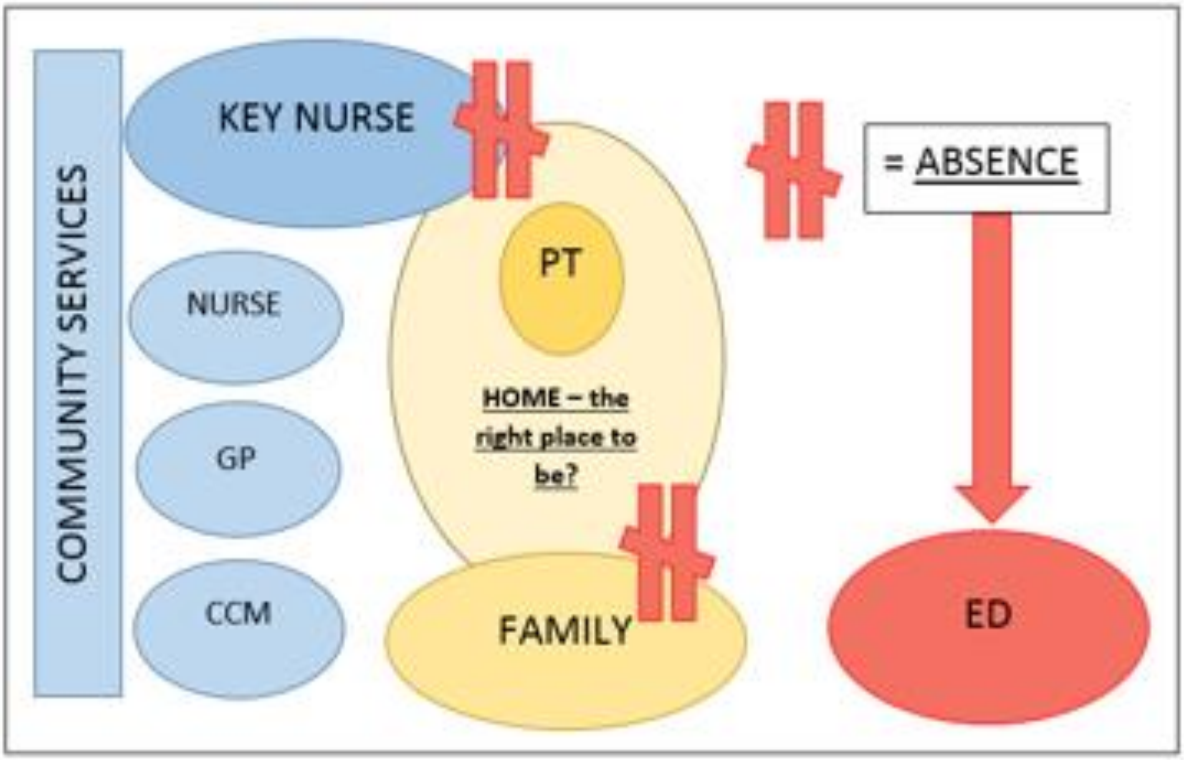
NHS everyday with findings showing that the limited availability of some services at the weekend can have a detrimental impact on patient outcomes. For the NHS to become a more patient focused service it has to be routinely available seven days a week.

Continuity of care is a concept which describes patient and healthcare professional contact across time and settings. It has been shown to have a positive effect on patient satisfaction and hospital readmission rates (Santomassino et al., 2012). Santomassino et al. (2012) showed that patients who were cared for in the community after an admission to hospital by nurses and advanced practice nurses with specialised training in the area of care along with a collaborated interdisciplinary team approach contributed to reduced hospital admission rates. Similarly, Purdy (2010) showed that a high continuity of care with a family doctor may be associated with lower risk of admission for all age groups. The Kings Fund (2014a) suggest there is a need for a greater continuity of care outside hospital, for example being seen by the same nurse each time in the community, however there are serious repercussions if this said nurse is unavailable. Findings showed that when this key nurse was absent, even temporarily, patients would not seek help from another community nurse within the team but would call 999 and be admitted to hospital. The nurses and doctors within the hospital wards were also well known and liked by the patients, as patients often experienced multiple admissions to the same hospital ward, with the same staff, in familiar surroundings, confirmatory to the findings of EURECA (Munday et al., 2013). Patients chose to bypass other community nurses as they were considered strangers, they did not want to admit these strangers into their own homes, instead preferring to seek the familiar hospital ward environment outside the home.

Concept Map

Based on the analysis a concept map was created to show the importance of relationships between the patient and their healthcare professional. Patients only utilised one key community nurse, despite being surrounded by other healthcare professionals. This concept map can be used to identify at risk areas for patients' who are cared for in the community. An absence from a key nurse or a family member often resulted in an admission to hospital.

Illustration Two – Concept Map



The government is focused on reducing emergency admissions, The *National Health Service Institute for Innovation and Improvement* (2007) introduced national targets set to do this. Findings from this study replicate the findings of Halpin et al. (2008), who reported that COPD patients are often cared for in the community and the responsibility of care falls on the community team involved. However, they did not comment on the effect an absence could have on the systems put in place to prevent an emergency admission. A review of the literature ascertained that this ‘absence effect’ had not previously been exposed in relation to its influence on patient emergency admissions to hospital. Being aware of the impact a breakdown in services can have on a patient’s pattern of behaviour is an important element to future policies. The role of community case managers must be considered as they could ultimately influence the way patients are cared for in the community, possibly preventing unnecessary emergency admissions in the future. The ‘absence effect’ may be avoided by patients interacting with more than one community nurse. This has implications for staffing and the allocation of patient case loads. Something as simple as being looked after by a number of community nurses familiar to the patient could prevent unnecessary hospital admissions.

Patients with palliative needs often experience a considerable number of preventable emergency admissions (Gott et al., 2013). This study revealed that a lack of practical community resources, for example, the inability to give IV antibiotics within the home environment often led to an emergency admission. Some patients were admitted to hospital for that reason alone. If services such as this could be provided in the home it may prevent these vulnerable patients experiencing a distressing hospital admission at the end of life.

The End of Life Care Strategy (DH, 2008b) advises that all individuals approaching the end of life should have equal access to high quality care regardless of their circumstances (NHS, 2011b). Findings suggested that patients with COPD and lung cancer experience unequal access to community resources. Some patients with lung cancer can fall through these gaps despite having a structured plan of care. Community case managers are not provided as they are for patients with COPD. The creation of this role for all patients with life limiting diseases could improve the way end of life care is delivered in the community. It would facilitate a clear pathway to who to access help from in an emergency, in order to avoid a hospital admission. NHS England (2013 p.5) acknowledge that patients “ are struggling to navigate and access a confusing and inconsistent array of urgent care services provided outside of hospital, so they default to A&E”. Emergency departments have become a victim of their own success, providing a responsive and effective service to those who need it, however NHS England admit that “millions of patients every year seek or receive help for their urgent care needs in hospital who could have been helped much closer to home” (NHS, 2013a p.5). Lung Cancer Nurse Specialists are available but they do not have equitable access, they should be available to all patients “at the time of diagnosis to guarantee that their physical, social and emotional needs, and their treatment options, are appropriately assessed and discussed from the beginning of their cancer journey” (Roy Castle Lung Cancer Foundation and the National Lung Cancer Forum for Nurses, 2013 p.12). Lung cancer nurse specialists can also improve the quality of lung cancer services by reducing adverse events, avoiding hospital admissions, reducing length of stay and helping patients with self-management (National Lung Cancer Forum for Nurses, 2010). LCNSs can be instrumental when helping patients avoid unplanned admissions. Initiatives such as nurse led follow up, including clinics, telephone and home visits and advice lines, aim to coach patients in self-management techniques, helping them recognise when to seek advice and potentially avoiding unnecessary hospital admission (National Lung Cancer Forum for Nurses, 2010). However the accessibility of these nurses is key to this avoidance. The

National Lung Cancer Audit (2012) revealed that only half (51%) of lung cancer patients are currently seen by a LCNS and only one in four have a LCNS present at the time of the diagnosis. Where lung cancer patients do not have access to a LCNS only three in ten (30.9%) receive any form of active treatment. The implications of this absence for lung cancer patients could contribute to a hospital admission. The importance of having a LCSN means that LCNS posts should be protected, especially during times of financial difficulty within the NHS to ensure that patients with lung cancer, and their families, are appropriately supported and offered informed advice throughout the complex and varied journey. Without this key support network in the community patients with lung cancer could potentially have increased emergency admissions to hospital.

Referral to services to assist patients avoid a hospital admission was seen, however, even though community nurses referred patients with COPD to services such as respite care, their referral was not facilitated. Similar findings were found by Ahmed et al. (2004) they referred to these patients as being ‘doubly disadvantaged’ due to their life threatening illness and being excluded from the benefits of palliative care services. Access to these crucial palliative care services should be based on need, not individual diagnosis (Higginson and Addington-Hall, 2001). Equity of access to palliative care services currently drives palliative care policies and guidelines (Mathew et al., 2003). If community nurses were aware that patients with COPD would not receive access to certain community services, would this ultimately lead to a reduction in referrals to services for patients with COPD? This goes against all current palliative care polices for equity of access to palliative services regardless of diagnosis (DH, 2008b; NHS, 2011b).

It was discovered that during a crisis, patients could not access community nurses due to the telephone number being engaged. The number for the community matrons and the district nurses was the same. If patients required their services during a period of distress and the number was engaged, this often left them with no alternative but to call 999. Findings echoed those of Quest et al. (2011), suggesting that there was no alternative for some patients to a hospital admission. Knowing this means that a different telephone number could be put in place for district nurses and community nurses or even for different teams. A simple measure such as this could potentially help prevent unnecessary hospital admissions for patients in the future.

There is limited evidence on what is effective in reducing unplanned emergency admissions. The National Audit Office (2013 p.8) suggest “there are many local initiatives to prevent avoidable emergency admissions, including risk prediction tools, case management, hospital alternatives and telemedicine, but limited evidence on what works”. Estimating that at least one-fifth of admissions could be managed effectively in the community (National Audit Office, 2013).Interventions to reduce emergency admissions take place within a complex environment. Purdey (2010 p.17) suggests that “the nature and structure of existing primary, secondary and social care services, individual professional attitudes, patient and family preferences, and general attitudes to risk management all combine to influence both the implementation process and the eventual outcome of successful implementation”. Interventions will seldom be implemented in isolation, in order to reduce emergency admissions a combination of interventions may be required, for example the ‘hospital at home’ scheme is a complex intervention requiring several components to be combined. Davies et al. (2000) showed that hospital at home care is a practical alternative to hospital in some patients with exacerbations of COPD. They showed hospital at home administered from the emergency departments, not involving an overnight hospital stay was as effective as conventional hospital management in some exacerbations of COPD. The National Co-ordinating Centre for NHS Service Delivery and Organisation Research and Development (NCCSDO) (2000 p.12) evaluated the effectiveness of innovations involving nurses for people in the community with COPD. They suggested "nurse led hospital at home or early discharge schemes for patients with COPD living in the community should be prioritised".

The implications of the 'absence effect' and the inaccessibility to healthcare services due to problems such as shared and engaged telephone lines can lead to unnecessary emergency admissions to hospital. Good nurse-patient relationships are crucial to managing a patient's condition effectively within the community. If not maintained, even temporarily, it can have repercussions, precipitating an emergency admission. Simple preventative measures as suggested above could also contribute to reducing these admissions.

5.4 Home – The Right Place To Be?

The roles of healthcare professionals and community services were complex and sometimes conflicting in nature. The awareness that hospitals should be avoided and home was seen as the best place to be by the patient and their healthcare professionals was apparent from the findings; however, it was discovered that all patient admissions within the study were seen to be appropriate. Patients were often battling with the idea that they should stay at home, viewing hospital as a last resort with the conflicting advice from healthcare professionals that in doing this, they had left seeking help too late.

Providing nursing care within the home environment is central to health policy (DH, 2000; DH, 2001a).The Department of Health *End-of-Life Care Strategy – 2nd Report* (DH, 2010) recognised the importance of home care at the end of life, suggesting that if the numbers of deaths at home rise, people will ultimately be receiving care and dying in the place of their choice. Similarly, the *National Cancer Plan* (DH, 2000) promoted patient choice regarding end of life care. Findings in this study showed that patients, carers and healthcare professionals were aware that hospital should be deemed as a last resort, and that care should be delivered within the community. Similar findings were discovered by Barbera (2010) who explained that patients near the end of life should be cared for in the environment of their choice rather than on an emergency basis. Likewise, *The Cancer Reform Strategy* (DH, 2007) promoted home care at the end of life in the community, not hospital, and the NHS *'Transforming Inpatient Care Program for Cancer Patients'* (NHS Improvement, 2008) focused on moving care from hospital into the community. Findings showed that some patients displayed self-management techniques, knowing that they should stay at home, cope with their condition and leave hospital to the last resort. Purdy (2010) found that self-management techniques in patients with COPD proved effective in reducing unplanned emergency admissions. Self- management education for patients with COPD reduces the risk of at least one hospital admission by about 36 per cent compared with usual care (Effing et al. 2007). However, despite government policies promoting care in the community, findings showed that all hospital admissions in this study were believed appropriate. A systematic review by McDonagh et al. (2000) found that only six to twenty percent of emergency medical admissions in the UK were inappropriate. Findings also revealed that most patients waited at home, trying to manage their deterioration and avoiding a hospital admission, until they were so ill, they were left with no choice but to attend the emergency department.

Findings from this study which highlight the importance of the relationship between healthcare professionals and patients and the privacy of the home environment suggest that the concept of 'home' from the patients' perspective is an important consideration. Patients only allow access to healthcare professionals they have established a close bond with. Findings suggest that the concept of 'home' is different from the perspectives of patients, healthcare professionals and governments. Likewise, Heath et al. (2012) found that the environment from which services are delivered is an issue in physical location and differing professional and patient perceptions. Similarly, Walshe and Luker (2010) discovered that 'home' is an important factor within the care context. They explored the roles of district nurses in palliative care provision, discovering that the home context affects the structure of care. It effects nurse-patient relationships, nurses must adapt their care within the context of a patient's home. They also discovered that caring for patients within the home environment did not prevent a hospital admission or determine the place of death despite peoples' perception that this would be the case. Findings from this present study suggested that caring for patients within the home environment could prevent an emergency admission, but if a key healthcare professional was absent, patients were reluctant to admit another team member into their homes, meaning that they were at risk of emergency admission.

Findings revealed that paramedics in several patient cases offered patients a choice when attending their house, on whether an admission to hospital was required. Emergency admissions for patients to hospital are used as an indicator of poor quality end of life care (Barbera et al., 2006; Earle et al., 2003). Pressure is felt by all members of the healthcare team to keep patients in the community at the end of life, avoiding emergency admission. Choice and the importance of choice is promoted by current end of life care policies. However, when patients find themselves in this vulnerable position, where they have sought the help of paramedics, it questions the clinical decision making behind the hospital admission. Anxiety is common to these respiratory patients who call 999 in an emergency to seek immediate help. This is not the time for patients to make informed decisions regarding their care. This study's findings suggested that patients would prefer the admission decision to be made for them during a crisis and not to be offered a choice on whether it was appropriate for them at this time.

Home and the concept of home had different connotations for different people. There is a need to fit community services into the concept of home as perceived by the individual. Government perceives that all patient homes are an appropriate environment for the delivery of specialised end of life care. How the patient sees the home environment is not considered and may not be consistent with how the government sees it. Remodelling patient services will enable them to continue to receive community palliative care within their home and would be a positive influence on unnecessary emergency admissions to hospital.

5.5 Study Limitations

As this study utilised previous data, original limitations apply (Munday et al., 2013). In particular, the lack of comparative data collected in the primary study from patients who were either too unwell to participate or coped with their condition at home therefore forgoing an emergency admission to hospital will affect the secondary analysis. Also the number of healthcare professional interviews gained from the primary study was not as hoped, this will impact upon secondary analysis, especially as the secondary analysis specifically aimed to investigate the role of healthcare professionals and community services in the emergency admission of people with advanced COPD and lung cancer. The secondary analysis process in itself could be seen as a limitation. The study was limited to ten patients who lived within the Birmingham area. This has implications for the generalisability of results. However, the aim of this study was to provide in-depth case studies whereby the roles of healthcare professionals and community services on patients were explored, so this number was deemed acceptable.

CHAPTER SIX - CONCLUSION

6.1 Chapter Overview

This chapter will suggest implications for future practice and further research and determine if this study’s findings could be used to inform future nursing policies, practice and education.

6.2 Recommendations for Further Research

The participants interviewed in the original study were primarily COPD and lung cancer patients, as this is what the research question required. An opportunity to study patients with other conditions which require palliation could uncover further aspects. Also, participants included in the study were only those who were admitted to the emergency department. The roles of community services and healthcare professionals could not be examined for those patients who were not admitted to hospital. Further research is required to explore this phenomenon.

Longitudinal studies using ongoing interviews with patients with advanced disease, could provide understanding into which patients might avoid admission. Substantial resources would be required to undertake such a study, but the results could be very beneficial in understanding the reasons for admission in greater depth.

6.3 Conclusion

This study has shown that the role of community healthcare professionals and community services preceding an emergency admission for people with advanced COPD and lung cancer are exceptionally complex and are often influenced by environmental factors. The clinical situation for these patients is unstable, their health can deteriorate rapidly and emergency admission for some patients is appropriate and is to be expected regardless of the community support in place. Findings suggest that clinical staff, health service managers and policy makers should understand it is very important that patients' and carers' experiences are taken into account when developing and providing future services.

A change in the patient's normal support network, for example, a period of temporary absence by their key healthcare professional or family member can precipitate an admission to hospital. This study also addressed the importance of relationships between patients and their community providers, indicating that patients only utilised one key community nurse, who they considered as an extension of their family. Findings showed that if this key nurse was absent, even temporarily, they would not access another community nurse despite their availability, again contributing to an emergency admission. Efforts need to be made to ensure adequate staffing levels of community specialist nurses are ensured and that every patient diagnosed with COPD or lung cancer has a specialist nurse available to them. Patient caseloads should be shared between community nurses to ensure patients can build an effective nurse patient relationship with more than one nurse meaning that if a temporary absence is experienced by the patient, they have more than just an emergency department alternative.

The importance of what the concept of home meant to the individual was discovered. There is also a need to fit these community services into this concept to enable the continuation of home care service provision.

The study suggested that a gap in service provision, for example, the inability to give IV antibiotics within the home environment, can also be instrumental in an emergency admission. Current initiatives such as the hospital at home scheme, whereby a patient receives extended nursing care according to clinical need, twenty four hours a day seven days a week, needs to be expanded. This assists in reducing unplanned emergency admissions not only by providing clinical services not normally available within the patient's own home, for example, the administration of oxygen therapy, intravenous fluids and antibiotics, but also they are available at all times.

Findings showed that patients fall ill not just between the hours of 9- 5 Monday to Friday, if patients deteriorated on a weekend their community care could be compromised. The NHS need to focus on providing effective community care at all times of the day or week. This would also forego the need for out of hours GP services, as findings showed if the GP does not know the patient this can also lead to an emergency admission. Previous studies have indicated that out of hours GPs consider if they have insufficient information to manage patients effectively it can lead to an emergency admission (Munday et al., 2002, Worth et al., 2006). Efforts to ensure continued professional development and training opportunities for community nurses are required. There is currently a lack of investment in district nurse education in palliative care. Not all district nurses feel they have the skills to look after a palliative patient appropriately in the community (Corroon and Munday, 2011).

Only by rethinking the model of palliative care provision within the community can we be responsive to those with conditions such as advanced COPD and lung cancer. There are clear pathways of care for patients with cancer, but this is not the case for patients with COPD. The development of services and packages of care and their equity would allow healthcare professionals to facilitate such patients a better end of life.

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APPENDICIES

APPENDIX ONE - Initial Database Search

DATABASE	KEYWORD	RESULT	DATE	#
MEDLINE	COPD (SST) Pulmonary Disease, Chronic Obstructive Disease	24645	20/05/2013	S1
MEDLINE	Lung cancer (SST) Lung Neoplasms	94961	20/05/2013	S2
MEDLINE	Respiratory Disease (SST) Pulmonary Disease, Chronic Obstructive/ or Respiration Disorders/ or Respiratory Tract Diseases/ or Respiratory Disease.mp. or Respiratory Hypersensitivity/ or Respiratory Tract Infections/	48658	20/05/2013	S3
MEDLINE	COPD patient* (SST) Middle Aged/ or Pulmonary Disease, Chronic Obstructive/ or COPD patient*.mp. or Aged/ or Lung Diseases, Obstructive/	2070299	20/05/2013	S4
MEDLINE	Lung cancer patient*(SSC) Adult/ or Lung Neoplasms/ or Middle Aged/ or Lung cancer patient* or Aged/	2905512	20/05/2013	S5
MEDLINE	Respiratory patient* (SSC) Carcinoma, Non-Small-Cell Lung/ or Aged/ or Respiration Disorders/ or Respiratory Tract Diseases/ or Adult/ or Home Care Services/ or Middle Aged/ or "Aged, 80 and over"/	2906543	20/05/2013	S6
MEDLINE	Terminally ill patient* Advance Directives/ or Middle Aged/ or Attitude to Death/ or Terminally Ill/ or Terminal Care/ or Aged/ or Palliative Care/ or Neoplasms/	2194595	20/05/2013	S7
MEDLINE	Critically ill patients* (SSC) Adult/ or Middle Aged/ or Critical Illness/ or Aged/	2873293	20/05/2013	S8
MEDLINE	Emergency patient* (SSC) Emergency Treatment/ or Adult/ or Emergency Service, Hospital/ or Middle Aged/ or Emergency patients*	2616974	20/05/2013	S9
MEDLINE	S1 OR S2 OR S3 OR S5 OR S6 OR S7 OR S8 OR S9	3117624	20/05/2013	S10
MEDLINE	End of Life*' (SSC) Palliative Care/ or Terminal Care/ or End of life*.mp. or Decision Making	77878	20/05/2013	S11
MEDLINE	EOL' (SSC) Terminal Care/ or 'EOL'.mp. or Critical Care/	24611	20/05/2013	S12
MEDLINE	End of life care' (SSC) Critical Care/ or Palliative Care/ or Decision Making/ or Terminal Care/ or Family/ or 'End of life care'. MP. or Social Support/	146832	20/05/2013	S13

DATABASE	KEYWORD	RESULT	DATE	#
MEDLINE	Palliative care' (SSC) Critical Care/ or Palliative Care/ or Decision Making/ or Terminal Care/ or Family/ or 'End of life care'. MP. or Social Support/	2776920	20/05/2013	S14
MEDLINE	Critical care' (SSC) Attitude to Death/ or Neoplasms/ or Patient Care Team/ or Terminal Care/ or Home Care Services/ or Palliative Care/ or Aged/	1457588	20/05/2013	S15
MEDLINE	Critical care' (SSC) or critical care	18575	20/05/2013	S16
MEDLINE	Palliative care services' (SSC) "Referral and Consultation"/ or Neoplasms/ or Palliative Care/ or Aged/ or Home Care Services/ or 'palliative care services'.mp. or Health Services Accessibility/	1475356	20/05/2013	S17
MEDLINE	Specialist palliative care services (SSC) General Practice/ or "Referral and Consultation"/ or Health Services Accessibility/ or Palliative Care/ or Terminal Care/	100321	20/05/2013	S18
MEDLINE	S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17	3146211	20/05/2013	S19
MEDLINE	Views* Nursing Staff/ or Attitude to Health/ or "Attitude of Health Personnel"/ or Caregivers/ or Health Personnel/	140263	20/05/2013	S20
MEDLINE	Attitudes* (SSC) Attitude to Health/ or "Attitude of Health Personnel"/ or Attitude/ or Health Knowledge, Attitudes, Practice/ or Middle Aged/ or Adult/	2864220	20/05/2013	S21
MEDLINE	Opinion* (SSC) Expert Testimony/ or Public Opinion/ or Middle Aged/ or Health Knowledge, Attitudes, Practice/ or "Attitude of Health Personnel"/	1861079	20/05/2013	S22
MEDLINE	Belief* (SSC) Adolescent/ or Adult/ or Health Knowledge, Attitudes, Practice/ or Middle Aged/ or Attitude to Health/	2882628	20/05/2013	S23
MEDLINE	Equality* Social Welfare/ or Prejudice/ or Minority Groups/	25021	20/05/2013	S24
MEDLINE	S20 OR S21 OR S22 OR S23 OR S24	2968756	20/05/2013	S25

DATABASE	KEYWORD	RESULT	DATE	#
MEDLINE	Death (SSC) Death/ or Death.mp. or Attitude to Death/ or Death, Sudden	334446	20/05/2013	S26
MEDLINE	Dying (SSC) Death/ or Attitude to Death/ or Palliative Care/ or Terminal Care/ or Family/	68763	20/05/2013	S27
MEDLINE	Dignity (SSC) Palliative Care/ or Attitude to Death/ or Personal Autonomy/ or Terminal Care/ or Nurse-Patient Relations/	60666	20/05/2013	S28
MEDLINE	Community (SSC) community.mp. or Residence Characteristics/	215594	20/05/2013	S29
MEDLINE	Emergency department' (SSC) Adult/ or Emergency Service, Hospital/ or Emergency Medical Services/	2024043	20/05/2013	S30
MEDLINE	Accident and Emergency' (SSC)	4191	20/05/2013	S31
MEDLINE	A&E' (SSC) Emergency Service, Hospital/ or Emergency Nursing/	32369	20/05/2013	S32
MEDLINE	Inappropriate admissions' (SSC) Health Services Misuse/ or Patient Admission/ or Hospital Departments/ or Patient Satisfaction/ or Emergency Service, Hospital/	90715	20/05/2013	S33
MEDLINE	ED (SSC) Emergency Service, Hospital/ or Adult/	2009035	20/05/2013	S34
MEDLINE	S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34	2507400	20/05/2013	S35
MEDLINE	S10 AND S19 AND S25 AND S35	2055997	20/05/2013	S36

DATABASE	KEYWORD	RESULT	DATE	#
CINAHL	COPD (SST) "COPD" (SST) OR (MH "Pulmonary Disease, Chronic Obstructive+")	10001	21/05/2013	S1
CINAHL	Lung cancer (SST) "lung cancer" OR (MH "Lung Neoplasms+")	18408	21/05/2013	S2
CINAHL	Palliative care (SST) (MM "Palliative Care") OR (MM "Terminal Care")	19949	21/05/2013	S3
CINAHL	End of life care' (SST) (MH "Multidisciplinary Care Team") OR "'end of life care'" OR (MH "Health Services Needs and Demand")	41256	21/05/2013	S4
CINAHL	Community' (SST) (MH "Communities") OR (MH "Community Health Centres") OR (MH "Hospitals, Community") OR (MH "Community Role") OR "Community"	146880	21/05/2013	S5
CINAHL	Emergency Department' (SST) (MH "Emergency Service+") OR "'Emergency Department'"	37893	21/05/2013	S6
CINAHL	S1 **AND** S2 **AND** S3 **AND** S4 **AND** S5 **AND** S6	0	21/05/2013	S7
CINAHL	S1 AND S2 AND S3 AND S4 AND S5	0	21/05/2013	S8
CINAHL	S1 AND S3 AND S5	9	21/05/2013	S9
CINAHL	S1 AND S4 AND S5	19	21/05/2013	S10
CINAHL	S2 AND S3 AND S5	10	21/05/2013	S11
CINAHL	S2 AND S4 AND S5	10	21/05/2013	S12
CINAHL	S1 AND S3 AND S6	2	21/05/2013	S13
CINAHL	S1 AND S4 AND S6	4	21/05/2013	S14
CINAHL	S2 AND S3 AND S6	4	21/05/2013	S15
CINAHL	S2 AND S4 AND S6	1	21/05/2013	S16

DATABASE	KEYWORD	RESULT	DATE	#
PsycINFO	COPD (SST) COPD.mp. or exp Chronic Obstructive Pulmonary Disease/	822	22/05/2013	S1
PsycINFO	Lung cancer (SST) exp Lung Disorders/ or exp Neoplasms/ or Lung cancer.mp.	23671	22/05/2013	S2
PsycINFO	Palliative care' (SST) 'Palliative care'.mp. or exp Palliative Care/	6245	22/05/2013	S3
PsycINFO	End of life care' (SST) 'End of life care'.mp. or exp Palliative Care/	6052	22/05/2013	S4
PsycINFO	Community (SST) community.mp. or exp Communities/	104572	22/05/2013	S5
PsycINFO	Emergency Department' (SST) exp Hospitals/ or exp Emergency Services/ or 'emergency department'.mp.	12830	22/05/2013	S6
PsycINFO	S1 **AND** S2 **AND** S3 **AND** S4 **AND** S5 **AND** S6	0	22/05/2013	S7
PsycINFO	S1 AND S2 AND S3 AND S4 AND S5	2	22/05/2013	S8
PsycINFO	S1 AND S3 AND S5	4	22/05/2013	S9
PsycINFO	S1 AND S4 AND S5	3	22/05/2013	S10
PsycINFO	S2 AND S3 AND S5	81	22/05/2013	S11
PsycINFO	S2 AND S4 AND S5	66	22/05/2013	S12
PsycINFO	S1 AND S3 AND S6	1	22/05/2013	S13
PsycINFO	S1 AND S4 AND S6	1	22/05/2013	S14
PsycINFO	S2 AND S3 AND S6	55	22/05/2013	S15
PsycINFO	S2 AND S4 AND S6	53	22/05/2013	S16

DATABASE	KEYWORD	RESULT	DATE	#
Science Citation Index (SCI)	COPD (SST)	20248	22/05/2013	S1
SCI	Lung cancer (SST)	135685	22/05/2013	S2
SCI	Palliative care' (SST)	15102	22/05/2013	S3
SCI	End of life care' (SST)	11479	22/05/2013	S4
SCI	Community (SST)	338013	22/05/2013	S5
SCI	Emergency Department (SST)	38317	22/05/2013	S6
SCI	S1 **AND** S2 **AND** S3 **AND** S4 **AND** S5 **AND** S6	0	22/05/2013	S7
SCI	S1 AND S2 AND S3 AND S4 AND S5	5	22/05/2013	S8
SCI	S1 AND S3 AND S5	26	22/05/2013	S9
SCI	S1 AND S4 AND S5	16	22/05/2013	S10
SCI	S2 AND S3 AND S5	62	22/05/2013	S11
SCI	S2 AND S4 AND S5	28	22/05/2013	S12
SCI	S1 AND S3 AND S6	3	22/05/2013	S13
SCI	S1 AND S4 AND S6	3	22/05/2013	S14
SCI	S2 AND S3 AND S6	16	22/05/2013	S15
SCI	S2 AND S4 AND S6	14	22/05/2013	S16

APPENDIX TWO - Summary of Articles

Title, Author and Date (Woolliams et al., 2009)	**Purpose / aim of study** (Woolliams et al., 2009)	**Data collection method / study** (Woolliams et al., 2009)	**Source** (Woolliams et al., 2009)
1) Caregivers for people with end stage lung disease: Characteristics and unmet needs in the whole population. Currow, D.C., Ward, A., Clark, K., Burns, C.M. and Abernethy, A.P. (2008) (Medline)	"To understand the population of caregivers for people with end stage lung disease (ESLD) leading to death."	"As part of the South Australian Health Omnibus, a random face-to-face, cross-sectional survey was conducted. 3000 respondents were asked annually (participation rate 77.9%). **Qualitative."**	South Australia
2) Caring for a person in advance illness and suffering from breathlessness at home: Threats and resources. Gysels, M. and Higginson, I. J. (2009) Medline	"To investigate the caring experience of carers for patients with an advanced progressive illness (chronic obstructive pulmonary disease [COPD], heart failure, cancer, or motor neuron diseases [MND]), who suffer from breathlessness."	"A **qualitative** study using a purposive sample of 15 informal carers was used. They were approached via the patients they cared for during their visits to respiratory clinics at the hospital, at specialist respiratory nurses' ward rounds and consultations, "Breathe Easy" service users meetings, and from the disease registers of the primary care team in a Family Doctor's surgery."	The study took place in a large teaching hospital and in the community in London between July 2005 and March 2006.
3) Differences between community professional and patient perceptions of chronic obstructive pulmonary disease treatment outcomes: a qualitative study. Cooke, M. and Thackray, S. (2012) 3 - Medline	"To define and compare the prioritised perspectives of respiratory specialist professionals and patients with COPD for expected outcomes of respiratory services."	"This **qualitative** study used separate focus group discussions for practitioners and patients."	"Volunteer multi-professional health and social care professionals in organisations involved with the COPD care pathway from four Primary Care Trusts."
4) Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community. Murray, S.A., Boyd, K., Kendall, M., Worth, A., Benton T.F. And Clausen, H. (2002) 4 - Medline	"To compare the illness trajectories, needs, and service use of patients with cancer and those with advanced non--malignant disease."	**"Qualitative** interviews every three months for up to one year with patients, their carers, and key professional carers. Two multidisciplinary focus groups."	Edinburgh

Title, Author and Date (Woolliams et al., 2009)	**Purpose / aim of study** (Woolliams et al., 2009)	**Data collection method / study** (Woolliams et al., 2009)	**Source** (Woolliams et al., 2009)
5) End of life care at a community cancer centre. Cowall, D.E., Bennett, W., Yu, M.D., Heineken, S., Lewis, E. N., Chaudhry, V. And Daughtery, J.M. (2012) 6-medline	"To evaluate data within a community to determine EOL cancer practices."	"Retrospective death study measuring the intensity ofEOL cancer care. **Quantitive."**	Wicomico County, Maryland
6) Evaluating a respiratory intermediate care team. Ward, S., Barnes H. And Ward, R. (2005) 7 - Medline	"To show that a respiratory team that cares for patients with COPD at home during an exacerbation is valued by patients and saves hospital bed days."	"A questionnaire was sent to RICT's patient group to establish their satisfaction with the care they had received. The questionnaire was sent to all 159 patients listed on the RICT database as either currently receiving care from the team or as having received care in the past. Patients known to have died since treatment from the RICT were excluded."	Oxford
7) Living with severe COPD. A Qualitative exploration of the experiences of patients in Leeds. Guthrie, S. J., Hill, K.M. and Muers, M.F. (2001) 8 - Medline	"A study of patients with severe COPD to illuminating standardized outcome measures and improving the understanding of these patients' needs."	"A sample of 35 patients from a group of 64 patients who took part in a randomized cross-over trial of nebulizer therapy vs. high-dose inhalers was interviewed at home using in-depth interviews."	Leeds
8) Older Adults experience s of transitions between care settings at the end of life in England: A Qualitative interview study. Hanratty, B., Holmes, L., Lowson, E., Grande, G., Addington-Hall, J., Payne, S. And Seymour, J. (2012) 9 - Medline	"To explore older adults' experiences as they move between places of care at the end of life."	"In-depth qualitative interviews and thematic analysis of the data/ Thirty adults aged between 69 and 93 years took part. Judged by their physicians to be in the last year of life, diagnosed with heart failure, lung cancer, and stroke)."	"This study took place in northern England in 2009-2010. It forms part of a larger project on transitions in health care settings at the end of life for people with stroke, heart failure, and lung cancer."
9) Palliative care or end of life care in advanced chronic obstructive pulmonary disease - a prospective community survey. White, P., White, S., Edmonds, P., Gyseles, M., Moxham, J., Seed, P. And Shipman, C. (2011) 10 - Medline	"To determine palliative care needs in advanced COPD."	"Cross-sectional interview study in patients' homes using structured questionnaires."	"44 south London general practices."

Title, Author and Date (Woolliams et al., 2009)	**Purpose / aim of study** (Woolliams et al., 2009)	**Data collection method / study** (Woolliams et al., 2009)	**Source** (Woolliams et al., 2009)
10) Rural/ urban differences in health care utilization and place of death for persons with respiratory illness in the last year of life. Goodridge, D., Lawson, J., Rennie, D. And Marciniuk, D. (2010). 11 - Medline	"To examine rural–urban differences in healthcare utilization and location of death for residents of Saskatchewan, Canada, with chronic obstructive pulmonary disease (COPD) or lung cancer in the last 12 months of life."	"A retrospective cohort study was undertaken of 1098 patients who died in 2004 with a cause of death recorded as COPD or lung cancer in administrative health data from Saskatchewan Health. Comparisons were made between three groups in terms of demographic characteristics, health care utilization (physician visits, length of stay, hospitalizations, institutional care, home care, transitions between care settings) and location of death (hospital, long-term care [LTC] or home)."	Saskatchewan, Canada.
11) The Care Needs of Community-Dwelling Seniors Suffering from Advanced Chronic Obstructive Pulmonary Disease. Wilson, D., Ross, C., Goodridge, D., Davis, P., Landreville, A. And Roebuck, K. (2008) 12 - Medline	"This study was undertaken to determine the care needs of Canadian seniors living at home with advanced chronic obstructive pulmonary disease (COPD)."	"An ethnographic qualitative approach was used. Twelve community-dwelling seniors living in a Canadian city and diagnosed with advanced COPD were interviewed three times in their homes over an eight-month period in 2006."	Canada
12) The last year of life of COPD: A qualitative study of symptoms and services. Elkinton, H., White, P., Addington-Hall. J., Higgs, R. And Pettinaru, C. (2004) 13 - Medline	"To assess the symptoms experienced and their impact on patients' lives in the last year of life of COPD, and to assess patients' access to and contact with health services."	"Qualitative analysis using the framework approach of in-depth interviews with 25 carers of COPD patients who had died in the preceding 3–10 months."	1 inner London health authority
13) The needs of patients dying of chronic obstructive pulmonary disease in the community. Jones, I., Kirby, I., Ormiston, P., Loomba, Y., Chan, K.K., Rout, J., Nagle, J., Wardman, L., Hamilton S. (2004) 14- Medline	"To determine the needs of patients dying in primary care from chronic obstructive pulmonary disease (COPD)"	"Semi-structured interviews were undertaken with 16 patients who were having therapy for COPD, who were thought likely to die in the year following them commencement of the study."	Not stated

Title, Author and Date (Woolliams et al., 2009)	**Purpose / aim of study** (Woolliams et al., 2009)	**Data collection method / study** (Woolliams et al., 2009)	**Source** (Woolliams et al., 2009)
14) Chronic care Model Implementation and Outcomes among patients with COPD in Care Teams with and without advanced practice Nurses. Duangbubpha, S., Hanucharurnkul, S., Pookboonmee, R., Orathai, P. And Kiatboonsri, C. (2013) 1) CINAHL	"To explore the level of implementation of a care model in chronic obstructive pulmonary disease care programs provided by healthcare teams with and without advanced practice nurses in community hospitals in northern and eastern Thailand; and, compare the difference of outcomes between the healthcare teams with and without advanced practice nurses"	"Data were analysed by descriptive statistics, Chi-square, t-test, PERMANOVA and the Mann-Whitney U test."	Thailand
15) District nurse interaction in engaging with end stage chronic obstructive pulmonary disease patients: a mixed methods study. Disler, R. And Jones, F. (2010) 2) CINHAL	"To explore the role of district nurses in caring for people with end-stage chronic obstructive pulmonary disease living in metropolitan London."	"A mixed-method design incorporating face-to-face interviews and mailed survey."	London
16) Lung cancer in the emergency department. Harding, A.D. And Simmons , C.C. (2012) 3) CINNALH	"To see why patients with lung cancer present to the emergency department."	None stated	Australia
17) Outcomes from a respiratory coordinated care program (RCCP) providing community-based interventions for COPD patients from 1998 to 2006. SPILIOPOULOS, N., CLARK, E., DONOGHUE, J., DUNFORD, M. (2008) 4) CINNAHL	"The RCCP based at St George Hospital. The aim of the program is to reduce hospital admission rates, readmission rates, and hospital length of stay. Additional components of RCCP include a Pulmonary Rehabilitation program and an early discharge service."	"In nine years 363 participants have enrolled from 1998 to 2006. Participants' mean age was 74.9 years and 53.8% were women. Ninety of the 363 have died and 29 were discharged because they were admitted to a fully dependent aged care facility or had moved out of the hospital catchment area."	Australia
18) The Comprehensive Care Team - A controlled trial of outpatient palliative medicine consultation. Rabow, M.W., Dibble, S.L., Pantilat, S.Z. And McPhee, S.J. (2004) 1) Science Citation Index	"A controlled trial of an intervention in which an interdisciplinary team offered palliative services to outpatients, their families and their primary care physicians."	"Conducted a yearlong trial involving 50 intervention patients and 40 control patients. Questionnaires were used to retrieve data."	America

Title, Author and Date (Woolliams et al., 2009)	**Purpose / aim of study** (Woolliams et al., 2009)	**Data collection method / study** (Woolliams et al., 2009)	**Source** (Woolliams et al., 2009)
19) Comparing Three Life-Limiting Diseases: Does Diagnosis Matter or Is Sick, Sick? Steinhauser K. E., Arnold, R.M., Olsen, M.K., Lindquist, J., Hays, J., Wood, L.L., Burton, A.M. and Tulsky, J.A. (2011) 2)SCI	"To observe patients with similar prognostic estimates, but a variety of diseases, and compare the overall patient illness experience."	"A cross-sectional cohort study of 210 patients living with advanced cancer, CHF, and COPD. Data reported are baseline assessments from a longitudinal study of patients and caregivers followed monthly for up to six years, or until death."	America
20) How to provide care for patients suffering from terminal non-oncological diseases: barriers to a palliative care approach. Mahtani-Chugani, V., González-Castro, I., Sáenz de Ormijana-Hernández, A., Martín-Fernández, R. and Fernández de la Vega, E. (2010) 3-SCI	"To explore palliative care service provision for patients suffering from non-oncological long-term life threatening in Spain. Aiming at identifying barriers in the provision of care and strategies to overcome them."	Interviews and focus groups	Spain
21) Living and dying with severe chronic obstructive pulmonary disease: multi-perspective longitudinal qualitative study Pinnock, H., Kendall, M. Murray, S.A., Worth, A., Levack, P., Porter, M., MacNee, W. and Sheikh, A. (2011) 4 -SCI	"To understand the perspectives of people with severe chronic obstructive pulmonary disease (COPD) as their illness progresses, and of their informal and professional carers, to inform provision of care for people living and dying with COPD."	"Up to four serial qualitative interviews were conducted with each patient and nominated carer over 18 months. Interviews were transcribed and analysed both thematically and as narratives."	UK
22) Palliative care for patients with chronic obstructive pulmonary disease: exploring the landscape. Philip, J., Lowe, A., Gold, M., Brand, C., Miller, B., Douglass, J. and Sundararajan, V. (2011)5 -SCI	"To use routinely collected hospital discharge abstract data linked to the death registrations in order to map acute care utilisation by patients with COPD and investigate factors associated with mortality in the 6 months following admission."	Interviews and focus groups	East Midlands, UK

Title, Author and Date (Woolliams et al., 2009)	**Purpose / aim of study** (Woolliams et al., 2009)	**Data collection method / study** (Woolliams et al., 2009)	**Source** (Woolliams et al., 2009)
23) Palliative care in the community for cancer and end-stage cardiorespiratory disease: the views of patients, lay-carers and health care professionals. Exley, C., Field, D., Jones, L. and Stokes, T. (2005) 6-SCI	"To explore the views of health professionals, patients and their carers about care provided at the end of life."	Interviews and focus groups	East Midlands, UK
24) Unmet needs of people with end-stage chronic obstructive pulmonary disease: recommendations for change in Australia. Crawford,G.B., Brooksbank,M.A., Brown, M., Burgess, T.A. and Young, M. (2012) 8 - SCI	"To explore the needs of people with end-stage COPD in South Australia and develop recommendations for a model of care."	"Three related studies were undertaken: Study 1, 15 people with advanced COPD and their carers were interviewed twice, 6 months apart. Study 2, investigated views of an Expert Panel and Study 3 conducted focus groups and interviews with service providers and community groups to examine service availability and accessibility."	Australia
25) Why do patients with cancer visit the emergency department near the end of life? Barbera, L., Taylor, and Dudgeon, D. (2010) 10 - SCI	"To describe the most common reasons for visits made to the emergency department during the final six months of life and the final two weeks of life by patients dying of cancer."	"A descriptive, retrospective cohort study using linked administrative sources of health care data."	Ontario
26) A comparison of the palliative care needs of patients dying from chronic respiratory diseases and lung cancer. Edmonds, P., Karlsen, S., Khan, S. and Addington-Hall, J. (2001) Google - 1	"To report on data from the Regional Study of Care for the Dying, conducted in 1990, and compares symptoms, care and service utilization for patients with chronic lung diseases (CLD) and lung cancer (LC) in the final 12 months of life."	"Post-bereavement structured interviews were conducted with informal carers of 449 LC patients and 87 CLD patients."	not stated

Title, Author and Date (Woolliams et al., 2009)	**Purpose / aim of study** (Woolliams et al., 2009)	**Data collection method / study** (Woolliams et al., 2009)	**Source** (Woolliams et al., 2009)
27) Differences in Health Care Utilization at the End of Life Among Patients With Chronic Obstructive Pulmonary Disease and Patients With Lung Cancer. Au, D. H., Udris, E.M., Fihn, S.D., McDonnell, M.B. and Curtis, J.R. (2006) Google-2	"To examine health care resource utilization in the last 6 months of life among patients who died with chronic obstructive pulmonary disease (COPD) compared with those who died with lung cancer and to examine geographic variations in care."	"A retrospective cohort study of patients diagnosed as having COPD or lung cancer, who were seen in 1 of 7 Veteran Affairs medical centres primary care clinics and who died during the study period. Our outcome of interest was health care resource utilization in the last 6 months of life."	not stated
28) Living with severe chronic obstructive pulmonary disease (COPD): perceptions of patients and their carers: An interpretative phenomenological analysis. Seamark, D.A., Blake, S.D., Seamark, C.J. and Halpin, D. MG.(2004) Google - 3	"To explore the experiences of patients with severe chronic obstructive pulmonary disease (COPD) and their carers, particularly with regard to ongoing and palliative care needs."	"Nine men and one woman with severe COPD and the carers of eight of the men. Semi-structured interviews were undertaken, transcribed and analysed using interpretative phenomenological analysis (IPA)."	East Devon, UK
29) Exploring the care needs of patients with advanced COPD: An overview of the literature. Gardiner, C., Gott, M., Payne, S., Small, N., Barnes, S., Halpin, D., Ruse, C. and Seamark, D. (2009) Google -5	"To provide an overview of relevant literature regarding the care needs in advanced COPD."	Systematic literature review	N/A
30) The Comprehensive Care Team - A controlled trial of outpatient palliative medicine consultation. Rabow, M.W., Dibble, S.L., Pantilat, S.Z. And McPhee, S.J. (2004) 1) Science Citation Index	"A controlled trial of an intervention in which an interdisciplinary team offered palliative services to outpatients, their families and their primary care physicians."	"Conducted a yearlong trial involving 50 intervention patients and 40 control patients. Questionnaires were used to retrieve data."	America

Description / Results (Woolliams et al., 2009)	**Relevant?** (Woolliams et al., 2009)	**Sampling and sample size (n)** (Woolliams et al., 2009)
1) "One third of participants had someone die in the last five years from a terminal illness, 644 from ESLD. One in five participants provided physical care, 43 of them provided day-to-day care and 63 provided hands-on care of and on for an average of 40.1 months. Caregivers were on average 51.2 years old and one in five was a spouse. There was an unmet need for additional support to provide physical care by 17% of caregivers. Only 31.1% were described as 'comfortable' or 'very comfortable' in the last fortnight of life."	maybe (caregivers views)	"3000 participants from the South Australian Health Omnibus"
2) "Several key issues affected caring in a positive or a negative way. The threats to caring were the carers' own health problems, negative reactions from the outside, person loss, and acute exacerbations. Resources that carers drew on were acceptance, self-care, availability of support, feeling that caring is a shared responsibility with the patient, and "getting on with" caring in case of emergencies. Breathlessness was noted as particularly challenging, and carers did not have any strategies to relieve the symptom. They were ill prepared for acute exacerbations."	Yes - acute exacerbations described - why and when caregivers called 999.	"15 informal carers were approached via the patients they cared for during their visits to respiratory clinics at the hospital."
3) "Four key perceptions showed both professionals and patients agreed that access to equitably to services included more respiratory rehabilitation; other priorities indicated key differences between professional's and patient's perceptions of financial support, the communication of health education and the need for better provision of palliative care at end of life."	Yes - contrasting pts. and healthcare professional views on management	"Volunteer multi-professional health and social care professionals in organisations involved with the COPD care pathway from four Primary Care Trusts met in one group (n = 8). Three groups were formed by volunteer patients (n = 30) and carers (n = 2) from a similar geographical area. All participants were recruited by the rehabilitation group nurse and were reported to be in a psychologically stable state."
4) "219 qualitative interviews were carried out. Patients with cardiac failure had a different illness trajectory than those with lung cancer. They also had less information and poorer understanding of their condition and prognosis were less involved in decision making. Health and social services including financial benefits were available to those with lung cancer, although not always used effectively. Cardiac patients received less health, social, and palliative care services, and care was often poorly coordinated."	yes - lung cancer patients description of community care	"Aimed to have 20 patients in each group. 84 patients were approached, 59 of whom consented."
5) "Mean age at death was 70 years; 52% of patients were male; 34% died as a result of lung cancer. Median survival from diagnosis to death was 8.4 months with hospice admission and 5.8 months without hospice. Four of eight intensity of-care indicators all significantly exceeded the referenced benchmarks."	yes - for lung cancer aspect but a Quantitive study so limited	"A random sample of 390 patients was obtained from the 942 cancer deaths in Wicomico County, Maryland, for 2004 to 2008."

Description / Results (Woolliams et al., 2009)	**Relevant?** (Woolliams et al., 2009)	**Sampling and sample size (n)** (Woolliams et al., 2009)
6) "The respiratory intermediate care team is an effective means of saving hospital bed days through prevention of admission and early discharge in patients with chronic respiratory disease. The results of the patient satisfaction postal questionnaire show that the majority of patients find hospital-at-home style care favourable because they feel well-supported at home to self-manage their condition. This outcome is important because it indicates that specialist nursing teams in primary care are valuable to patients and save the NHS money."	Yes - details of COPD patient s and their use of services at the end of life.	"The RICT received 502 referrals, including multiple admissions for the same patients. Of these, 225 referrals were for prevention of admission during an acute episode and 107 were to support a patient on early discharge from an acute hospital admission. The other referrals received were for terminal care, patient education or assessment, and advice. The questionnaire was sent to all 159 patients listed on the RICT database as either currently receiving care from the team or as having received care in the past. Patients known to have died since treatment from the RICT were excluded."
7) "Quality of life was seen as depending mainly on family relationships, opportunities afforded locally for neighborliness and freedom from fear, mobility and independence in the activities of daily living, and the absence or successful mitigation of symptoms of concomitant disease. Disease-specific, symptom-oriented outcome measures may miss these. Additionally, the near and repeatedly threatening approach of death recommended extension of a palliative approach to end stage COPD."	no - only the conclusion - not the study	"A sample of 35 patients from a group of 64 patients who took part in a randomized cross-over trial of nebulizer therapy vs. high-dose inhalers was interviewed at home using in-depth interviews."
8) "Four themes were identified from the data relating to 1) the prioritization of institutional processes, 2) support across settings, 3) being heard, and 4) dignity. As they moved between different settings, much of the care received by older adults was characterized by inflexibility and a failure of professional carers to listen. Liaison between and within services was not always effective, and community support after a hospital admission was perceived to be, on occasions, absent, inappropriate, or excessive."	Yes - lung cancer patients were included. Gives views about patients on their perspective of package of care they received.	"Thirty people agreed to be interviewed; they were aged between 69 and 93 years, diagnosed with lung cancer (13), heart failure (14), or stroke (3)."
9) "One hundred and twenty-eight participants reported shortness of breath most days/every day, 45% were housebound, 75% had a carer. Eighty-two had severe breathlessness; 134 said breathlessness was their most important problem; 31 were on suboptimal treatment; 42 who were severely affected had not been admitted to hospital in the previous 2 years; 86 of 102 who had been admitted would want admission again if unwell to the same extent."	Yes	"One hundred and sixty-three (61% response) patients were interviewed Patients with advanced cancer, severe alcohol-related or mental health problems, or learning difficulties, were excluded; 145 patients were included in the analysis."

Description / Results (Woolliams et al., 2009)	**Relevant?** (Woolliams et al., 2009)	**Sampling and sample size (n)** (Woolliams et al., 2009)
10) "The study population was 57% male with a mean age of 77 years. Demographic characteristics, underlying cause of death and number of comorbid conditions were similar between urban, small urban and rural/remote groups. Demographic characteristics, underlying cause of death and number of comorbid conditions were similar between urban, small urban and rural/remote groups. Participants were comparable in terms of the likelihood of: any hospitalizations, having had 5 or more transfers between settings, and dying in hospital. The proportion of home deaths in rural settings was 15.4%, and was comparable to the rate in urban settings (16.3%). Urban residents were more likely to have had 24 or more physician visits in the last year of life compared with small urban, while rural/remote residents were more likely to have received any institutional than the other groups. Hospital as a location of death was more likely for those with a UCOD of cardiovascular disease, but was less likely for those aged 80-85 years, those aged more than 85 years and those who had never married. Residents of rural/remote areas were significantly less likely than those in urban or small urban settings to receive any home care or home physiotherapy services. Rural/remote residents were, however, much more likely to receive home supportive care and home meal preparation."	yes - a little bit shows the stats for deaths at hospital and home	"1098 patients who died in 2004 with a cause of death recorded as COPD and lung cancer."
11) "Three themes emerged, each with concrete care needs: (a) self-reliance and independence through adaptation, (b) stable health through maintenance, and (c) living with constraints. The predominant theme was that all participants wanted to maintain their independence. This required considerable adaptation, as well as assistance from others."	Yes	Twelve community-dwelling seniors
12) "The average age of death was 77.4 years. The majority of patients died in hospital. The major symptom reported by the carers was breathlessness which impaired the deceased's mobility and contributed to their being housebound. Anxiety and panic were also associated with breathlessness. Depression was reported. Oxygen, though beneficial, was seen to impose lifestyle restrictions due to increasing dependence on it. Some patients only health care contact was through repeat prescriptions from their GP whereas three had regular follow up by a respiratory nurse specialist who linked community and secondary care. Overall, follow-up, systematic review or structured care were uncommon."	yes - very	"25 carers of COPD patients who had died in the preceding 3–10 months."

Description / Results (Woolliams et al., 2009)	**Relevant?** (Woolliams et al., 2009)	**Sampling and sample size (n)** (Woolliams et al., 2009)
13) "Five themes were identified. (i) Patients' information needs and the future course of their illnesses. Information needs were often variable and patients were sometimes unwilling to contemplate the future. (ii) The impact of symptoms on patients' lives. Dyspnoea was a particular problem. (iii) Attitudes towards and opinions on smoking. (iv) Attitudes to help received. Many patients relied on their family; most patients felt their doctors were helpful although some expressed reservations. (v) Patients' expressed needs. These usually focused on mobility, and many patients would not express needs even when prompted."	Yes - but only the conclusion - shows pts. Concerns about being looked after at home.	16 patients
14) "The results revealed that all of the chronic care model components, except self-management support within the care team without advanced practice nurses, were implemented, at an acceptable level, within the chronic obstructive pulmonary disease care programs of both types of care teams."	yes	"210 Thais (105 for each type of care team) with chronic obstructive pulmonary disease who were receiving care from six selected community hospitals in northern and eastern Thailand"
15) "District nurses were found to lack confidence in their own knowledge about, and in their ability to interact with end-stage chronic obstructive pulmonary disease patients. While district nurses did interact with these patients, this was limited to tasks unrelated to chronic obstructive pulmonary disease. Referrers appeared to misunderstand the district nurse role in end-stage care and therefore its application to the care of end-stage chronic obstructive pulmonary disease patients."	yes	43 district nurses
16) "Patients with lung cancer present to the emergency department for a wide range of concerns."	Only slightly	none stated
17) "Since its inception, the RCCP has consistently demonstrated a cost effective reduction in hospital admission rates, LOS and reduced readmission"	no	363 patients were enrolled in the programme
18) "A similar number of patients dies during the study, the intervention group had less dyspnoea and anxiety and improved sleep quality and spiritual wellbeing but no change in pain , depression, quality of life or satisfaction with care. Intervention group had decreased primary care without an increase in emergency department visits."	yes - but nothing new to include	90 patients
19) "A majority of illness outcomes did not differ by diagnostic category .Functional status was associated with diagnosis, Patients with cancer fared better. Overall, illness experience was most significantly related to disease severity, demographics, and emotional and social well-being."	Yes	210 patients

Description / Results (Woolliams et al., 2009)	**Relevant?** (Woolliams et al., 2009)	**Sampling and sample size (n)** (Woolliams et al., 2009)
20) "The barriers identified were as follows: lack of clarity about prognosis, the hegemony of the curative approach, avoiding words and the desire to cheat death."	Yes	"A total of 78 participants took part in the study: eight patients, 23 caregivers and 47 professionals."
21) "Eleven patients died during the study period. Final datasets were comprised 92 interviews (23 conducted with patient and informal carer together). Severe symptoms that caused major disruption to normal life were described, often in terms implying acceptance of the situation as a "way of life" rather than an "illness." Patients and their informal carers adapted to and accepted the debilitating symptoms of a lifelong condition. Professional carers' familiarity with the patients' condition, typically over many years, and prognostic uncertainty contributed to the difficulty of recognising and actively managing end stage disease. Overall, patients told a "chaos narrative" of their illness that was indistinguishable from their life story, with no clear beginning and an unanticipated end described in terms comparable with attitudes to death in a normal elderly population."	yes- very	21 patients, and 13 informal carers (a family member, friend, or neighbour) and 18 professional carers (a key health or social care professional) nominated by the patients
22) "The majority of patients are cared for in the public hospital system (64%) and generally die in hospital (72%) with a number of identifiable predictors of 6-month mortality."	Yes	"22 019 individual patients who met the inclusion criteria, comprising 40 071 hospital admissions (ranging from 1 to 41 admissions per participant)."
23) Differences between the care of people with cancer and those with end-stage cardiorespiratory disease were found in four main areas: management and progression of disease, communication and information, health care in the community and awareness of dying. The research shows that even in PHCTs (primary health care teams) committed to the delivery of palliative care, people dying with end-stage cardiorespiratory disease are less likely than those with cancer to receive full, and easily understood, information, to be aware that they are dying. "Receive district nursing care.	yes - very	Not stated
24) "This project demonstrated that the needs of people with COPD are not being met. There was an absence of a coordinated pathway for support. Care was fragmented, episodic and reactive. The role of carers was poorly recognised. Health professionals identified the lack of a clear transition to an end-stage and significant barriers to obtaining support for activities of daily living. Communication issues were identified in all studies, including the absence of advance care planning conversations."	Yes	15 people

Description / Results (Woolliams et al., 2009)	**Relevant?** (Woolliams et al., 2009)	**Sampling and sample size (n)** (Woolliams et al., 2009)
25) "Between 2002 and 2005 in Ontario, 91 561 patients died of cancer. Of these, 76 759 patients made 194 017 visits to the emergency department during the final six months of life. Further, 31 076 patients made 36 600 visits to the emergency department during the final two weeks of life."	yes	91561 cancer deaths
26) "The LC patients were significantly younger than those with CLD and these respondents were more likely to have been a spouse. No differences were found in the mean number of symptoms reported by the two groups in the final year or week of life, although the CLD patients were more likely to have experienced these symptoms for longer. Significantly more patients with CLD than LC experienced breathlessness in the final year of life. Significantly more LC patients were reported to have experienced anorexia and constipation in the final year of life. There were no differences in general practitioner use, but LC patients were reported to have received more help from district nurses and from a palliative care nurse. More CLD patients were reported to have received help from social services. LC patients were reported to be more likely to have known they might die and to have been told this by a hospital doctor. Among those that knew, LC patients were told earlier prior to death than CLD patients. This study suggests that patients with CLD at the end of life have physical and psychosocial needs at least as severe as patients with lung cancer."	Yes	"449 carers of lung cancer patients and 87 carers of lung cancer patients."
27) "In the last 6 months of life, patients with COPD were more likely to visit their primary care providers but had fewer hospital admissions compared with patients with lung cancer. Patients with COPD had twice the odds of being admitted to an intensive care unit (ICU), 5 times the odds of remaining there 2 weeks or longer, and received fewer opiates and benzodiazepine prescriptions compared with patients with lung cancer. There were geographic variations in the use of ICUs for patients with COPD but not for those with lung cancer. Total health care costs were $4000 higher for patients with COPD because of ICU utilization."	yes - partially	"Of 1949 patients who had died, 1490 had COPD, 349 had lung cancer, and 110 had both lung cancer and COPD."

Description / Results (Woolliams et al., 2009)	**Relevant?** (Woolliams et al., 2009)	**Sampling and sample size (n)** (Woolliams et al., 2009)
28) "The emergent themes were of losses, adaptation, relationships with health professionals and effect on carer. Losses reflected the loss of personal liberty and dignity and of previous expectations of the future. Adaptation included strategies to cope with the effects of the disease. Relationships related to both positive and negative aspects of contact with health professionals. There was appreciation for continuity of care and reassurance. The effect on the carer was evident particularly as they had to take on multiple roles. They also experienced some of the same losses as the patient and appeared enmeshed with the illness."	yes	8 men
29) 295 papers located, 280 papers excluded. 15 selected articles	yes - for background	N/A
30) "The intervention group had less dyspnoea and anxiety and improved sleep quality and spiritual wellbeing but no change in pain, depression, quality of life or satisfaction with care. Intervention group had decreased primary care without an increase in emergency department visits."	yes - but nothing new to include	90 patients

Self-reported limitations (Cronin et al., 2009)	**Recommendations** (Cronin et al., 2009)
1) "Assessment on patients who are near death is problematic. Patients may under report symptoms to avoid distressing their carers. Timings of interview about the care of the deceased may be traumatic to caregivers. Recall of events can be compromised by the life changing event (death). Only people who were living in remote settings were used, not all cultural backgrounds were represented. People who live alone, or whose caregiver subsequently died were not represented. Participants whose first language was not English were under-represented in the data. Recall error due to life-changing or highly emotional life events."	"By linking diagnoses with other co-morbidities would help to understand of the total burden experienced by the care recipients. Interventions are required to support caregivers they need to be tested in randomized studies compared to current models of care. The study should be repeated in different cultures, health and social systems."
2) "Carers in this study identified the threats to their caring capacities and the resources they used to cope with these were inevitably specific to the conditions their husbands suffered from. However, further studies could determine to what extent these threats and resources feature in other conditions and are part of the caring experience in general."	"Active participation or availability of healthcare professionals when needed can help carers strengthen the coping strategies they are already using and suggest approaches to the threats they need to deal with. Involvement of health professionals could lead to information and advice, and this enhances competence, especially in managing difficult symptoms such as breathlessness. Professional support can reduce isolation for carers, which is a major complaint for people disabled by breathlessness. Care can be negotiated in interaction between the carer, the patient, and a professional carer, which will alleviate stresses through sharing responsibility."

Self-reported limitations (Cronin et al., 2009)	**Recommendations** (Cronin et al., 2009)
3) "This study included a range of volunteer clinicians and self-selected patients with their carers who provided or used the COPD services. Those patients recruited to the study of both professionals and patients are not ethnically representative of the city population with diagnosed or undiagnosed COPD. The sample that indicates an unforeseen bias. In some wards of this British inner city, the population is made up of 39% people from Asian or African culture who inhabit areas of the city. The issue was discussed with the Asian member of the research team identified that the reason is that health beliefs linked to breathing, breathlessness coughing and the release of phlegm contraindicate Asians and Africans identifying symptoms of COPD. The individual's adaptation to these symptoms continues until COPD is at an advanced stage before seeking treatment."	"The findings add to a national understanding of the basis for respiratory care professional's approaches and perceptions of treatment outcomes and compare them to patient's perceptions. The specificity of the qualitative findings in this study could enhance government strategy for long-term conditions and respiratory care in particular. Patient's perceptions of their adaptation to the symptoms of COPD and ability to maintain independence are important when considering changes to care in the community. Evidence-based developments in other care pathways such as cancer and heart disease could be applied to respiratory pathways. Professionals cannot always interpret the needs of patients when commissioning health care or delivering services. Patients when invited to provide information offer reasoned expectations of their care, based on their life experiences with the long-term condition COPD. These perceptions can differ considerably from professional's perceptions when prioritised and compared."
4) none	"Care for people with advanced progressive illnesses is currently prioritised by diagnosis rather than need. End of life care for patients with advanced cardiac failure and other non-malignant diseases should be proactive and designed to meet their specific needs."
5) No - but does claim they did not have data for all time periods throughout the study.	"Early concurrent palliative care and earlier hospice admission may improve quality of life as a result of better symptom management and the avoidance of aggressive and/or toxic therapies at EOL. Future studies need to look at whether hospice is the intervention that reduces aggressive EOL care or whether patients who accept hospice would have opted for less aggressive care anyway."
6) No	"It is hoped that patients will be identified and treated much earlier during an exacerbation. An increase in the current provision of pulmonary rehabilitation services is also being considered. This evaluation has provided evidence to support the future of specialist nursing services in primary care."
7) "Standardized tools for the measurement of QoL risk loss of relevant information as they impose a narrow framework of analysis. In this study of chronically ill patients, the qualitative interviews showed that existing QoL instruments might fail to reflect the true experience of patients."	"End stage treatment should be seen as palliative; its goal is `the achievement of the best quality of life for patients and their families'. The `whole needs of the individual' require an integrated approach. This implies not only multi-disciplinary teamwork within the specialty, but also planned active co-operation between specialties, with the general practitioner, and with patients and their families so that there is clarity about the goals and progress of treatment. Secondly, the opportunity to talk over one's feelings with an appropriately trained counsellor or nurse seems as important a part of routine services here as in cancer care. The important role of the Respiratory Nurse Specialist."

Self-reported limitations (Cronin et al., 2009)	**Recommendations** (Cronin et al., 2009)
8)"Participants were identified by a range of health professionals, so some variation in the application of selection criteria is possible A disproportionate number of interviewees, particularly those with lung cancer, were from disadvantaged areas. This may explain some of the difficulties described in negotiating the system, but as experiences of health and social services should not vary with the social background of the care recipients, this also is a strength of our design. There were differences in the patterns of transitions between care settings by diagnosis. People with lung cancer had fewer inpatient episodes compared with those with heart failure or stroke. They also had more contact with hospital consultants than people with heart failure."	"The future vision for the U.K. NHS is of a service that is genuinely centered on patients and carers, achieving quality and outcomes that are among the best in the world.28 Dignity and respect are fundamental components of such high-quality care Yet, if the experiences of individuals in this study are shared by others, major differences between theory and practice remain."
9) "A high response rate (80%) was obtained among the general practices invited to take part. The response rate among patients (61%) was less satisfactory, but the finding that responders were at least as severely affected as non-responders and were no different in demographic characteristics and deprivation, was reassuring. Almost all of the subjects were white, despite being recruited in areas in which 26% of the population was black. Some subjects in this study who had end of-life care concerns may not have been identified, either through a desire not to embarrass the researcher, or through reticence to acknowledge their concerns."	"Patients whose symptoms in advanced disease have increased slowly over years rather than weeks may experience continuing 'response shift' in their experience of their disease, and as a result may focus on the struggle to live rather than on end-of-life care There is a striking contrast between these patients and those with severe breathlessness from advanced malignancy in whom breathlessness is usually associated with impending death in days or weeks. Severe breathlessness in advanced COPD is a daily reality. Many, if not most, of these patients know they may die from the disease, but death is not imminent inmost, and is not specifically signaled by their breathlessness. In this context, the palliation of breathlessness in advanced COPD appears more important for patients than consideration of end-of-life care."
10) "Using an administrative database could cause inaccuracy of coding and lack of contextual detail. The data represented one Canadian province only and regional variation in practice may affect the generalizability of the findings. The data analysed in this report did not allow for assessment of the quality of life, or the appropriateness and adequacy of care for those who died with respiratory illness."	"Novel uses of innovative technologies by specialist home care providers need to be investigated to ensure that care at the end of life is equitable for persons dying with respiratory illness in rural/remote areas. This may include designing healthcare services in such a way as to maximize their efficiency and reach in rural areas, and making greater use of health technology. Further investigation of issues related to differences in quality of care and unmet healthcare needs between rural and non-rural settings will strengthen the evidence base to improve care at the end of life."
11) none reported	"Given that some of this study's findings diverge from what was expected, it is particularly important that further research be conducted to validate and expand upon these findings COPD appears more important for patients."

Self-reported limitations (Cronin et al., 2009)	**Recommendations** (Cronin et al., 2009)
12) "The small numbers involved in this study mean that any conclusions and recommendations should be interpreted with caution."	"The carer accounts have implications for general practice where COPD accounts for a sizeable workload. GPs may need to play a more active role in managing these patients, monitoring their condition on a regular basis (rather than responding to acute exacerbations) and providing back up to carers. GPs may find it difficult to take on the additional task of regularly visiting these housebound patients themselves given their existing workload. Additional resources, in the form of respiratory nurse specialists, may assist GPs in meeting patients' expectations and needs although the small numbers involved in this study mean that any conclusions and recommendations should be interpreted with caution."
13) "Two factors may limit the generalizability of this study. First, our patients were selected by their own GP to take part in the research, and this probably implies a good doctor–patient relationship for the majority. Secondly, our study was restricted to a group of illnesses where it is particularly difficult to identify prospectively the patient who is dying, although in all cases the patient's doctor felt that the patient was receiving palliative care."	"Poor symptom control remains an important cause of distress. The low number of expressed needs may reflect patients' unwillingness to appear ungrateful, but the variability of information needs emphasizes the importance of an individual approach to patients with an apparently homogenous disease."
14) "Problems were encountered in administering some parts of the Self-Care Behaviour Questionnaire. Patients from northern Thailand are multi-ethnic and use multiple languages. Although they can understand Thai, some of the items in the questionnaires were too difficult for them to comprehend. This may have affected the outcome of the measurements. Secondly, generalizability of the findings is limited because the community hospitals, used as study sites, were from specific areas in Thailand. Thus, generalizability to all parts of Thailand is not possible."	"In order to compare the process/level of CCM implementation and care outcomes, the study of CCM implementation should be replicated using: patients with various chronic conditions; a variety of healthcare organizations; and various types of multidisciplinary teams."
15)"Generalizability was not possible due to the sample size of the survey (44% of population). Furthermore, the tool's purpose-developed nature made reliability difficult."	"District nurses need to closely engage with people with end-stage chronic obstructive pulmonary disease. In addition, referrers must alter their discourse to engage these high-risk patients with health services early in their disease trajectory. Infrastructural change is furthermore required to assist district nurses to provide patient-focused care in the community and implement the holistic nursing roles outlined in the literature."
16) none reported	"It is important for the emergency nurse to identify oncologic emergencies, such as SVC, early to quickly intervene. When patients are in acute respiratory distress typical therapy should not be changed solely related to the patient's diagnosis of lung cancer. The use of CPAP and oxygen should be provided as the patient's condition requires. Urgent consultation with the patient's oncology team is recommend to assist the emergency department team in providing expert patient centered care."
17) No	"Consequently, successful programs such as RCCP that work to maintain people in optimal states of wellness in their homes, will be required to assist hospitals and GPs to manage an increasing disease burden."

Self-reported limitations (Cronin et al., 2009)	**Recommendations** (Cronin et al., 2009)
18) "Patients were not individually randomised. Interviews limited by acquaintance bias. Sample studied was small. The benefits shown may not be generalizable to any other disease."	"A palliative care consultation service can improve patient outcomes."
19) The study is limited by the cross-sectional nature of data.	"Patients living with life-limiting illnesses other than cancer may benefit from whole-person services often extended to cancer patients."
20) none reported	"Provision of palliative care services for these patients should be guided by the trajectory of each type of disease. Even if healthcare systems were capable of providing specialized palliative care services to this large group of patients, other barriers should not be overlooked. It would be appropriate to provide therapeutic and palliative care simultaneously, thus facilitating adaptation processes for both patients and relatives."
21) "Our 21 participants may not fully represent the diversity of people with very severe COPD. In particular, none was from an ethnic minority background, although the study cohort encompassed a broad range of demographic, social, clinical, and healthcare backgrounds. All our participants were smokers or ex-smokers, it cannot be assumed that their attitudes can be extrapolated to non-smokers."	"Careful assessment of possible supportive and palliative care needs should be triggered at key disease milestones along a lifetime journey with COPD, in particular after hospital admission for an exacerbation."
22) none reported	"Palliative care services need to be redirected from a community-based admission focus to a model that is responsive to emergency and acute care hospital systems."
23) " A small scale qualitative study conducted in two general practices in the East Midlands, England. It was designed to explore the differing experiences of people dying with cancer with those dying of end-stage cardiorespiratory disease."	"There is an increasing call for palliative care to be extended to all, but further work is needed to develop appropriate packages of care for those dying with conditions other than cancer."
24) none reported	"A flexible model of care is needed that assists people with COPD to navigate the health system. This should be patient centred and coordinated across primary, acute and community sectors. Neither respiratory nor palliative care services alone can adequately support people with COPD. The integration of a multidisciplinary palliative approach within a chronic disease management strategy will be central for the best care for people living with advanced COPD."
25) "The limitations of this study include those typical of studies relying on administrative data."	"Understanding why patients visit the emergency department near the end of life provides insight into the nature of the problems they experience and provides direction for possible interventions."
26) "This study was conducted in 1990. At that time no patients with CLD in our sample received help from a community palliative care nurse and only one patient with CLD help from a Marie Curie nurse.10 years later the access to specialist palliative care services remains poor and inconsistent for patients with CLD, this study and others suggest that they have a similar symptom experience to cancer patients. This paper used information provided by relatives, friends and carers of the deceased."	"Further, prospective studies are required to more clearly identify and manage the physical, psychological and social effects of living and dying from a chronic lung disease."

Self-reported limitations (Cronin et al., 2009)	**Recommendations** (Cronin et al., 2009)
27) "No assessment of preferences for care at the end of life or whether discussions had occurred between health care providers and their patients and therefore the concordance between preferences and care cannot be determined. Information about the number of patients who were referred to hospice was not recorded. Estimates are conservative because patients with COPD are rarely referred to hospice and any differential would likely favour palliative care for patients with lung cancer. Lung cancer stage was not known. It was hypothesized that frequent visits for COPD or lung cancer would accurately identify patients who had symptomatic disease."	"Because of its prevalence and burden, COPD is an important paradigm for future research about advance care planning and decision making regarding the balance and integration of palliative and life-prolonging therapies."
28) "Findings will not be generalizable."	"The concept of a more structured sharing of information and a surveillance role mediated by health care professionals known to the patient and carer would be a pragmatic approach to improving care."
29) none reported	"Research is needed on strategies to facilitate improved care of patients with COPD."
30) "Patients were not individually randomised. Interviews limited by acquaintance bias. Sample studied was small. The benefits shown may not be generalizable to any other disease."	"A palliative care consultation service can improve patient outcomes."

APPENDIX THREE - Excluded Interviews

PATIENT 06	**PATIENT 06** at home during interview	**SON**
PATIENT 18	**PATIENT 18** in hospital during interview	**WIFE**
PATIENT 26	**PATIENT 26** at home during interview	**WIFE**

APPENDIX FOUR - Completed Interviews

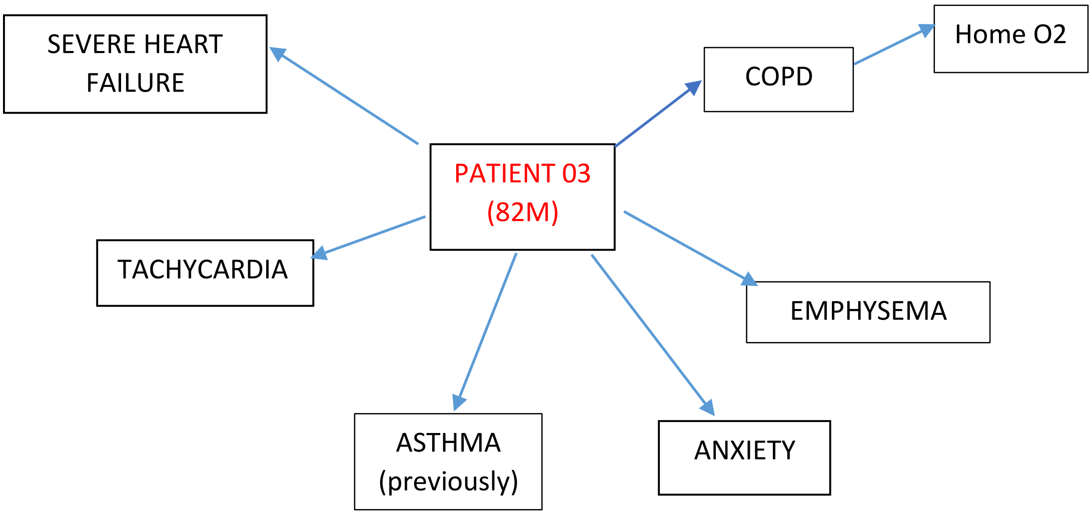
PATIENT 03	**PATIENT 03** in hospital during interview	**PATIENT 03** with **WIFE** at home, post admission	**RESPIRATORY CLINICAL NURSE SPECIALIST #1**	**RESPIRATORY CLINICAL NURSE SPECIALIST #2**	**COMMUNITY CASE MANAGER**
PATIENT 08	**PATIENT 08** in hospital during interview	**PATIENT 08** at home, post admission	**DAUGHTER**	**COMMUNITY CASE MANAGER**	
PATIENT 09	**PATIENT 09** in hospital during interview	**HOSPITAL RESPIRATORY NURSE SPECIALIST**	**CLINICAL CASE MANAGER**		
PATIENT 10	**PATIENT 10** in hospital during interview	**COMMUNITY RESPIRATORY CLINICAL NURSE SPECIALIST**			
PATIENT 01	**PATIENT 01** in hospital during interview	**PHYSIO**			
PATIENT 16	**PATIENT 16** in hospital during interview	**STAFF NURSE** in hospital	**DISTRICT NURSE**		
PATIENT 22	**PATIENT 22** with **WIFE** in hospital during interview	**PALLIATIVE CARE NURSE**			
PATIENT 28	**PATIENT 28** in hospital during interview	**STAFF NURSE** in hospital	**SENIOR SISTER PALLIATIVE CARE TEAM**		

PATIENT 31	**PATIENT 31** in hospital during interview	**STUDENT NURSE**			
PATIENT 33	**PATIENT 33** with **WIFE** and **DAUGHTER** at home	**COMMUNITY PALLIATIVE CARE NURSE**			

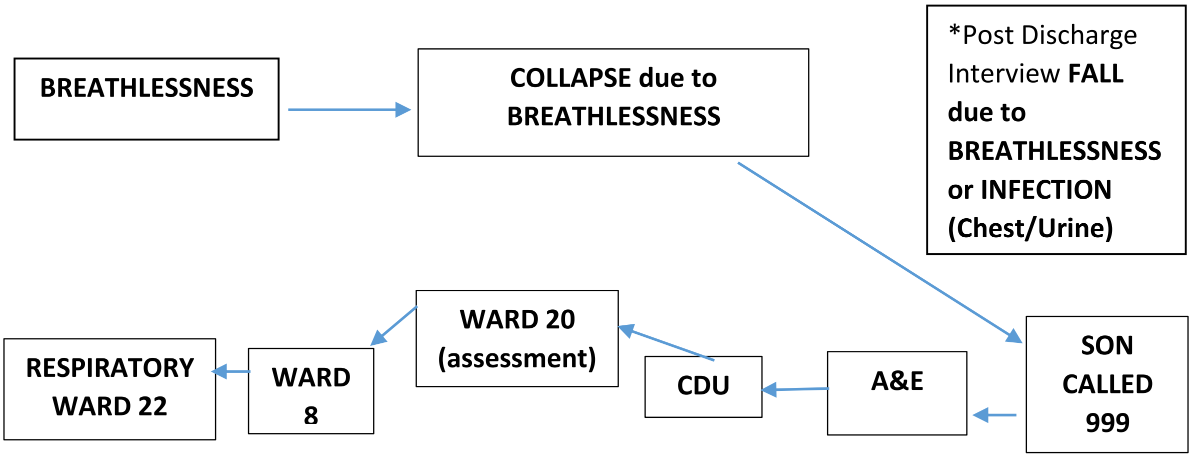
APPENDIX FIVE – Illustrative Patient Schematics

PATIENT 03 – 82M Lives with WIFE

PATIENT PROFILE



PATIENT JOURNEY TO THE ED



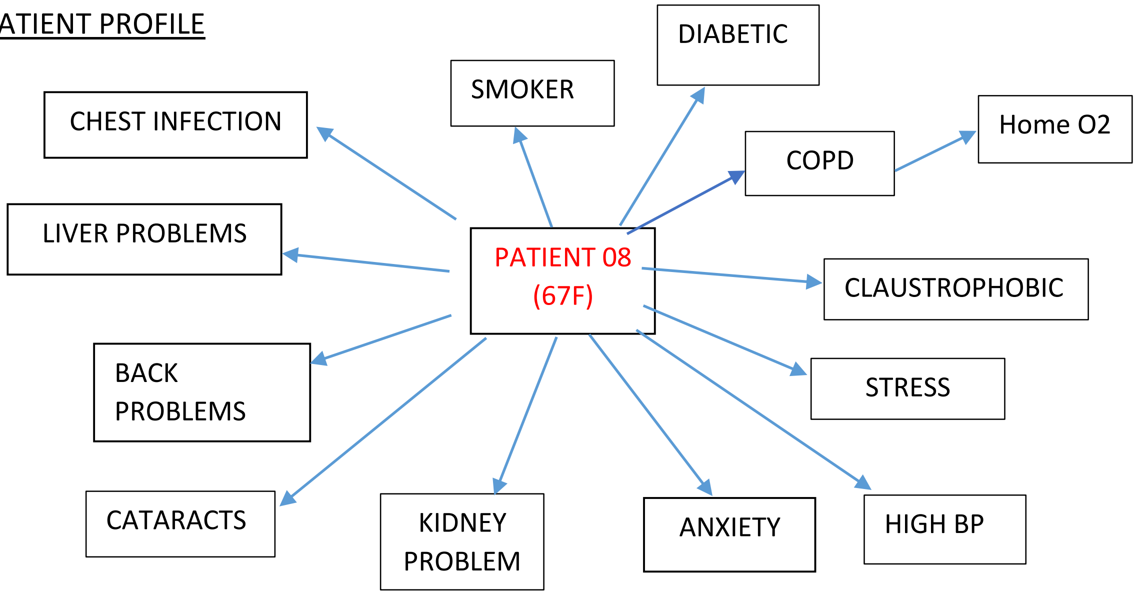
PROFFESIONALS AND FAMILY INVOLVED IN PATIENT 03's CARE

HEALTHCARE PROFESSIONALS	**FAMILY & FRIENDS**
COMMUNITY MATRON	WIFE - 80
DEPT MATRON	SON 'PETER' (lives at home)
RESPIRATORY NURSE	2 x other SONS
GP	DAUGHTER
OT	
MENTAL HEALTH TEAM	
COMMUNITY NURSE	
COPD COMMUNITY NURSES	
PHYSIO	
DRS SURGERY & CHEMIST	
FALL PREVENTION TEAM	
HOSPITAL DRS & NURSES	
DISTRICT NURSE	
RAPID RESPONSE	
ADVANCED NURSE PRACTIONER	
INTERMEDIATE CARE TEAM	

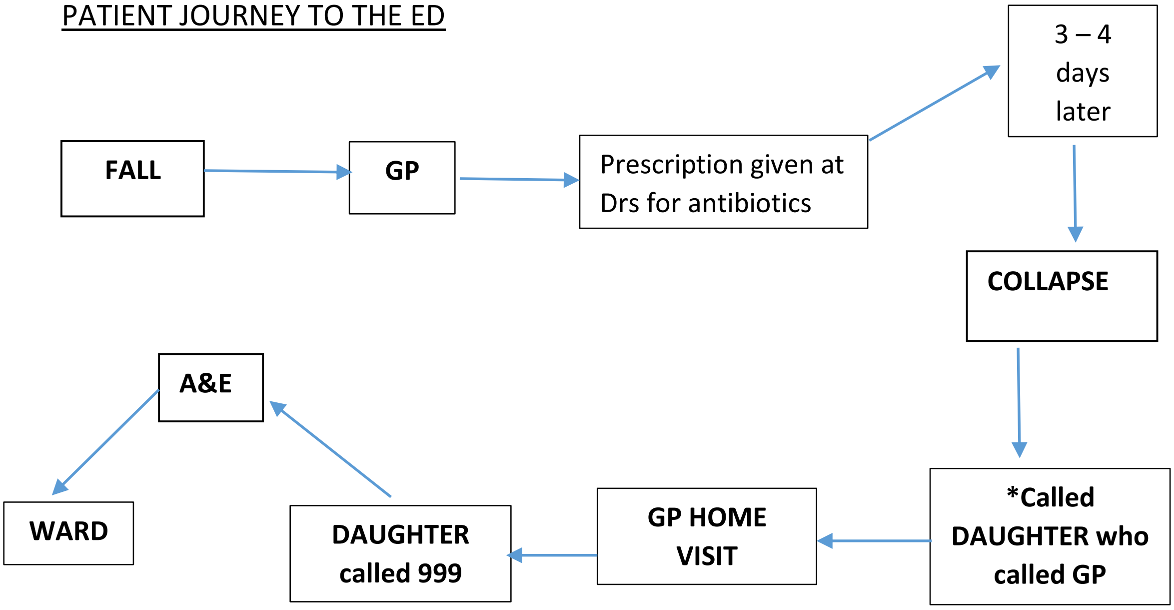
APPENDIX FIVE

PATIENT 08 – 67F Lives ALONE

PATIENT PROFILE



PATIENT JOURNEY TO THE ED



*Daughter was on holiday at the time. She'd also called COPD team who told her to call GP

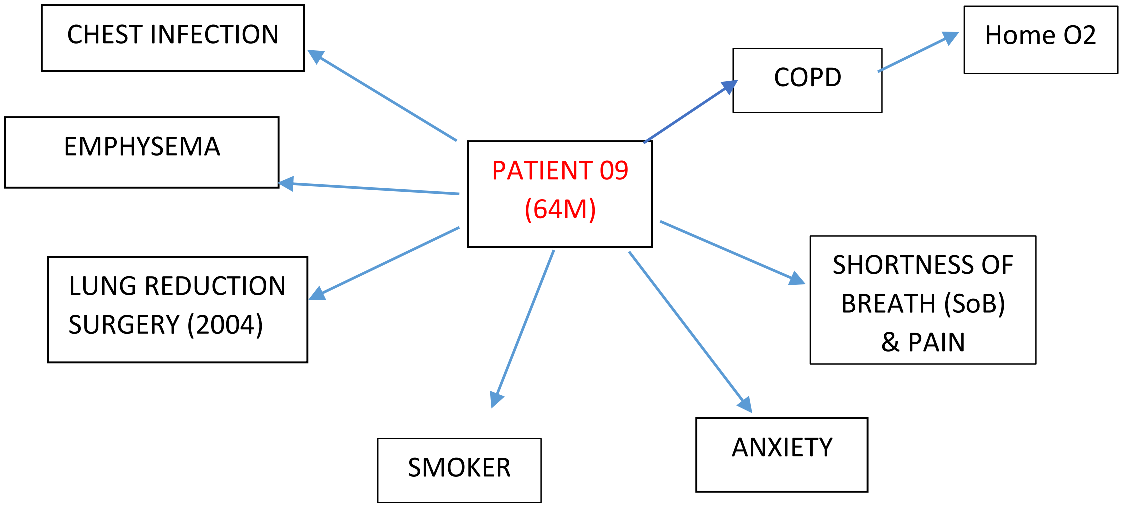
PROFFESIONALS AND FAMILY INVOLVED IN PATIENT 08’s CARE

HEALTHCARE PROFESSIONALS	FAMILY & FRIENDS
RESPIRSTORY NURSE	DAUGHTER
CLINICAL CARE MANAGER	SON & DAUGHTER IN LAW
DISTRICT NURSE	GRANDDAUGHTER & GRANDSON
COPD ‘PEOPLE’	NEIGHBOURS
HOSPITAL STAFF	FRIENDS
GP	
BADGER CLINIC	
PoC ON DISCHARGE -> 2 x DAILY VISITS	

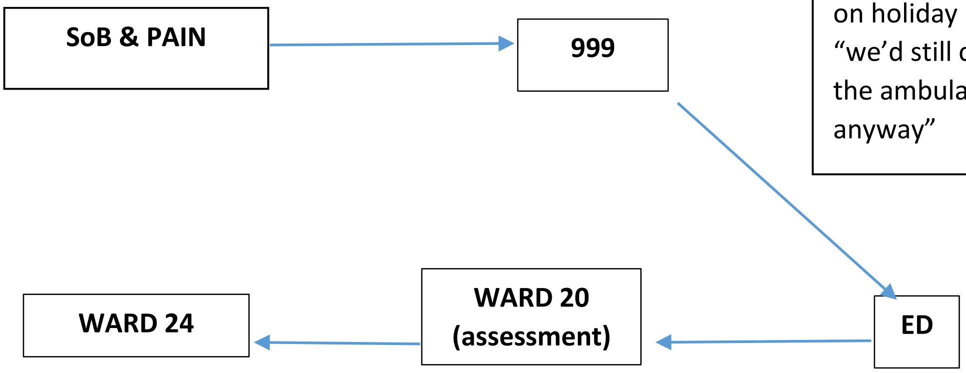
APPENDIX FIVE

PATIENT 09 – 64M Lives with WIFE

PATIENT PROFILE



PATIENT JOURNEY TO THE ED



*Patient states his CCM was on holiday but “we’d still call the ambulance anyway”

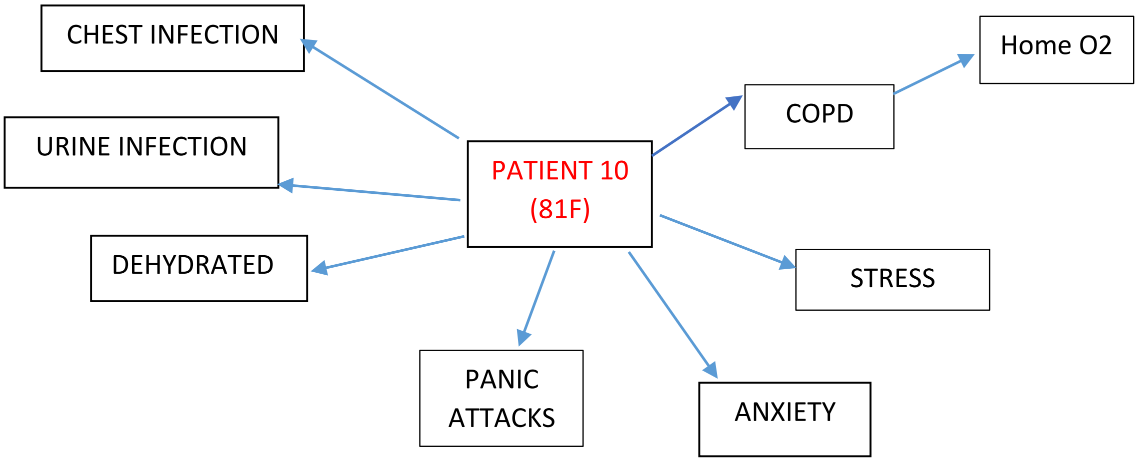
PROFFESIONALS AND FAMILY INVOLVED IN PATIENT’S CARE

HEALTHCARE PROFESSIONALS	FAMILY & FRIENDS
RESPIRSTORY NURSES (3 involved)	WIFE (78) *(live together in a warden controlled flat)
GP	‘ABOUT’ SIX CHILDREN
DISTRICT NURSES	
MACMILLAN NURSE	
CLINICAL CASE MANAGER	
OT	
COMMUNITY MATRON	
COMMUNITY PHARMACIST	

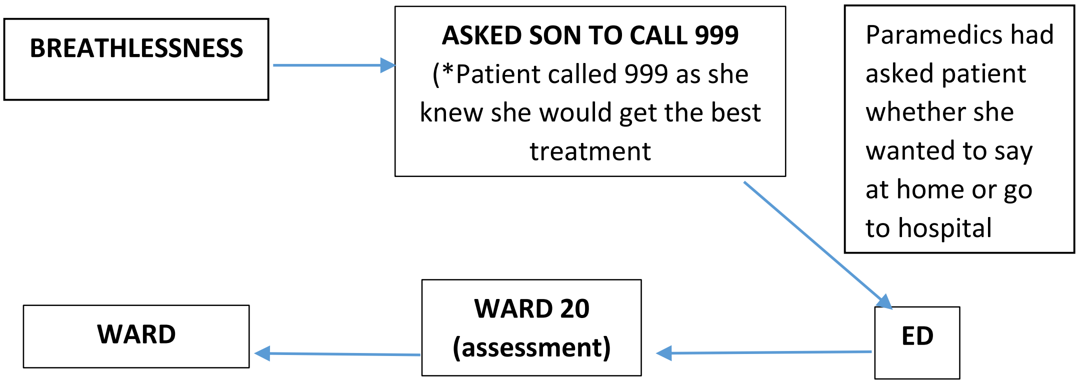
APPENDIX FIVE

PATIENT 10 – 81F Lives with HUSBAND

PATIENT PROFILE



PATIENT JOURNEY TO THE ED



PROFFESIONALS AND FAMILY INVOLVED IN PATIENT'S CARE

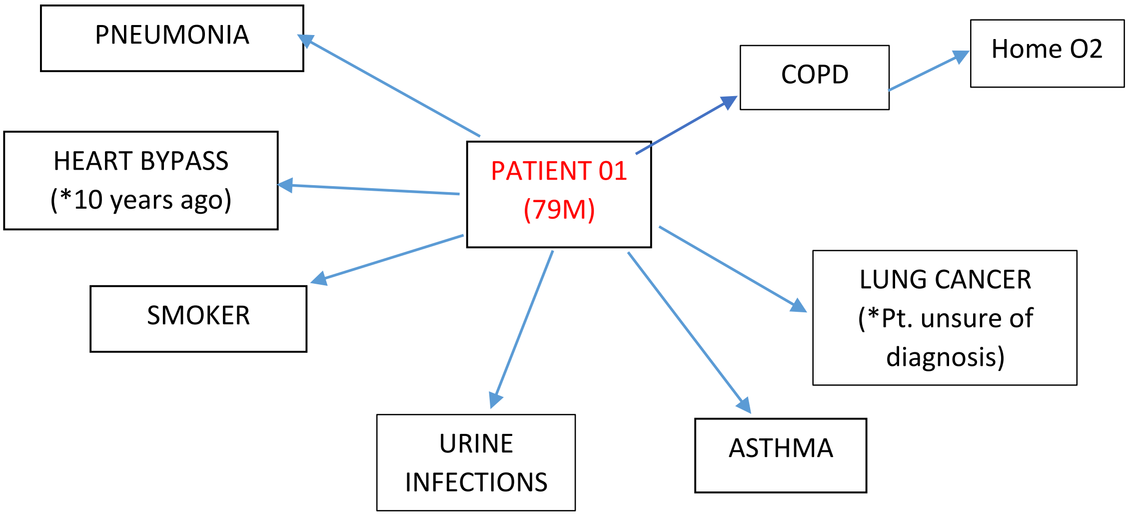
HEALTHCARE PROFESSIONALS	**FAMILY & FRIENDS**
RESPIRSTORY NURSE and her ASSISTANT	HUSBAND (90)
GP	SON
OUT OF HOURS GP	CLEANER (once a week)
COPD OUTREACH	
HOSPITAL DR'S	
HOSPITAL NURSES	

*HUSBAND has carers in 3x a day

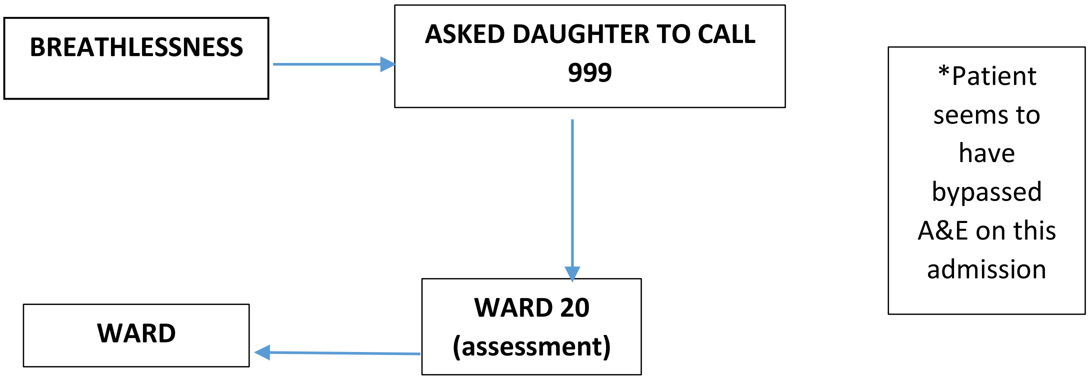
APPENDIX FIVE

PATIENT 01 – 79M Lives with WIFE

PATIENT PROFILE



PATIENT JOURNEY TO THE ED



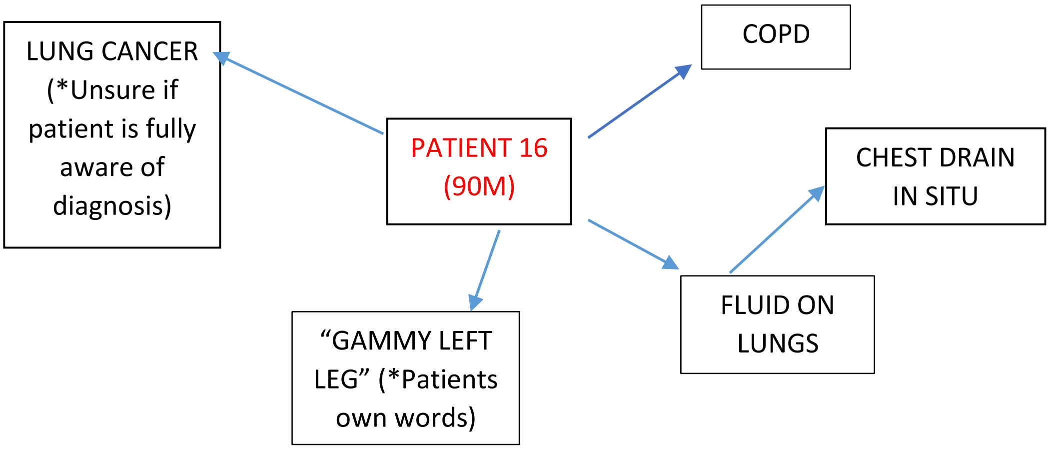
PROFFESIONALS AND FAMILY INVOLVED IN PATIENT'S CARE

HEALTHCARE PROFESSIONALS	FAMILY & FRIENDS
PHYSIOTHERAPIST	WIFE
GP	DAUGHTER & SON-IN-LAW
OT	CLEANER (twice a week)
SOCIAL SERVICES	
HOSPITAL DR'S	
HOSPITAL NURSES	
GP SURGERY	
MCMILLIAN NURSES	

APPENDIX FIVE

PATIENT 16 – 90M Lives with WIFE

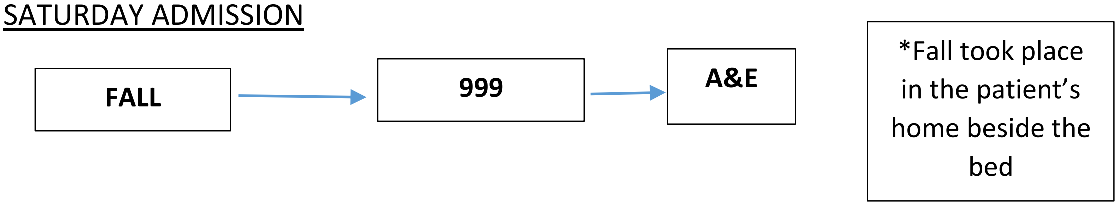
PATIENT PROFILE



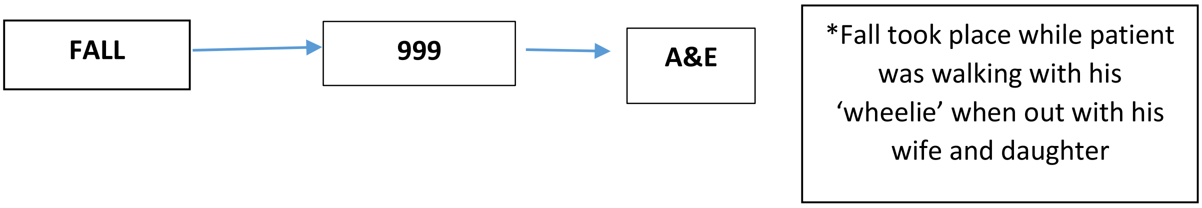
PATIENT JOURNEY TO THE ED

* Patient states he was admitted for reasons unrelated to his 'diagnosis' and that he had 'two falls within a few days'.

SATURDAY ADMISSION



THURSDAY ADMISSION



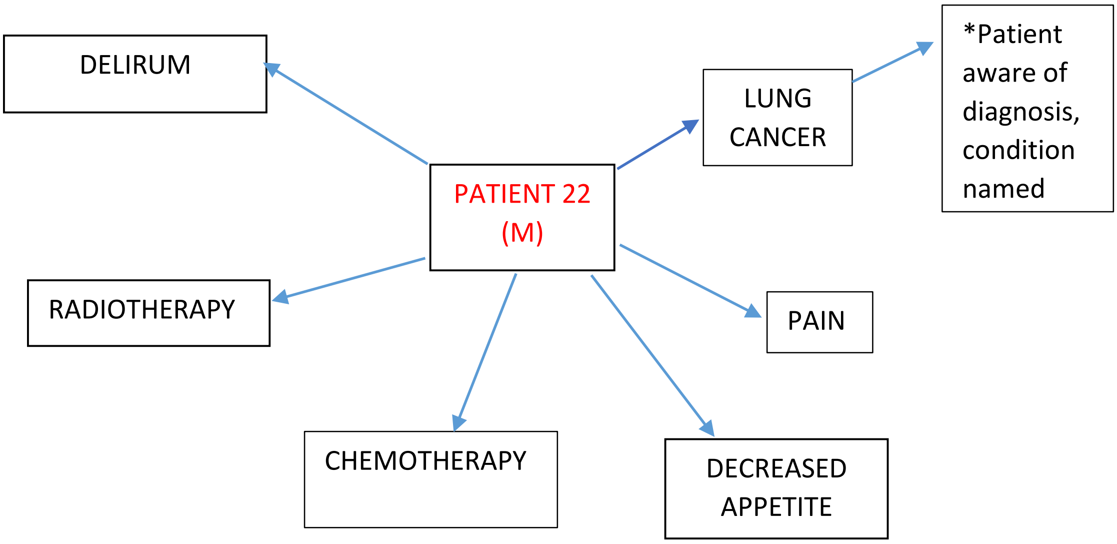
PROFFESIONALS AND FAMILY INVOLVED IN PATIENT 16’s CARE

HEALTHCARE PROFESSIONALS	**FAMILY & FRIENDS**
DISTRICT NURSE	WIFE (88)
GP	BROTHER
RESPIRATORY DR (hospital)	DAUGHTER
RESPIRATORY SENIOR NURSE (hospital)	FRIEND
PARAMEDICS	
RADIOLOGISTS	
OT	
FALLS CO-ORDINATOR	
RESPIRATORY TEAM	
MARIE CURIE	

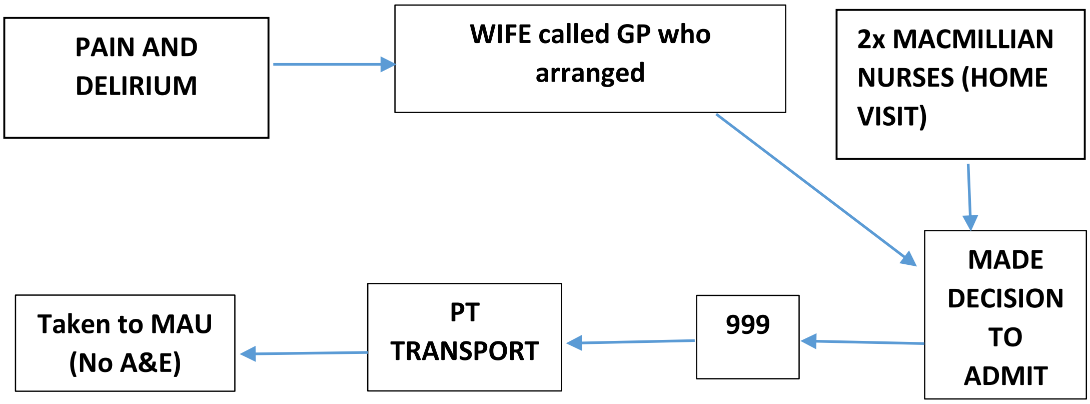
APPENDIX FIVE

PATIENT 22 – M Lives with WIFE

PATIENT PROFILE



PATIENT JOURNEY TO THE ED



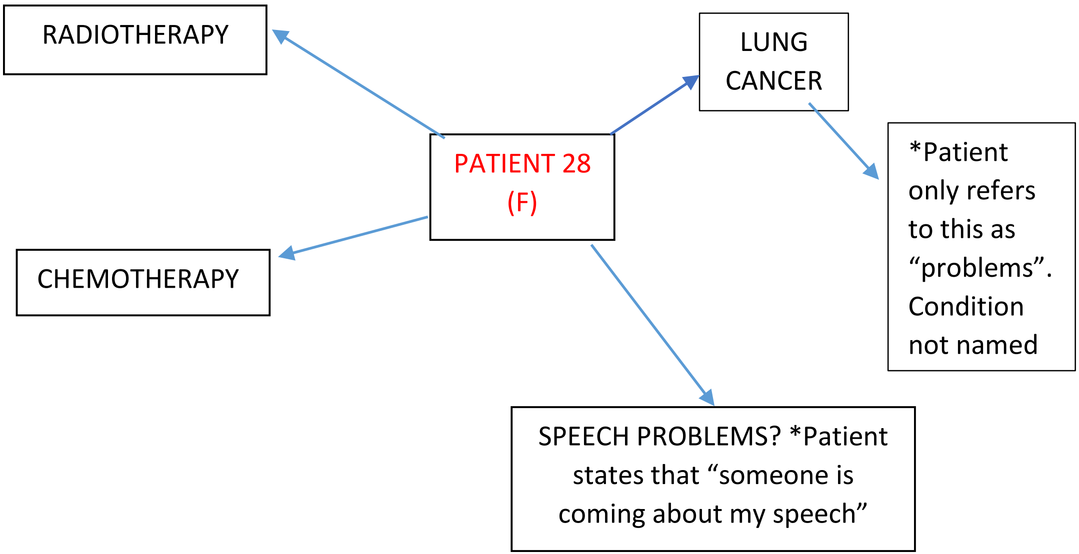
PROFFESIONALS AND FAMILY INVOLVED IN PATIENT'S CARE

HEALTHCARE PROFESSIONALS	FAMILY & FRIENDS
MARIE CURIE NURSE	WIFE
MACMILLIAN NURSE	DAUGHTER
HOSPITAL DOCTOR	2 x SONS
DISTRICT NURSE	GRANDCHILDREN
HOSPITAL TRANSPORT	
CANCER NURSE	
BADGER CLINIC DRS	
PALLIATIVE COMMUNITY CARE	

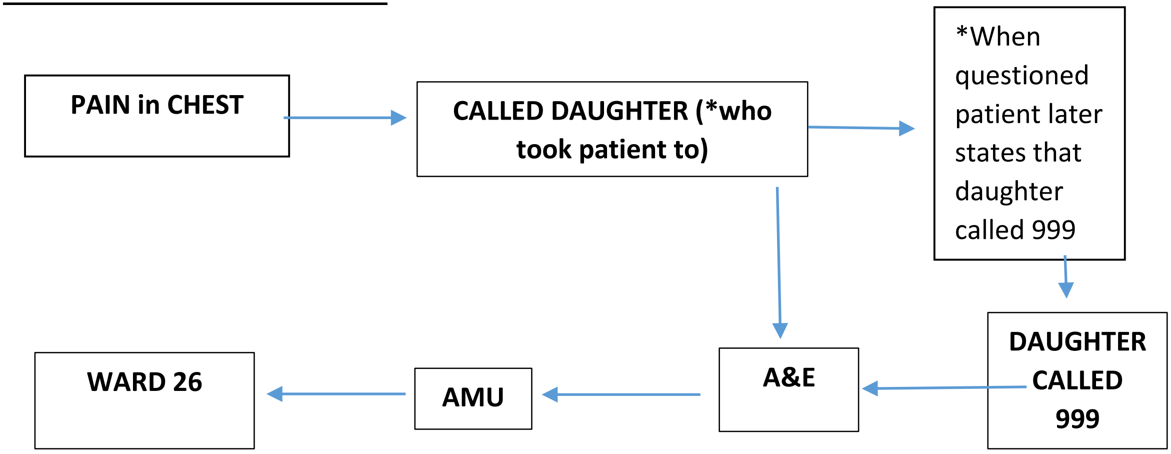
APPENDIX FIVE

PATIENT 28 – F Lives ALONE

PATIENT PROFILE



PATIENT JOURNEY TO THE ED



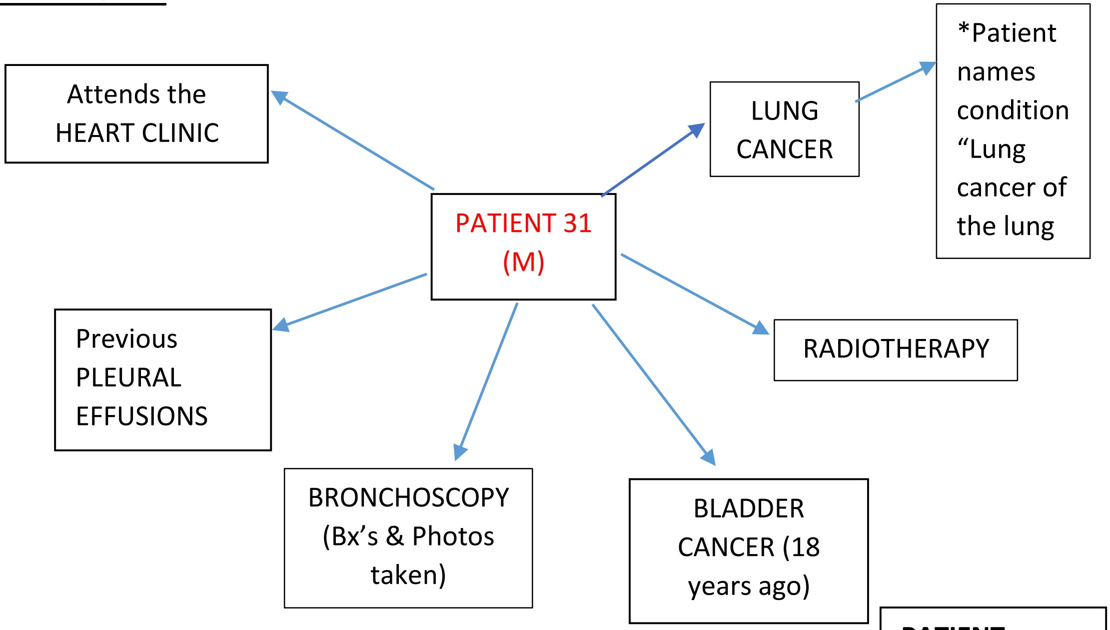
PROFFESIONALS AND FAMILY INVOLVED IN PATIENT’S CARE

HEALTHCARE PROFESSIONALS	FAMILY & FRIENDS
GP *Patient mentions two Doctors	DAUGHTERS x3
DISTRICT NURSE (*Not know to pt. pre admission)	SON
MACMILLIAN NURSES	GRANDCHILDREN
SPEECH THERAPIST?	AUNTIE
OT	
DISCHARGE LIASION NURSE	
WARD STAFF (in hospital)	
CARER (2x visits a day – morning and night)	

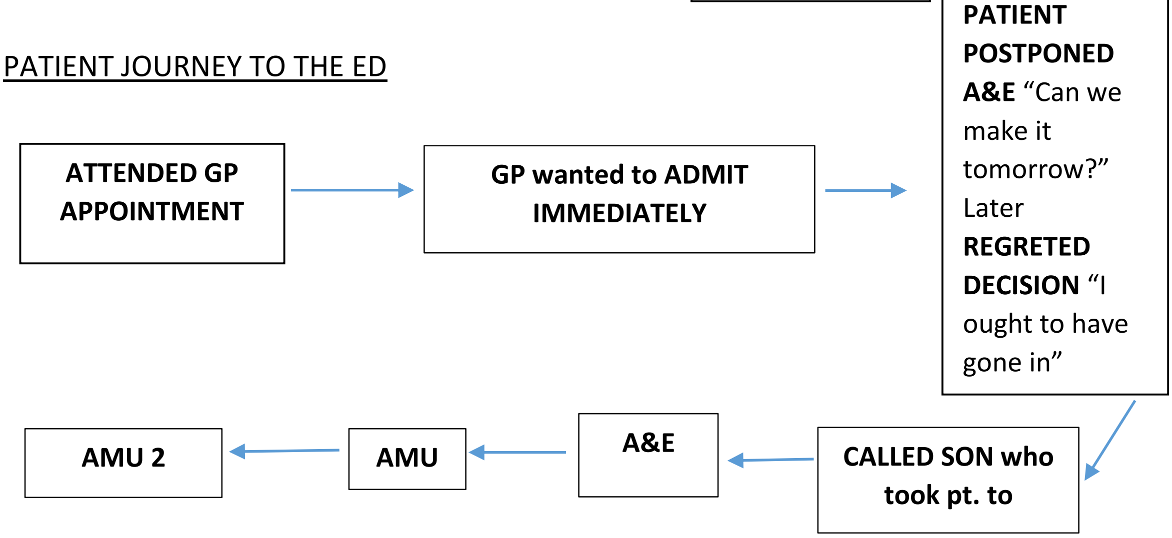
APPENDIX FIVE

PATIENT 31 – M Lives with WIFE

PATIENT PROFILE



PATIENT JOURNEY TO THE ED



PROFFESIONALS AND FAMILY INVOLVED IN PATIENT'S CARE

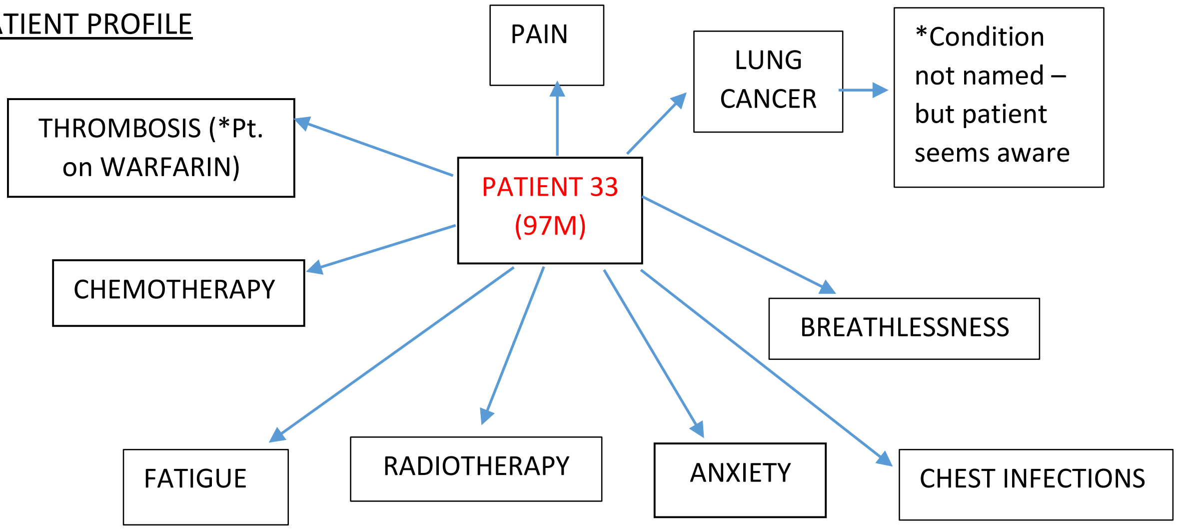
HEALTHCARE PROFESSIONALS	FAMILY & FRIENDS
GP	WIFE
RESPIRATORY TEAM	SON and DAUGHTER IN LAW
	DAUGHTER (lives in France)
	GRANDCHILDREN (2 in France, 2 in UK)

*Patient was offered community services when he was diagnosed with cancer but refused. *He donates to Macmillan nurses but they do not visit him.

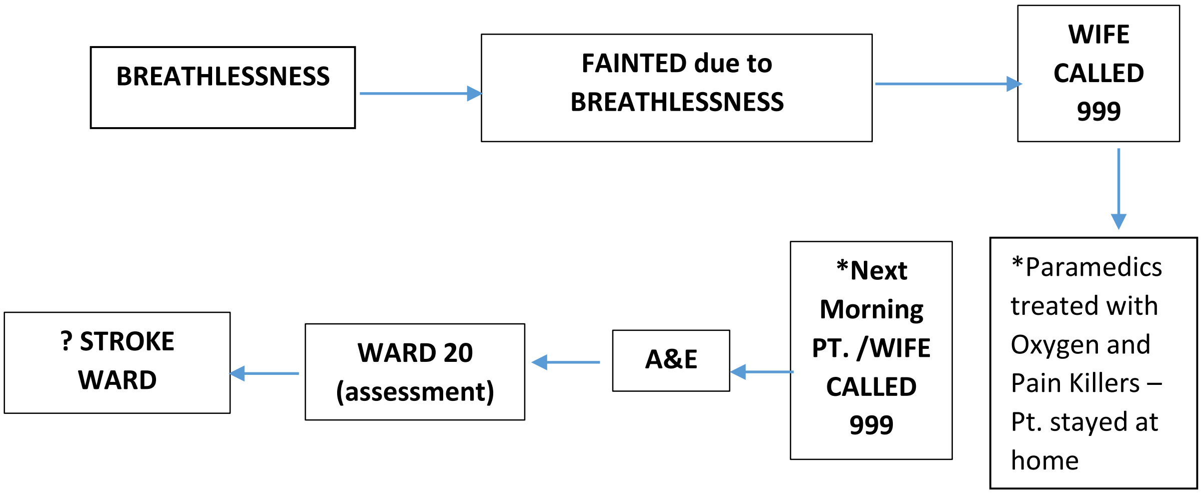
APPENDIX FIVE

PATIENT 33 – 97M Lives with WIFE

PATIENT PROFILE



PATIENT JOURNEY TO THE ED



PROFFESIONALS AND FAMILY INVOLVED IN PATIENT'S CARE

HEALTHCARE PROFESSIONALS	FAMILY & FRIENDS
MACMILLIAN DOCTOR	WIFE
DISTRICT NURSE	DAUGHTER
MACMILLIAN NURSE	
GP	
PATIENT TRANSPORT	
CLINICAL NURSE SPECIALIST	
MARIE CURIE CENTRE	
MEDICS FROM THE HOSPICE	

APPENDIX SIX - Patient Transcripts

CODE	**PATIENT PROFILE**	**What is the patient's perception of the reason behind admittance?**	**HCP perception?**
O9 - COPD 64M Lives with WIFE 78 *PATIENT (pre interview *CCM *RESP NURSE (hospital)	*COPD - Home O2 *Chest Infection *SoB and Pain *Smoker *Anxious *Emphysema *Lung reduction surgery - 2004	SOB & PAIN -> 999 **"I wasn't very well, so we dialed 999, ambulance people, and that was it really I couldn't get my breath…Shortness of breath and pain" I: Had you contacted your GP?" "No, we don't bother with the GP…we just call the hospital" (1)**	RESP NURSE TYPE 2 RESPIRATORY FAILURE -> NEEDING NIV **"Patient continues to smoke, so obviously lung function has declined and his exacerbation frequency has increased" (2)** CCM (* Who was on holiday at the time) **"They hold on and hold on, and they think they'll be okay" (3)**
10 - COPD 81F Lives with HUSBAND (90) and SON *PATIENT (pre interview) *RESPIRTARY NURSE (community)	*COPD - Home O2 *Chest Infection *Urine Infection *Dehydrated (at the time of admission) *Stress *Panic attacks *Anxiety	BREATHLESSNESS -> 999 (SON called) **"Well I felt breathless really all afternoon, but it gradually got worse, and about 8o'clock I said to my son 'I think you'd better phone an ambulance'" (1)**	RESP NURSE (*On annual leave at the time) **"I was on annual leave at the time…the health care assistant that works with me went out to see her" (3)***Surprise admittance **"We were surprised by [name] admission because when Dena saw her, she [patient] was all set to go on the ring and ride to go out shopping, and was going on about how much better she felt and then that evening she ended up going into hospital"(4)** *Patient prone to panic **"She was a very anxious lady as well, she talks about having panic attacks" (2)**

CODE	**PATIENT PROFILE**	**What is the <u>patient's</u> perception of the reason behind admittance?**	**<u>HCP</u> perception?**
<u>O1 - LUNG CANCER - M79 Lives with WIFE</u> *PATIENT *PHYSIO	*Lung cancer (pt. unaware) *COPD *Pneumonia *Heart Bypass (10 years ago) *Smoker *Urine Infections	BREATHLESSNESS -> DAUGHTER called 999 **"Now one day, well I say one day, probably two days I'd had a little bit of [demonstrates chesty breathing]…and then I got this bad flu, well not the flu, the bad attack of asthma and they haled me in here then" (1)** Interviewer goes on to clarify **I: "Okay, so you were really getting difficulty with your breath were you?" "Yeah" (2)**	<u>PHYSIO</u> FALL -> DECREASED MOBILITY **"Let's have a think Mr [name] has been in for two days now, why did he come in? He, I think he had a fall and his mobility decreased" (3)** *Later went on to say **"I mean he has got lung cancer and COPD and, but as a physio I haven't actually treated him for this on this admission, so he's actually, his physio care has really been involved in his mobility and social situation...he could well have been admitted for deterioration in his COPD or exacerbation of that in which case I'd be involved more specifically in his chest care. So just because he's got COPD doesn't mean he can't be admitted for other things and that's exactly what's happened here" (10)**
<u>16 - LUNG CANCER - M90 - Lives with WIFE (88)</u> *PATIENT (pre interview) *STAFF NURSE (on ward) *DISTRICT NURSE	*Lung cancer (Pt. refers to Diagnosis, chest x rays and chest drains but does not name condition) *COPD *Fluid on lung *Chest drain in situ *'Gammy left leg'	FALL -> 999 -> A&E *Patient describes two admissions to A&E not due to his diagnosis but due to two falls **"I think I was diagnosed in about March time [This was 7 months ago]…I haven't come in for that reason, I had two falls within a few days. Up until then my breathing was alright" (1)**	<u>STAFF NURSE</u> FALL **"Patient admitted 2 days ago at the weekend because of a fall" (4)** EXACABERATION OF COPD **"He has an exacerbation of his COPD" (2)** <u>DISTRICT NURSE</u> CHEST TUBE FELL OUT -> A&E **"His chest tube had fallen out, we phoned the ward, the ward actually said he needed to come to A&E. [name] didn't want to go into A&E, he didn't want to go into hospital, he said he felt fine, he was going out at the time, he was still out and about. But in the end, we contacted his daughter and his daughter said she'd get him there...No one has said to us he'd had a fall" (3)**

CODE	PATIENT PROFILE	What is the patient's perception of the reason behind admittance?	HCP perception?
28 - LUNG CANCER -F - Lives ALONE *PATIENT *STAFF NURSE (hospital) *SENIOR SISTER PALIATIVE CARE TEAM (hospital)	*Lung cancer (patient refers to "problems" rather than naming condition) *Chemotherapy *Radiotherapy *Speech problems *On tablets (not named)	CHEST PAINS -> CALLED DAUGHTER -> 999 **"I was on me own, and I had these terrible pains in the chest, so I phoned [daughter] and she brought me up here, and I haven't been out since" (2)** * Later patient states that an ambulance was called **"Yeah, we rung for an ambulance" (3)**	STAFF NURSE *Does not comment on reason for admittance - However does later state that patient should normally be on the oncological ward **"Oh yes, very unusual, she's not normally on this ward, she would normally be on a cancer ward" (4)** SENIOR SISTER BREATHLESSNESS and CHEST PAINS -> 999 **"From what I can remember she presented with acute shortness of breath and chest pains and when I saw her...she was very unwell, she was acutely breathless" (5)**
31 - LUNG CANCER - M - Lives with WIFE *PATIENT *STUDENT NURSE	*Lung Cancer (Patient names condition) *Bladder Cancer *Previous pleural effusions *Radiotherapy *Attends a heart Clinic *Previous Bronchoscopy - Biopsies and Photographs taken	GP VISIT -> who states he should be admitted -> Patient DELAYS but later REGRETS -> CALLS SON -> who drives him to A&E **"I'd seen the GP, and he said, we better have you in, come in today? I said well it's a bit awkward, can I make it tomorrow...But I ought to have gone in that night as they suggested, but I'd got things to do, paperwork and everything. But as the night progressed I realised I was foolish to do that, so we got on to the doctor and my son brought me up here" (1)**	STUDENT NURSE BREATHLESSNESS -> Condition worsening? Pleural Effusion **"He came in with shortness of breath and that it was worsening than he was already used to and then they were querying pleural effusion" (2)**

CODE	**PATIENT PROFILE**	**What is the <u>patient's</u> perception of the reason behind admittance?**	**<u>HCP</u> perception?**
<u>33 - M97 - LUNG CANCER</u> *PATIENT *WIFE *DAUGHTER (all interviewed together) *COMMUNITY PALLIATIVE CARE NURSE	*Lung Cancer (condition not named although patient is aware) *Radiotherapy *Chemotherapy * Thrombosis - on warfarin *Pain *Fatigue *Anxiety *Breathlessness *Chest Infections	BREATHLESSNESS -> GOT WORSE -> WIFE CALLED 999 -> TREATED by PARAMEDICS -> STAY AT HOME. **NEXT MORNING** PT CALLED 999 -> A&E **"It's a breathing problem got worse and worse and worse, I had to call out this morning for the ambulance I just couldn't breathe" (1)**	<u>PALLIATIVE NURSE</u> BREATHLESSNESS-> wanted some oxygen ->DISTRICT NURSE VISIT -> GP VISIT -> PAIN -> 999 -> TREATED by PARAMEDICS. **NEXT MORNING** SAME AGAIN -> 999 -> A&E **"He was struggling to breathe and he wanted some oxygen, so we arranged for some home oxygen to be sorted and got the district nurse in. And it was his breathlessness really that was the problem, he was seen by the GP...his wife told me he's had two very bad mornings, the one morning he woke up, he was in terrible pain and she rang for the paramedics who came out gave him some oxygen and gave him his painkillers and stayed with him until he settled. The following morning the same again basically, he was really poorly, she said he was very very hot and she rang for the paramedics and they took him" (2)**

Family perception?	**Does pt. know their HCP?**	**Does HCP know their Pt.?**	**Why does Pt. / family say they called 999? (Rather than somebody in the community?)**
(03) WIFE FALL (Due to breathlessness? Urine infection? Chest Infection?) Patient and wife not sure if fall was due to breathlessness or infection? **I: "Now do you think the fall had anything to do with your breathlessness?" "I don't really know. They found out I'd got two infections didn't they" (4)**	RESP CNS 1 *Patient knows her by name (5) CCM (com) **"It's my own fault because I didn't call her" (6)**	RESP CNS 1 *Knows patient very well (7) CCM *Known pt. since 8th Jan 2010 - has had intensive contact with health services, seeing the community matron since May 2007. **"He has been my patient since 8th January 2010" (8)**	**"I've got to stop getting to the point where I'm so desperate I've got to call an ambulance" (1)** Patient stated he could have called CCM but left it too late, His SON was his first port of call and he called 999 (10)
(08) DAUGHTER COLLAPSE (at home) -> called NEIGHBOUR -> who called DAUGHTER -> who called GP (as COPD nurses refused to visit) -> who called 999. **"Well we thought it was the result of a new tablet she's started…it was the week of mine and my brothers holiday…she [mother] managed to get herself, somehow, after three hours, to the phone… She rang the neighbour... and then they got us and we all had to come home" (2)** Whilst family were away they received a call from the Dr who told them not to come home it was a reaction to the tablets but the neighbour asked them to come home anyway. **"When I got back I rang for the Doctor again, and they didn't want to come out. I'd also tried the COPD people to come out and asked them to check her oxygen. They didn't come out" (2)**	Patient mentioned the District Nurse **"yes she's very good" (4)** but no other HCP. States **"I have asked and asked, don't think it's fair" [talking about the allocation of community resources] (5)**	CCM *Knows patient - Oct/Nov 2010 **"I met her, I think it was following her previous admission…I think I met her October/ November of 2010" (6)**	DAUGHTER *COPD Team refusal of visit **"If the COPD operation had of come out, they'd have known her oxygen was dangerous, and they'd have admitted her straight away…Instead, we had to administer CPR on her and everything, while we were waiting for the ambulance" (7)** COPD nurses had informed daughter to call the GP again - visit the previous day by the team showed everything to be normal so was assumed it was not a respiratory connection - thought it was a reaction to a tablet she'd recently been given.

Family perception?	**Does pt. know their HCP?**	**Does HCP know their Pt.?**	**Why does Pt. / family say they called 999? (Rather than somebody in the community?)**
(09) *WIFE not interviewed as PT. DIED before Post discharge Interview was completed	*Knows CCM. Patient mentioned the Community Matron (CCM) **"Yes she was on holiday" (4)** States they get on well and they have a good relationship (5)	RESP NURSE *Knows patient **"He's been in and out of hospital a couple of times a year over the past three to four years" (2)** CCM *Knows patient since June 2009 **"When did I take him up? June 2009, So after I took him on June 2009, he didn't have an admission for over 12 months" (4)**	*Called 999 **I: Had you contacted your GP?" "No, we don't bother with the GP…we just call the hospital" (1) "Well I'd rather call the hospital anyway because they're the gaffers aren't they, they know what they're doing" (7)**
(10) *NO FAMILY INTERVIEW	**YES - Knows RESP NURSE* by name **"I've got a respiratory nurse" (5) I: They would come out, the same day "Yes yes yes" (6)**	**YES has been involved in patients care for a year*: **"How long have you been involved with this lady? "With this lady? It must be a year now" (7)**	*AMBULANCE gave patient the option when called from 999 as to stay at home or go into A&E. **"No I'll go to hospital. They can do more for you in there" (9)** *Also states she did not call the GP as they don't come out **"They won't [GP] come out really" I: So you felt calling 999 was..." "Oh yes, the best thing, I knew I'd get the best treatment [in hospital]" (12)**

Family perception?	**Does pt. know their HCP?**	**Does HCP know their Pt.?**	**Why does Pt. / family say they called 999?**
(01) NO FAMILY INTERVIEW	*PHYSIO -*YES* - **"Oh yeah, the one had me walking up and down" (4) "the one that took me to the, test me on the walking, and upstairs and what not, she were great she were" (8)** *GP - *YES - Patient seems to know his GP very well* **"My doctors been great…I mean my doctor has been over three times in about, I'd say a fortnight and he wanted to know how I was" (5) I: "Do you think the doctors been quite influential in your care?" "He has...It's the doctor, who's been good to me, put it that way" (6)**	*PHYSIO - *YES* - Seems to know patient and discusses family members but does not identify correct reason for admittance to hospital. **"Let's have a think Mr [name] has been in for two days now, why did he come in? He, I think he had a fall and his mobility is decreased. So my role is to get him back on his feet" (3)**	*Patient doesn't state this. His GP was on holiday (Can't be sure if this was pre or during admission to hospital) **"You can't go on bloody holiday... I'm in bloody hospital…you can bloody well stop here" (7)**
(16) NO FAMILY INTERVIEW	*HCP only became involved after hospital admission before then patient did not have any support I: "Were you seeing the district nurse or anybody like that?" **"No, not really" (6)**	STAFF NURSE *YES **"Patient admitted 2 days ago at the weekend because of a fall" (4)** DISTRICT NURSE *YES but knew wife before patient **"We knew [name - wife] already because she'd been a patient of ours before, his wife. So we'd seen [name] around, but not actually looked after him" (5)**	*Apart from his GP this patient was not under any other services - so had no alternative to calling 999 and attending A&E - However he was seeing Marie Curie nurses.

<u>Family</u> perception?	**Does <u>pt.</u> know their HCP?**	**Does <u>HCP</u> know their Pt.?**	**Why does <u>Pt. / family</u> say they called 999?**
<u>(22)</u> <u>WIFE</u> DELIRUM -> CALLED GP -> GP SENT 2x MACMILLIAN NURSES - > DECIDED TO ADMIT -> 999 -> PATIENT TRANSPORT **"I noticed a change in him, as a person. He was like Jeckal and Hyde, I couldn't get any common sense out of him at all, and he was totally delirious. He was like that from probably Wednesday, Thursday and it just got worse and worse. So I got in touch with the doctor and the doctor said 'I think we should send somebody out to have a look at him', and this was on the Friday night. They sent two nurses out to have a look and he was still, you know, really incoherent and didn't know what time of day it was....they decided to admit him" (1)**	*Patient knows GP, Marie Curie the Macmillan Nurses and the District Nurses **I: "The Macmillan nurses that came out to see you, how long have you been in touch with them then?" "Virtually since the first day really, since the day we went to Solihull hospital, we were introduced to them....your cancer nurse and in fact, it was her that explained everything to us, about what was going to happen, regarding whatever happens sort of thing" (2)** *<u>WIFE</u> explains that DAUGHTER has a good relationship with the family doctor **"She's got a good rapport with our doctor, they get on really well, and she knows she can tell the doctor anything she wants to tell him" (3)**	<u>PALLIATIVE NURSE</u> *Has known patient since December **"He was referred to me on 20th December 2011" (11)**	*Patient or Wife did not call 999, they called the GP who arranged a visit from Macmillan who made the decision to admit. Decision was taken out of patient and families hands. **I: "So did those nurses ring the hospital for you then? <u>WIFE</u> "Yes, they phoned for the ambulance" (4)**

Family perception?	**Does pt. know their HCP?**	**Does HCP know their Pt.?**	**Why does Pt. / family say they called 999?**
(28) NO FAMILY INTERVIEW	*Patient has two visits (morning and night) from carers - Later linked to Macmillan nurses **"Yeah, cos the carers come in every night anyhow, one of a night and one of a morning" (6)** *Patient states she receives no other community help **I: "Do any other nurses or doctors come and see you at home?" "No" (7)**	STAFF NURSE - *States patient has been moved about a bit so isn't sure whether the issues leading to admission have been addressed - but is looking after patient whilst in hospital (8) SENIOR SISTER *Knows patient from this admission **"The referral came up direct for A&E to palliative care... we had to have a telephone referral from a staff nurse in A&E asking if we could see her urgently, so I went down later on that day and saw her in A&E" (9)**	*Patient does not state why they didn't seek an alternative to A&E even though she had 2 visits a day from a Macmillan nurse / carer) **"I was on me own, and I had these terrible pains in the chest, so I phoned [daughter] and she brought me up here, and I haven't been out since" (2)**
(31) NO FAMILY INTERVIEW	*Patient knows GP well and praises him **"Dr. [name] is my GP, Attentive lad…but he was very attentive and he is an attentive man" (3)** *Patient later states other services were offered to him but he refused. **I: "And you don't have any nurses coming in to see you or..?" "No, that was offered to me especially, when the realisation that I'd got lung cancer, they went through a whole splurge" (4)**	STUDENT NURSE *Only know patient through this admission to hospital	*Patient did not call 999 and when instructed by the GP to go to hospital the patient refused, trying to delay the admission **"I was pushing off the inevitable" (5)**

Family perception?	**Does pt. know their HCP?**	**Does HCP know their Pt.?**	**Why does Pt. / family say they called 999?**
(33) DAUGHTER BREATHLESSNESS - FAINTED same description as patient as they were interviewed together. Wife added that patient eventually went to hospital on his own as it was early in the morning **"He went on his own, because it was 4 o clock in the morning" (3)** *Was a weekend admission WIFE **"In the ambulance on his own he went yes" (4)**	* YES - Patient talks about knowing the DR from Macmillan, the DISTRICT NURSE and the Macmillan NURSE. **I: "Who do you see in terms of health care professionals?"** DAUGHTER "**District Nurse"** WIFE **"District nurse and a Macmillan nurse"** PATIENT **"and a doctor"** WIFE **"She's very good at getting [difficult to hear but they are very responsive when the family calls them]" (5)**	PALLIATIVE NURSE * YES - Has known patient since September last year - 8 months **"I think it was probably going back to September last year. I can tell you exactly…He was put on the Gold Standard Framework in September. Yes I think August 31st August when I first..." (6)**	*Patient and family say they called 999 because of the time of day it was. **I: "Right, so it was because it was that was the only thing you could do really is to call the ambulance?"** DAUGHTER **"Yes, he was struggling with his breath and that, and I think you fainted as well" (7)**

Why does HCP think they called 999? (Rather than somebody in the community?)	**Has Pt. been referred to the appropriate services?**	**Does HCP believe pt. is accessing services properly?**
(03) RESP CNS 1 *GP receptionist making a clinical decision on patient calling an ambulance. **"They ring the surgery for advice, or to speak to the GP, and they're told by the receptionist that they need to ring an ambulance instead. So we weren't sure as to whether it was that they felt someone had given them permission to ring an ambulance to come in, or that we know believe it is actually the GP surgery giving the same messages to these gentlemen and they will ring up and they say to the receptionist 'I can't breathe' and the receptionist will automatically make the decision" (11)** *Community matron telephone number the same as the district nurses. **"They don't have the direct line telephone numbers [for the community matrons], and we do know that the single number that everyone uses is also the referral line, it's used for both District Nurses and Community Matrons, and we get many patients that will ring us and say 'can you get hold of such and such a matron, because I've been trying to get hold of her all day and can't get through" (12)** RESP CNS 2 *Patient always calls 999 **"Patient lives over the road from his GP, a good practice, but he always rings for an ambulance, when the respiratory nurses used to home visits he would ring them up, it was a bit of a nuisance...Now the patient has a community matron, but instead of contacting her when he starts to become ill, he waits for a few days, will become worse and then ring for an ambulance" (18)** CCM *Frequent attender *Pattern of behavior for him **"He's the highest hospital admission patient by a long way that I know... and I think he's had that pattern of behavior" (14)**	*RAPID RESPONSE * DEPT MATRON *RESP NURSE *GP *HOSPITAL DRS & NURSES *PHYSIO *COMMUNITY MATRON *OT *COMMUNITY NURSE *DRS SURGERY *RESP NURSE (hospital) *MENTAL HEALTH TEAM *INTERMEDIATE CARE TEAM *FAB *ADVANCE NURSE PRACTIONER *FALL PREVENTION TEAM *COPD COMMUNITY NURSE	RESP CNS 1 _*NO_ **"He's a revolving door patient" (16)** RESP CNS 2 **"Patient lives over the road from his GP, a good practice, but he always rings for an ambulance, when the respiratory nurses used to home visits he would ring them up, it was a bit of a nuisance, she had to drop everything and go visit him" (17)** CCM _*NO_ **"He has had a huge amount of involvement from the community services and secondary care. He's had numerous visits by myself, and telephone conversations." (18)** *Sometimes patient REFUSES services and is a non-attender. **"We've got a service called FAB, which is very good, its run by the hospice; Fatigue, Anxiety and Breathlessness Clinic. But unfortunately, he doesn't want to attend any of those, which is why in the past we've requested services to come to the house to him. I believe he's not attended a few visits in the past, to hospital appointments, certainly with the respiratory team....a lot of my involvement has been psychological, trying to prepare him for those appointments and booking, but then unfortunately, he cancelled on several occasions, when the day came, he was unwell and unable to attend" (19)**

Why does HCP think they called 999? (Rather than somebody in the community?)	**Has Pt. been referred to the appropriate services?**	**Does HCP believe pt. is accessing services properly?**
(08) CCM *Family were away on that occasion **"the family were actually away on that occasion…the GP actually went out the day before" (8)** no mention of a chest complaint and patient went into hospital the day after. **"This lady always says to me she goes off very quickly" (3)**	*DISTRICT NURSE *? RESP NURSE *GP *HOSPITAL STAFF *PoC DISCHARGED WITH (2x daily visits) *COPD PEOPLE *BADGER *CARERS *A&E STAFF *CCM	* _YES_ -Patient has had good contact with community services **I: "So you managed to keep her at home for a year…She's not been admitted since referral has she?" "No she hasn't" I: "So in terms of keeping her out of hospital, is she one of the better patients, in a way...she doesn't have frequent admissions" (8)**
(09) RESP NURSE *Patient is gradually deteriorating and needed admission **"when he's been in, he's required NIV each admission, so the last couple of times it's taken us longer to wean him off the NIV, and including the last admission" (8)** CCM * Patient required admission **"On his last admission, he had to have NIV" (10)**	*COMMUNITY MATRON *OT *HOSPITAL RESPIRATORY NURSE *GP * COMMUNITY PHARMACIST *MCMILLIAN NURSE *CLINICAL CASE MANAGER *DISTRICT NURSE	RESP NURSE _*YES - although referral for some services not accepted_ - Patient has **"had great community support, great family support. And end of life care planned, the things that were quite frustrating to the community matron, they had twice referred him for respite with the hospice, and for - she's never got to the bottom of it...nothing ever materialised" (11)** *Patient used services appropriately **" It's down to the patients appropriately using the service, either ringing the community matron, rather than 999...This gentleman in particular didn't panic" (19)** CCM _*YES_ - described patient as **"one of her success stories"(12)**

Why does HCP think they called 999? (Rather than somebody in the community?)	**Has Pt. been referred to the appropriate services?**	**Does HCP believe pt. is accessing services properly?**
(10) RESP NURSE * Does not mention this but did comment that it was a surprise admission **"We were surprised by [name] admission because when Dena saw her, she [patient] was all set to go on the ring and ride to go out shopping, and was going on about how much better she felt and then that evening she ended up going into hospital"(4)** *Also comments about patient being anxious and having panic attacks **"She was a very anxious lady as well, she talks about having panic attacks" (2)**	*RESPIRATORY NURSE and her ASSISTANT *GP * CLEANER *HOSPITAL DRS *HOSPITAL RESP NURSES * OUT OF HOURS GP *COPD OUTREACH TEAM	**MAYBE? Had tried with patient to put a plan together which would avoid calling the out of ours GP, which would suggest this is what patient had been doing* **"So when I was talking her through this I said, what's the plan, so she couldn't breathe, so you get that element of anxiety and panic in there, so rather than calling out the out of hours GP, who on the phone might have said 'call and ambulance, they tend to call an ambulance direct" (10)**
(01) PHYSIO *Not really mentioned - however did comment on the patients social side **"He's main issue is actually a social issue, his family are not happy with the demands that he makes on them at home; so even though he appears very compliant, very good here, his family tell me he's very demanding"(9)** Could help explain why daughter rang 999 - however it is hard to tell exactly what happened as patients explanation was brief.	*GP *PHYSIO *SOCIAL SERVICES *HOSPITAL DRS *HOSPITAL NURSES *CLEANER *GP SURGERY *OCCOPATIONAL THERAPIST *MCMILLIAN NURSES	PHYSIO **YES* - seems like patient has been referred to appropriate services - He has carers twice a day which could be increased. **"It's pretty much I think; especially for him, it's sorted now; he'll only have two calls a day…but he's got the option or his family have the option of turning that into three or four calls a day because they are in touch with the agency" (11)** *Also mentioned Macmillan input **"He was having community input anyway from the Macmillan nurses" (12)** *Patient didn't admit to knowing cancer diagnosis however Physio stated **"He's a bit inconsistent with what he says...He's had this diagnosis for over a year I think in his lung cancer" (13)**

Why does HCP think they called 999? (Rather than somebody in the community?)	**Has Pt. been referred to the appropriate services?**	**Does HCP believe pt. is accessing services properly?**
(16) *HCP only became involved after first hospital admission before then patient did not have any support **I: "Were you seeing the district nurse or anybody like that?" "No, not really" (6)**	*GP * DISTRICT NURSES (only after first admission -who attended him at home to change his chest drain dressing) *RESPIRATORY DOCTOR (hospital) *RESPIRATORY SENIOR NURSE (hospital) *RADIOLOGISTS *PARAMEDICS *PHYSIO *OT * FALLS CO_ORDINATOR *RESPIRATORY TEAM *MARIE CURIE	STAFF NURSE *Explains that there is **"a palliative care plan in the medical notes, which indicated that the family were in agreement with the plan. However, although he referred to his chest drain, chest X rays and the word 'diagnosis', the patient did not refer to his lung condition by name" (7)** DISTRICT NURSE *Patient only involved with district nurses for palliative care **"We were asked to go into [name] as a palliative patient. First of all we were asked to go in because he had a chest drain inserted, and to go in and actually change his chest drain" (8)** *Not involved in any other community services **I: "Is he having other community PR actioners involved at the moment?" "No, he's just having Marie Curie...that's it"** *Details of Marie Curie input are not disclosed in interviews. *Not talking about the patient specifically but about the team **"We're lucky in our team, there are teams out there that don't have appropriate, but our patients will contact us appropriately. You might have the odd question that comes through, we always say 'just phone us and if it's not us you need, we will point you in the right direction'" (9)**

Why does HCP think they called 999? (Rather than somebody in the community?)	**Has Pt. been referred to the appropriate services?**	**Does HCP believe pt. is accessing services properly?**
(22) PALLIATIVE NURSE * There is some confusion here - As previously stated by the patient and his wife - they did not call 999 the nurse did, however it was not the palliative nurse as she did a home visit on Saturday when the patient had been admitted Friday night, she was not aware of **admittance. "He'd commenced chemo just before that. I had a call from his wife on the 27th to say that he was poorly and increasingly confused and then I spoke to the GP...and suggested he needed a medical review, which didn't happen then I went to visit him on Saturday morning, but he had actually been admitted to hospital the night before, so the GP didn't go out to review him unfortunately" (10)**	* MARIE CURIE *MACMILLIAN NURSE *HOSPITAL DOCTORS *PREVIOUS DOCTOR *GP *DISTRICT NURSE *HOSPITAL TRANSPORT *HOSPITAL NURSES *CANCER NURSE *BADGER CLINIC DOCTORS *PALLIATIVE COMMUNITY CARE	PALIATIVE NURSE *At the time the HCP got involved in patients care he had 3 admissions to hospital and he was at the end of his life - patient later died in a hospice - so he was utilizing the community services at the very end of life - would an earlier referral of services help improve the quality of life for this patient at the end of life? **"He was only home a few days before he was readmitted with sepsis, I think from what it says here he self-discharged...and he was admitted at the QE actually after that about 5 weeks later with spinal cord depression...he came into a hospice" (14)**
(28) SENIOR NURSE *Not discussed - however did state that patient was acutely unwell and required admission **"It was the right thing for her to be admitted"(11)**	SENIOR NURSE *States that patient was known to community **"She was already known to community palliative care, I must admit I don't think they'd seen her recently but the GP had certainly been out twice and tried oral antibiotics (10)**	SENIOR NURSE *States that patient had a higher frequency of community services but patient rejected it - Also REFUSED a hospice **"They increased her package of care as she was discharged home with district nurse and Macmillan increased. We did offer the hospice but she didn't want the hospice" (12)** *Patient trying to keep her independence **"She was fiercely independent...we actually felt that a short stay in the hospice probably would have been quite beneficial, and we did raise it but she just wouldn't entertain it at all, so we had to go with the increased care package and I think she only allowed us to increase it I think to three times a day from twice a day...she declined, we can but offer (13)**

Why does HCP think they called 999? (Rather than somebody in the community?)	**Has Pt. been referred to the appropriate services?**	**Does HCP believe pt. is accessing services properly?**
(31) STUDENT NURSE *Not discussed	*YES patient has been referred to services but refused them. **I: "And you don't have any nurses coming in to see you or..?" "No, that was offered to me especially, when the realisation that I'd got lung cancer, they went through a whole splurge" (4)**	STUDENT NURSE *Does not comment on this during interview
(33) PALLIATIVE NURSE * Community support had been accessed. Patient called the Palliative Care Nurse to instruct the District nurse to visit with oxygen and pain relief "**He was struggling to breathe and he wanted some oxygen, so we arranged for some home oxygen to be sorted and got the district nurse in. And it was his breathlessness really that was the problem, he was seen by the GP...his wife told me he's had two very bad mornings, the one morning he woke up, he was in terrible pain and she rang for the paramedics who came out gave him some oxygen and gave him his painkillers and stayed with him until he settled. The following morning the same again basically, he was really poorly, she said he was very very hot and she rang for the paramedics and they took him" (2)**	*GP *MACMILLIAN DOCTORS *DISTRICT NURSE *MACMILLIAN NURSE *PATIENT TRANSPORT *CLINICAL NURSE SPECIALIST *MARIE CURIE CENTRE	PALLIATIVE NURSE *MAYBE - In the past talks about patient not using services appropriately but believes this admission the patient and his family did the right thing **"And [wife], acknowledged that she does tend to panic and that she would dial 999 if she was really worried. And we've had lots and lots of discussions about who to call, to call the GP or call the district nurse in the first instance. But I think on reflection I think she did the right thing that morning by dialling 999, and getting the paramedics out and getting him admitted to hospital" (8)** *Goes on to say that patient feels safe in hospital **"And I think as well for [name], he always feels very safe in hospital, I think, and we've had a conversation about that about how sometimes you do feel safe when they're surrounded by doctors and nurses who know what they are doing and when you're at home and you're feeling unwell then, I can understand why you pick up the phone and call for an ambulance, because you know at hospital there are people who can look after you" (9)**

Does pt. think they have access to specialist services?	**Does HCP think they could have done anything to prevent an emergency admission?**	**Does pt. think admission could have been avoided?**	**Does family think admission could have been avoided?**
(03) * _YES_ - Patient feels well equipped **"I've got everything actually, I've got a chair lift, scooter, walk in shower" (20)** *Patient feels well supported **"I've had District Nurses, Deputy Matrons, Rapid Response (21)** *In Post discharge interview patient admits to having to call DRS for OT assessment **"I don't want none of these side rails but I'm going to have them to put your mind and Peter's [SON] at rest" (23)** *Seems like patient has been offered lots of services but until now has refused some. #assisted technology (26) #FAB (19) #Smoking cessation (27) #Community matron "**Why would I want a visit from the community matron?" (28)**	RESP CNS 1 *_YES_ - If the telephone number for the DN's and Community matrons was different the patient might have been prevented an admission? *Community telemetry - patient now has this in place **"the one thing he has agreed to, which he wasn't keen on before, was to have the community telemetry, to monitor his observations at home. He wasn't keen on that before, but I think we're looking at a different tact and looking at his safety and what's important to him…the community matron can respond herself or with an ambulance, depending on his oxygen levels, he'll realise the importance for him, that. To whether he actually needs to come into hospital or not" (25)** RESP CNS 2 *_NO_ -Unwillingness to access **"He doesn't like to contact her [community matron] (18)** CCM * _YES_ Assisted technology (monitoring) **"The community COPD nurses...get in contact quite regularly. We asked him whether he would have a monitoring system called assisted technology back in place, but he's declined that service. When I first met him he had it"**	*_MAYBE?_ If he'd called community matron earlier and not left it to the point of desperation (9) *Community Services unavailable **"They don't respond like they should" (29)** [Talking about the community matrons]. **" I phoned up once when I was in trouble and she was on leave...you can panic a bit, you can't help it" "She's a lovely person but she always seems to be on leave" (30)**	*_MAYBE?_ Patient would prefer to call 999 even though has good contact with GP **"He's even come over to the house unannounced hasn't he, just how you are keeping like, they're alright aren't they [yeah]" I: "So if you needed him, do you feel you could ring and get an appointment straight away?" "Oh yeah, they'd come out" I:"But in preference, if you were struggling with your breath you would just ring 999? "I would yeah, yeah" (31)** Patient states that the community team would help him, but if he thought he needed hospital - 999 was the quickest way **"and they come straight out don't they [yeah], they're great people" (33)**

Does pt. think they have access to specialist services?	**Does HCP think they could have done anything to prevent an emergency admission?**	**Does pt. think admission could have been avoided?**	**Does family think admission could have been avoided?**
(08)* *NO* - patient dissatisfied with community health care services **"There's only one trouble. I'm bloody annoyed I've had to pay for everything I've got. Bought my own wheelchair. My own stair lift. My own walk in shower, a new bed, they haven't given me a bit of help at all" (5)***Not sure whether the DN patient refers to is the CCM interviewed? **"Only the one woman [name] a district nurse, she comes in about once a month. And she was testing my oxygen and that. She was a lovely person. But that was the only time… once a month" (4)**	**NO* - CCM thinks that admission could NOT have been avoided **"No not for this one as I say there was no mention of any respiratory changes what so ever and especially seeing the GP the day before" (10)**	**NO* **I: Did you need to come into hospital? "Oh yes. Yes. Oh yeah. Yeah. I might not have been here if I hadn't have come into be honest with you" (12)** *Post discharge interview patient still believes hospital was right **"I was lucky to be bloody well alive they brought me round" (13)**	**YES daughter suggests that patient should still have been admitted but thinks it should have been done earlier.* **"Yes. If her own GP that came out when she had the fall, and realised that she wasn't somebody who had COPD, she would have been admitted something, she eventually came to her at 4o clock she ended up in hospital at 11o'clock, So there's like a seven hour gap...and she may not have gone unconscious so where CPR and everything had to be administered" (11)**
(09) **YES* - **"I'm looked after quite well" I: You think you've got enough help and support?" "Mmm" (13) I:"Do you feel there is anything missing at the moment?" " Not at the moment because the wife helps me a lot" (14)** *Sees community team regularly **"Sometimes weekly, sometimes two weeks, it depends, with phone calls, are we alright" (15)**	**NO - both HCP interviewed for this patient believed that admission to hospital was necessary for this patient* RESP NURSE *Patient is gradually deteriorating and needed admission **"when he's been in, he's required NIV each admission, so the last couple of times it's taken us longer to wean him off the NIV" (8).**	**NO*	*NO FAMILY INTERVIEW

Does pt. think they have access to specialist services?	**Does HCP think they could have done anything to prevent an emergency admission?**	**Does pt. think admission could have been avoided?**	**Does family think admission could have been avoided?**
(10) *YES - Patient comments that she has a respiratory nurse and they would come out to her when she asked* **"I've got a respiratory nurse" (5) I: They would come out, the same day "Yes yes yes" (6)**	* *NO* -RESP NURSE Patient's admission was a surprise to respiratory nurses **"We were surprised by [name] admission because when Dena saw her, she [patient] was all set to go on the ring and ride to go out shopping, feeling much better she felt and then that evening she ended up going into hospital"(4)** *Also stated that assistant had given advice on the phone **"The healthcare assistant that works with me, she went out see, gave advice" (12)**	NO - Patient felt admission was required as she couldn't get her breath. **I: "Do you feel you needed to come into hospital?" "Oh yes, yes, I really did. Well I just couldn't get my breath are all, and of course you don't know what to do…I thought 'well I can't go to bed like this', I just couldn't breathe at all" (11)**	*NO FAMILY INTERVIEW
(01) * *MAYBE?* **- I: "Because you currently don't have any help at home do you" "No no no, we never have" (14) I: "Do you think the problems with your breathing and not feeling particularly well. Do you think it had anything to do with you not having any help at home?" "Oh no, I've had help all the way through" I: "So that's off the family?" "Well, oh year, and the doctors...the doctors been great" (15)**	* *NO - PHYSIO interviewed could not have prevented admission however she did comment* **I: "So you think it was right that he came into the hospital?" "Oh yeah" I: "It wasn't something that could have been handled in the community?" " No I don't think so because he was having community input anyway from the Macmillan nurses...He's has this diagnosis for over a year I think in his lung cancer; so they've had input but whatever happened just tipped it over the edge it couldn't be sorted in the community, so he's come in. But they will always try and sort things out in the community, just as we will try and get them back out as soon as we can" (12)**	*NO - Patient doesn't answer this question but states that his daughter called the ambulance as she was worried **"Well, she was worried" (16)**	NO FAMILY INTERVIEW

Does pt. think they have access to specialist services?	**Does HCP think they could have done anything to prevent an emergency admission?**	**Does pt. think admission could have been avoided?**	**Does family think admission could have been avoided?**
(16) *HCP NOT INVOLVED PRE ADMISSION	NO - patient felt admission was required. **I: "Did you feel that you needed to come into hospital?" "Oh well, I needed to come in, because, although you've got district nurses and that there, they can't do everything" (7)**	NO - patient felt admission was required. **I: "Did you feel that you needed to come into hospital?" "Oh well, I needed to come in, because, although you've got district nurses and that there, they can't do everything" (7)**	NO FAMILY INTERVIEW

Does pt. think they have access to specialist services?	**Does HCP think they could have done anything to prevent an emergency admission?**	**Does pt. think admission could have been avoided?**	**Does family think admission could have been avoided?**
(22)*Patient has Macmillan and District nurse involvement - however at the start of the referral there seemed to be some confusion on who to call WIFE **"I've lost the name of the one that kept ringing you up; she was trying to get his pain under control, but the trouble is, when your under Solihull, this hospital [named], you don't know who to turn to. In the end, we thought 'it's easier to go to our own doctor and let our own doctor prescribe the pain drugs, so that's what happened at the end of the day (5)** *Wife also states that she thinks patient may not be getting the visits he should do **"The nurse that comes out, she's not due… until February, because when they come to the house and they see how well he is, they think, well they've got patients who are desperate for care. Then there's the other one, she came out once to assess him and then we hadn't seen her again, I phoned up a few times, but she never returned my calls. I'd phone her on a Tuesday and say [names] still in pain, is there anything you can do? 'I'll get in touch with the doctor and phone you back' and she never used to phone back.(6)**	PALLIATIVE NURSE*Was not involved in patient care prior to this admission - had spoken to the family but had not visited yet - when she did visit the patient had already been admitted (14) * Believed patient required an admission because he needed his bloods doing and it was too late in the day for them to be done in the community **"it was probably the best place for him to be honest, there was no way he was going to have bloods done in the community at that time of day, so it was the best place for him really, it was appropriate for him to be admitted (12)** *Later said that **"I think if we can't get medical review either from the GP or from the hospice medical team themselves, and I think trying to get bloods done as quickly as well can be difficult to rule out, sort of calcium levels and things like that can often be quite difficult, if you miss the morning slot to get them up to hospital on time...They've got to be done in the morning then get the GP so they can be sent off in the afternoon, so anything after lunchtime it can be difficult to get bloods done unfortunately (13)**	*As previously mentioned - Patient or Wife did not call 999, they called the GP who arranged a visit from Macmillan who made the decision to admit. Decision was taken out of patient and families hands. **I: "So did those nurses ring the hospital for you then?** WIFE **"Yes, they phoned for the ambulance" (4)**	*Wife and Patient interview completed together.

Does pt. think they have access to specialist services?	**Does HCP think they could have done anything to prevent an emergency admission?**	**Does pt. think admission could have been avoided?**	**Does family think admission could have been avoided?**
(28) *Patient has Macmillan involvement everyday **"Yeah, cos the carers come in every night anyhow, one of a night and one of a morning" (6)** *Home is well equipped **I: "Was the bed recommended to you then?" " Macmillan's year, I've got a bed, I've got a wheelchair, I've got my frame, Got my two sticks and I've got a commode, but I don't like using that" (14)** *Patient is visited by the GP **I: Do you see your GP often?" " Oh yes , they come in every week" (17)**	STAFF NURSE *could not have prevent admission and does not know whether community teams could have either **I: Do you think she could have been managed as effetely in the community or in a hospice bed?" "I really don't know, no [laughter]" (16)** SENIOR NURSE *No thinks admission was necessary **" So in my mind it was the right thing for her to be admitted, she needed...and I think we...she needed every chance to try and respond and get [yes] cos she had a potentially reversible problem, i.e. the chest infection" (11)**	*Patient does not comment on alternatives to 999 **"I was on me own, and I had these terrible pains in the chest, so I phoned [daughter] and she brought me up here, and I haven't been out since" (2)**	NO FAMILY INTERVIEW
(31) *As previously mentioned patient feels he was offered lots of relevant services, especially when cancer was diagnosed but he refused them all.	STUDENT NURSE *Would not have the capacity to prevent admission as a student nurse working on the ward. Student Nurse would not have known patient previous to his admission.	*As previously mentioned patient did try to avoid admission by putting it off after instruction to go into hospital by the GP, but realised this was a mistake and called his son who drove him to A&E	NO FAMILY INTERVIEW

Does pt. think they have access to specialist services?	**Does HCP think they could have done anything to prevent an emergency admission?**	**Does pt. think admission could have been avoided?**	**Does family think admission could have been avoided?**
(33) *Patient states that the Macmillan nurse is most influential in his care. **"The Macmillan nurse" "She [name] certainly gets things going, I mean the doctors wonderful, but you know she's very good". (10)** *WIFE talks about previous use of patient transport facilities **"That's when he has to have lifts like the transport, but they're very good, you phone them up, and they do their best to do it" (11)**	PALLIATIVE NURSE *As previously mentioned patient was involved in community resources before the admission and made the right call in the end as an admittance to A&E was deemed necessary (8) (9)	*NO - As patient and wife were interviewed together their comment on the question are joined ->	*WIFE -NO - thought that an admission to hospital was required. **I: Did you need to go into hospital?" "Oh yes, yes" "She said [the Dr?]'just in time' he did it just in time, she said 'yes we did the right thing'" "They wouldn't have kept me in, because they kept me in, it must have been... something serious like otherwise they wouldn't have had me in for five days or whatever it was" "Yes, we often think, well you know, when I phone up the ambulance, is this really necessary, But you know, it has been so...basically [husband] or I will make a decision, if you understand what I mean...so we say hold on, hold on, hold on and then..." "She says I can't do no more now, do you want us to carry on or would you like to go to hospital...so they gave me a choice" "They don't like to if it's not necessary, if you know what I mean?(12)**

Any changes in practice HCP would like to see?	**Any changes in practice pt. would like to see?**	**Any changes in practice family would like to see?**	**Comments**
(03) RESP CNS 1 *Different contact number for the District Nurses and Community matrons - Emergency hotline? **"They don't have the direct line telephone numbers [for the community matrons], and we do know that the single number that everyone uses is also the referral line, it's used for both District Nurses and Community Matrons, and we get many patients that will ring us and say 'can you get hold of such and such a matron, because I've been trying to get hold of her all day and can't get through" (12)** *Weekend and overnight service **"Those who live on their own, become very anxious at night. They're in the dark, they're breathless anyway, no matter whether its anxiety or it’s an episode where they just can’t get their breath...we have most COPD admissions, come in overnight, over a weekend and over a night, and personally I would love to see a telephone service with even a carer or somebody able to , not necessarily a night sitter, but a bit of a response, that either they could talk them through their breathlessness episode or somebody that could just nip out and 'are you ok'? (35)** RESP CNS 2 *Education of identification of early symptoms **"instead of contacting her[community matron] when he starts to become ill, he waits for a few days, will become worse and then ring for an ambulance" (18)** CCM *Anxiety management and recognition of early deterioration a bit sooner **" A big part of Mr [name's] care, from my input has been anxiety management and trying to help him cope with his condition and recognise early deterioration a bit sooner"** (3) *GP Liaison service **"I did speak to the GP to say the importance of us trying not to send him straight into hospital, if he ever contacted the GP, whether they can contact me because it's much easier for me or my colleagues to be able to go and spend a good hour with him, whereas the GP are obviously far more restrictive with their time" (38)** *Break Routines **"he's had a pattern of behaviour for so long where he would go into hospital, that that's reassuring for him, because he feels then he knows the staff and things like that. So it's very much a battle, to try and break that routine with him" (14)**	*Only change relates to being in hospital and the answering of the buzzer **"they will not respond to that bell you could die and I told them" (41)**	NONE STATED	_* CCM was on holiday at the time of patient’s admittance. *Patient suggested that the RESP CNS was the most influential_ **"I've known her for over four years now" (22)** _*CCM suggested that if patient engaged in all services offered e.g. FAB he may reduce his emergency admissions (19)_

Any changes in practice <u>HCP</u> would like to see?	**Any changes in practice <u>pt.</u> would like to see?**	**Any changes in practice <u>family</u> would like to see?**	**Comments**
(08)*Be informed when patient goes into hospital **"Sometimes we don't know that they've gone into hospital…which I think was the case with her. We often don't know until we go and visit someone again…we don't automatically get told, which is such a shame" (14)** *Patient Education **I:"from what you're saying, the patient education is really" "A biggie, absolutely, absolutely"** to ensure inappropriate phone calls aren't made, but if they are then patient gets advice to be better informed **"Once they have the number, they ring inappropriately, you know you get loads of phone calls and they aren't necessary and then you get the patients that just would never use it...some people are afraid to use it...it doesn't matter really, it's better to get the advice. Then through that they learn" (15)**	NONE STATED	*Blister Packs **"They have made things a bit better for her at home: her tablets are now on blister packs. They think she might have been confused taking them" (17)** *Commode **"They've supplied her with a commode upstairs because she's got a toilet downstairs" (18)** *Lack of communication needs to be improved (mainly talks about hospital communication) **"It's the lack of communication between all of them and with the patient you know, their family, that is the biggest problem with, you know the ward...Mums very forgetful as it is so you tell Mum one thing, by the time we've got up here she's got confused and she's telling me they've said this and that... well if you perhaps pulled one of us two [brother and sister] aside and told us - that's what they need to perhaps be doing" (19)**	**CCM managed to keep patient in the community out of hospital for a year (so something was obviously working correctly) <u>*Family was on holiday at the time of admission</u> *HCP's thinks admission could not have been prevented - GP saw patient the day before and there was no respiratory concerns *Family thinks admission could have been earlier but agreed that admission was necessary *Patient seems to have everything in place and is well supported by community but feels bitter that she had to pay with thing with her own money e.g. stair-lift etc.*

Any changes in practice HCP would like to see?	**Any changes in practice pt. would like to see?**	**Any changes in practice family would like to see?**	**Comments**
(09) RESP NURSE *Equal access to hospice and respite services for patients who have COPD as opposed to lung cancer **"The community matron…had twice referred him for respite with the hospice…nothing ever materialised. And I know… that's one of the things she's feels let down by. Because that - she knows that if her patient has lung cancer, then he would have gone in...But the fact in terms of COPD, she doesn't know why" (17)** *Improved communication between the hospital and the District Nurses **"I think what the matron actually wanted was a settle visit...she was telephoned and yet he hadn't been visited by the district nurses. She's asked for that. But they'd [district nurses] liaised with the ward, and they- whether it's because they didn't know fully about his condition, they were thinking for pressure area care he didn't need a visit until Sunday. But he didn't get one" (18)** *Resources to be equal between lung cancer patients and COPD patients **"I think If you have a cancer diagnosis, then I think you're very well supported. But I think people have a little bit more difficulty with palliative patients that have a non-cancer diagnosis, but is a deteriorating condition, long term, and especially when they reach that end of life, and of course with COPD patients, they have the same type of symptoms that cancer patients have in terms of their breathing, pain, anxiety, the emotional side. BUT the resources aren't available to address that, and especially in terms of, I don't actually think there's enough palliative care beds. I think that maybe what the issue is, but it's also about the clinicians identifying that and initiating discussions and having the support available, I think that's where are gaps are, for someone as end stage as this gentleman" (21)"**	NONE STATED	*NO FAMILY INTERVIEW	*When reading the patient interview, it seems patient does not engage with services, just calls 999 and bypasses community services and GP. However as CCM explains the pt. was not well on the day of the interview - may explain why we see conflicting reports. *CCM* **"people don't do much with these patients because COPD is not very sexy" (25)** **CCM was on holiday at the time of admission *All involved in patients care including the patient thinks that hospital admission was necessary*

Any changes in practice <u>HCP</u> would like to see?	**Any changes in practice <u>pt.</u> would like to see?**	**Any changes in practice <u>family</u> would like to see?**	**Comments**
<u>(10)</u> <u>RESP NURSE</u> * Mechanisms needed for informing HCP's that patients are in hospital **"I would have gone and visited her, discussed with the doctors and respiratory nurses there if we could get her home earlier, and we would have gone in and seen her on a daily basis" (13)** There are two ways this is currently done - by the COPD outreach team **"would notify me of any [name of her patch] that are in" (14)** and secondly by attending hospital herself **"I tend to go in, I try to go in two to three times a week...to try to find...which COPD patients are in" (15)** Or sometimes relatives will phone **"Sometimes a relative will phone and say so and so has gone in and then I'd be in" (16) "But ideally you'd like to pick them up and see what can be done to get people out much sooner than they were" (17)** *Improved communication for patients with COPD **"With cancer, you've had a diagnosis of cancer, they have got time to get used to it. Everybody knows that if you have a diagnosis of cancer, that the outcome might not always be one of survival" I: "yes yes, and yet that is not such common knowledge to all in COPD" "No it's not and, we do try and cover palliative care and NIV...and some patients find that we do give them a health warning. We are going to be talking about end of life and palliative care, and some patients do get up and walk out because they know that they can't face at the time" (18)** * Out of hours service should be established **"Things like our service anyway works Monday to Friday, nine till five, and the number of patients, I've got with the anxiety element, it always seems to be out of those hours" (19) "We are a safety net, I know, because I'll say don't leave it until four o'clock, phone me in the morning, at least then I can get out and visit you. Because there's certain things that we can put in to prevent admission (21)**	NONE STATED	*NO FAMILY INTERVIEW	*<u>*RESP NURSE was on holiday at the time of admission*</u> **Ambulance offered patient the choice of attending A&E* **Patient cares for her husband - he has 3x carers a day and they have a cleaner*

Any changes in practice <u>HCP</u> would like to see?	**Any changes in practice <u>pt.</u> would like to see?**	**Any changes in practice <u>family</u> would like to see?**	**Comments**
<u>(01)</u> <u>PHYSIO</u> * Improved communication with family members of patients **"It's always worth saying…what's always worth talking to the relatives, I think within the elderly group of patients, you often get a different story form the patient that you'd get from the family because either through dementia, confusion, just a lack of awareness...I would never just take the patients word for it, I would always either phone the family or wait for them to come and confirm the situation" (17)**	*Only comments relates to hospital staff **" I think it could be improved with, if they…like if you ask for a bottle, or a toilet and they, well I wouldn't say they don't come but they don't come straightaway 'all right now wait a minute, now don't get. They've got other people to see too" (18)**	*NO FAMILY INTERVIEW	*<u>*GP was on holiday at some point during the patient's admission to hospital.</u>* **Difficult to derive answers from this of interviews - no community HCP or family were interviewed and patient died 20 days after initial interview* **Patient stated his GP had been most influential in his care*

Any changes in practice <u>HCP</u> would like to see?	**Any changes in practice <u>pt.</u> would like to see?**	**Any changes in practice <u>family</u> would like to see?**	**Comments**
<u>(16)</u> <u>DISTRICT NURSE</u>*Nothing mentioned specifically, however does talk about her case load being about 400 **I: "Approximately how big is your caseload?" "Probably about 400…at the moment I'm the only district nurse in this team because our team leader is on maternity leave and we've got a DN vacancy. So I'm the caseload holder for all of those" (12)** *Also talks about not seeing the patients with LC unless their symptoms need management **"...but if they've got no symptoms, we don't actually see them, they see the GP, they come to us once they've got symptoms and need more management really" (13)**	NONE STATED	NO FAMILY INTERVIEW	**Seems patient only got involvement with the district nurses after his admission this was primarily to change dressings on his chest drain and for palliative care *Patient is seen by Marie Curie - but details are not disclosed in interviews *Confusion in awareness of diagnosis?*As patient had no health care professional input (apart from his GP) there were no alternatives to calling 999 when in crisis *In comparison to the COPD patients looked at this patient has far less community input involved in his care.*

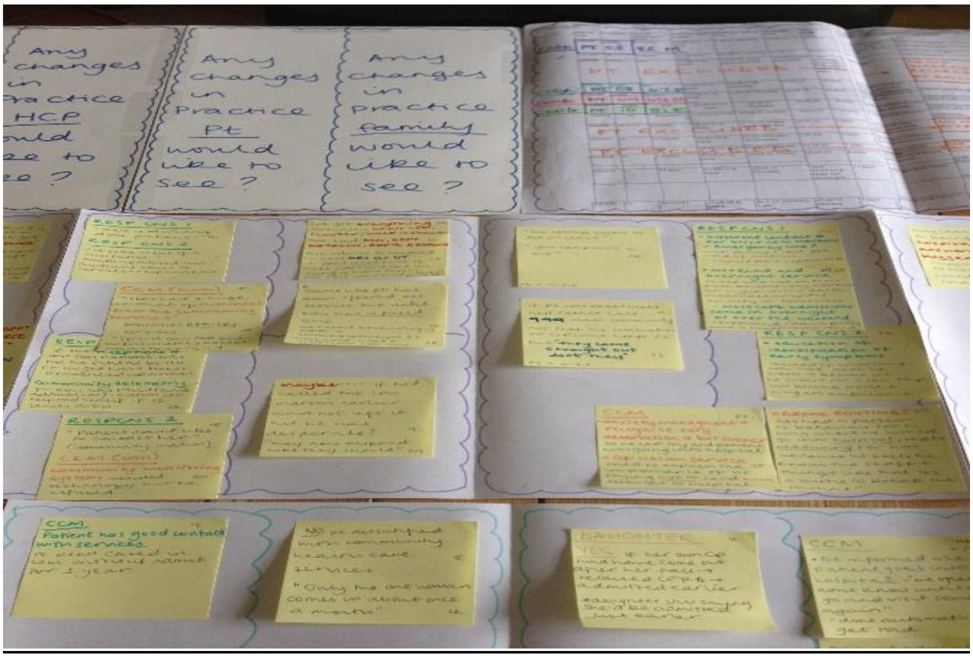
Any changes in practice HCP would like to see?	**Any changes in practice pt. would like to see?**	**Any changes in practice family would like to see?**	**Comments**
(22) PALIATIVE NURSE *Blood collection in the afternoon from GP practices could prevent admission for patients who just require their bloods taken and have missed the morning slot **"I think if we can't get medical review either from the GP or from the hospice medical team themselves, and I think trying to get bloods done as quickly as well can be difficult to rule out, sort of calcium levels and things like that can often be quite difficult, if you miss the morning slot to get them up to hospital on time...They've got to be done in the morning then get the GP so they can be sent off in the afternoon, so anything after lunchtime it can be difficult to get bloods done unfortunately (13)**	*Patient and Wife interview completed together ->	WIFE *Thinks there should be better communication between services - When patient had been admitted - they had a nurse turn up at the house **"She came knocking on the door Saturday morning, I said 'He's not here, he's in hospital, I said Do you not have any communication between your people that are in your offices and yourself, rather than you have a wasted journey here" (7)** *Better weekend service - unhappy with Badger service - Badger Dr came out unprepared for visit **"I said 'Well it's a good job he's not in cardiac arrest then cos he'd be dead wouldn't he waiting" (8)** *Thinks the idea of bypassing A&E is brilliant **"I think the idea of this unit [MAU] if there is an emergency for instance, that you bypass A&E, that's brilliant isn't it...Because you can be sitting in A&E triage for ages, but knowing that you're going onto a ward...is a good side of it really (9)**	**Seems patient was involved with community services as soon as cancer was diagnosed - however it seem as patient was relatively well at the time - visits were decreased - the community palliative care nurse only got involved at the very end of this patients life * However Marie curie, Macmillan and the district nurses were all mentioned during the patients interview*Wife does speak on behalf of patient a lot in this interview - but patient was present during interview so could have interjected *Patient had been struggling with pain*

Any changes in practice HCP would like to see?	**Any changes in practice pt. would like to see?**	**Any changes in practice family would like to see?**	**Comments**
(28) SENIOR NURSE *Education about palliative care services **"A lot of people equate community palliative care nurse with dying and we actually see the nurse and palliative care nurses see people all the way through their cancer journey, not just at the end but the misconception is that you only see them at the end" (18)** *Referral to District Nurse Services sooner **"Sometimes quiet often district nurses may not be involved, and quite often I'm having to refer, not because they've got specific nursing needs, but it's to start that relationship to get to know them, this patient is going to deteriorate over the next few weeks, they need to have met the district nurse, she needs to have them on her radar, they need to know how to contact her and we often...I do that a lot" (19)** *GP's referring patient correctly to the Gold Standards Framework **" We're always pointing out to the doctors saying can they make sure that people are put on the GSF, you know within the GP setting so that they're clearly aware their palliative, they may have symptom needs, and so they should be being discussed on a monthly basis at the GSF meetings with the district nurse, the GP and their palliative care team" (20)** *IVs and Oxygen for patient at home **"If they could all have IVs at home... if they had oxygen and IV antibiotics at home they mightn't need to come in at all (21)** *Patients needs need to be considered fully by hospital nurses before discharge home **" It amazes me, the number of times I see patients on the wards and I'm saying to the nurse 'Does she need a care package? What about equipment and to me that's not specialist role that's basic common sense" (22)** *Later talks about the knowledge base of newly qualified nurses? How do they learn about the patients' needs in the community (23)	NONE STATED	NO FAMILY INTERVIEW	** Daughter was on holiday* **"I've got plenty to look after me now boss [daughter is back from her honeymoon" I: "Sorry?" "She's been on honeymoon" (1)** **District Nurses only got involved after patient was admitted to hospital *Was known to the community palliative care teams but visits had decreased and patient had not been visited for some time - when questioned patient stated she only had the Macmillan nurses involved in her care *Condition not named - believe patient is aware of her condition*

Any changes in practice <u>HCP</u> would like to see?	**Any changes in practice <u>pt.</u> would like to see?**	**Any changes in practice <u>family</u> would like to see?**	**Comments**
<u>(31)</u> <u>STUDENT NURSE</u> *None suggested in interview	NONE STATED	NO FAMILY INTERVIEW	**Cannot draw much from Student Nurse interview, it is a recollection of events and provides little insight into patients holistic needs. *Seems patient was offered community services, especially after his cancer diagnosis - but patient refused their services - Patient donates money to Macmillan but does not use their services!*

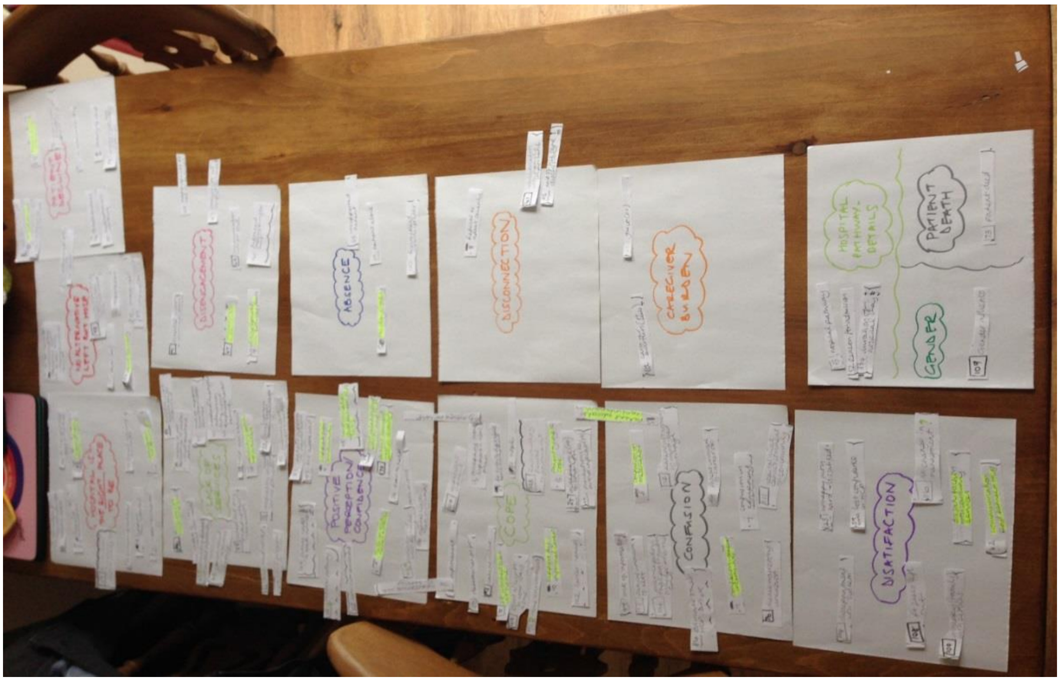
Any changes in practice <u>HCP</u> would like to see?	**Any changes in practice <u>pt.</u> would like to see?**	**Any changes in practice <u>family</u> would like to see?**	**Comments**
(33) PALLIATIVE NURSE *An advice line especially for these patients, especially at the weekend so they wouldn't have to call a generic line for example 'Badger'. Talking about another patient **"One of my lung cancer patients was very breathless and was having a panic attack, his first panic attack, and he always, always said he didn't want to go to hospital, doesn't want to go back to hospital and his wife knew that, so she rang Badger, and Badger doctor said dial 999 and quite often Badger advise that, and she said to the badger doctor 'no my husband doesn't want to go to hospital, I want a doctor here' so they sent out a badger doctor, but it was only because she was very firm in what she said and I think sometimes as well, and I know at the weekends, when we're doing on call badger doctors quite often will say 'oh well just dial 999 and get the paramedics out" (13)**	NONE STATED	WIFE *As previously mentioned wife called 999 due to it being 4 o clock in the morning. If there was a weekend / night advice line would it prevent admissions late at night or during the weekend?	**Patient is aware of his condition and is accepting of his prognosis. Seemed to have good access to services and utilised them well. *As stated Palliative care nurse states wife tends to panic and call 999 but with this admission she did the right thing.*

APPENDX SEVEN - Early Stages of Patient Analysis


Any changes in Practice HCP would like to see?
Any changes in Practice Pt would like to see?
Any changes in practice family would like to see?
CCM
Patient has good contact with services.
DAUGHTER

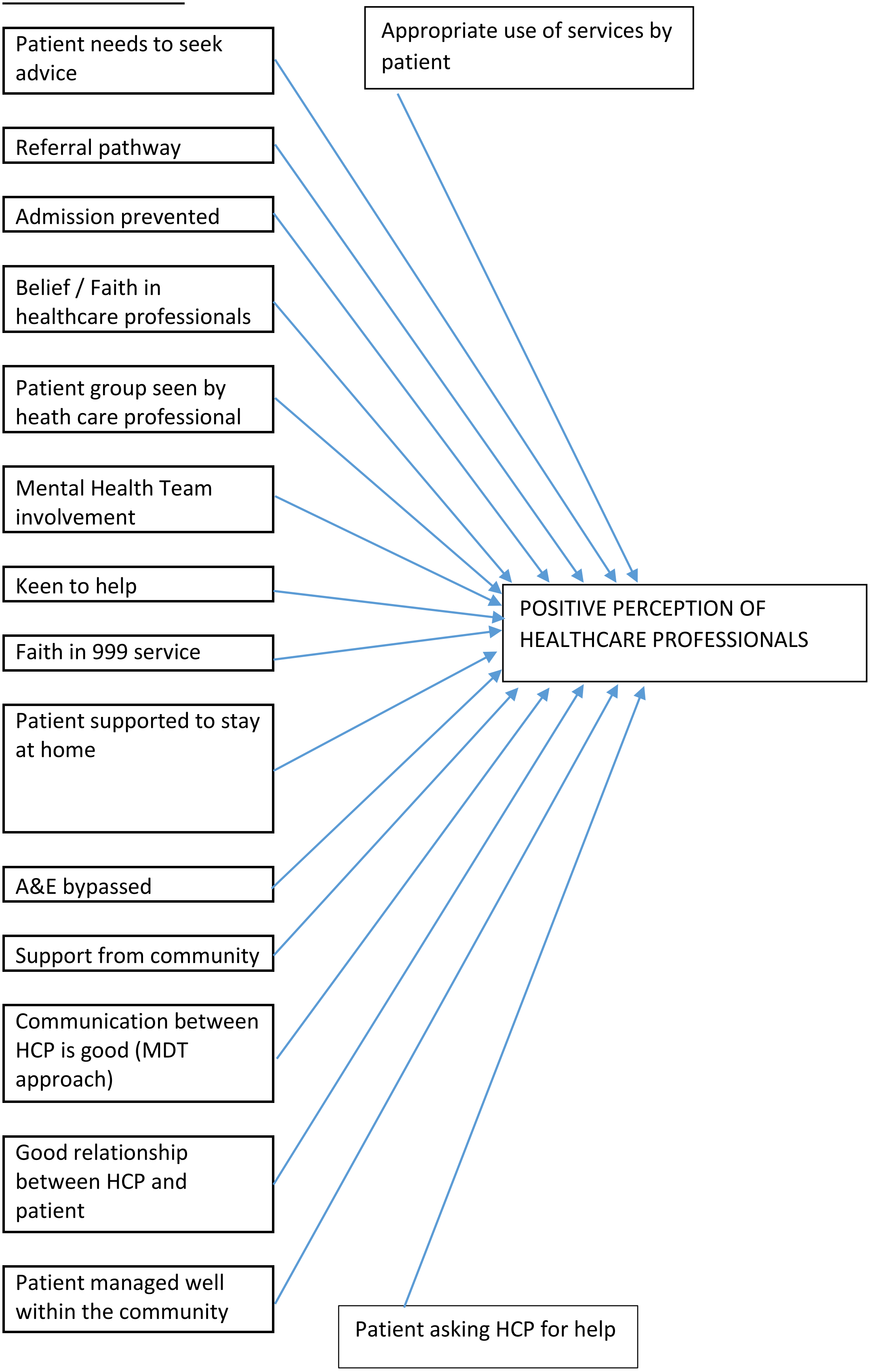

Does HCP believe Pt is accessing services properly?
Does Pt think they have access to specialist services?
Does HCP think they could have done anything to prevent admission?
Does Pt/family think admission could have been avoided?
Does family think admission could have been avoided?
Any changes in Practice HCP would like to see?
Any changes in Practice Pt would like to see?
BREATHLESSNESS
COLLAPSE
SON
999
FALL
FALL (WIFE)
RESP CNS
COLLAPSE
DAUGHTER
FELT WOBBLY
CCM
COPD TEAM

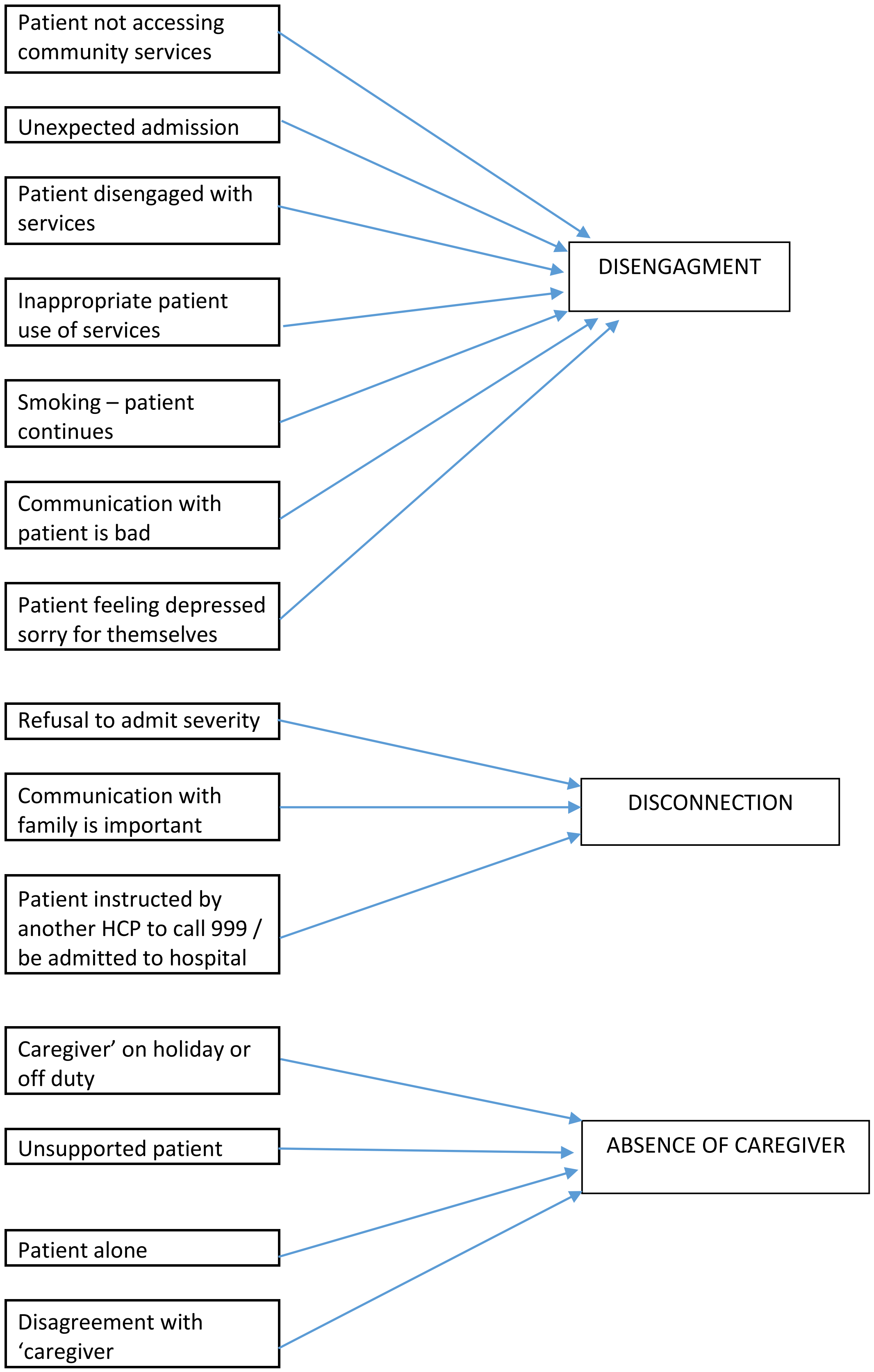
APPENDIX EIGHT - Coding and Theming

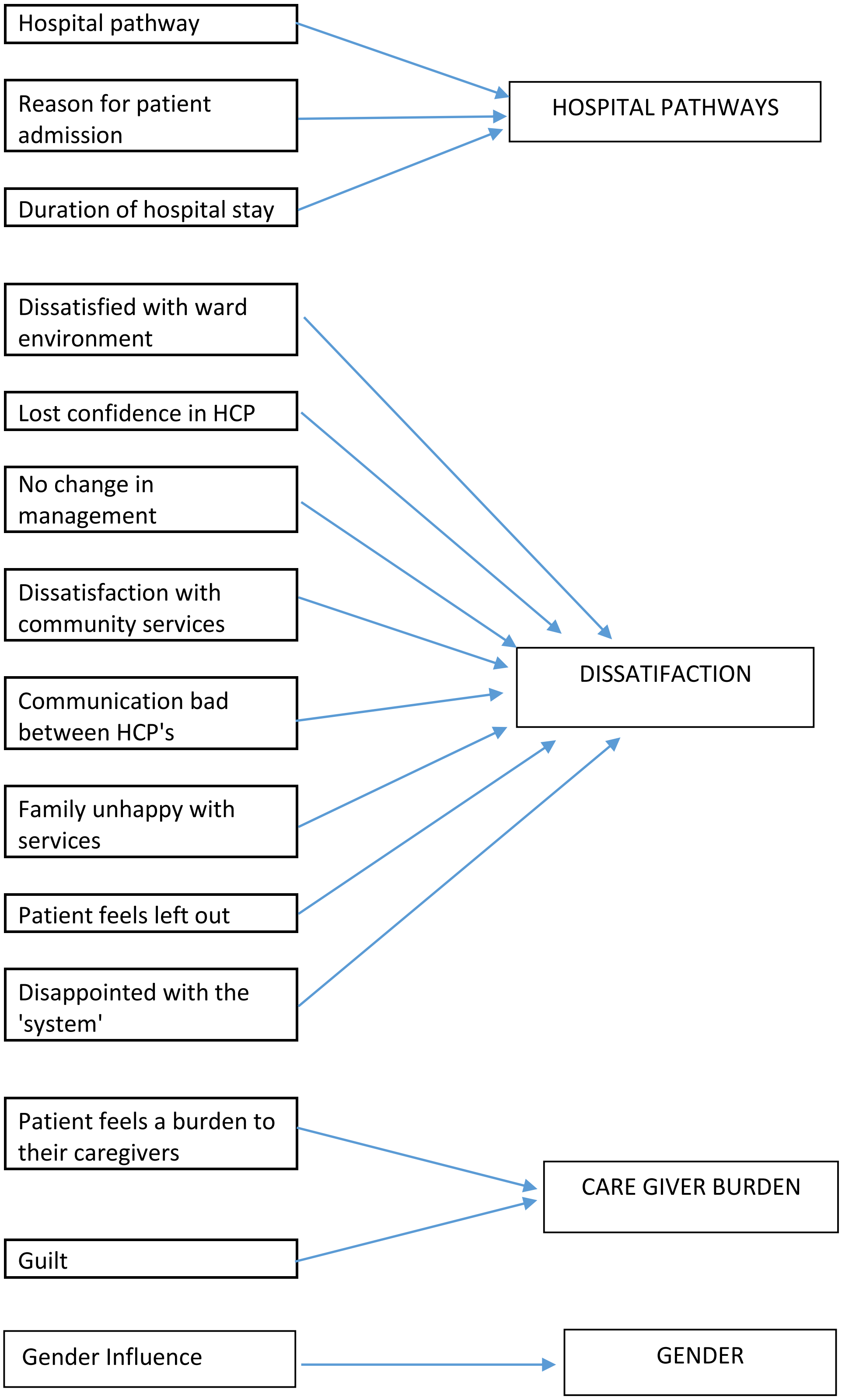


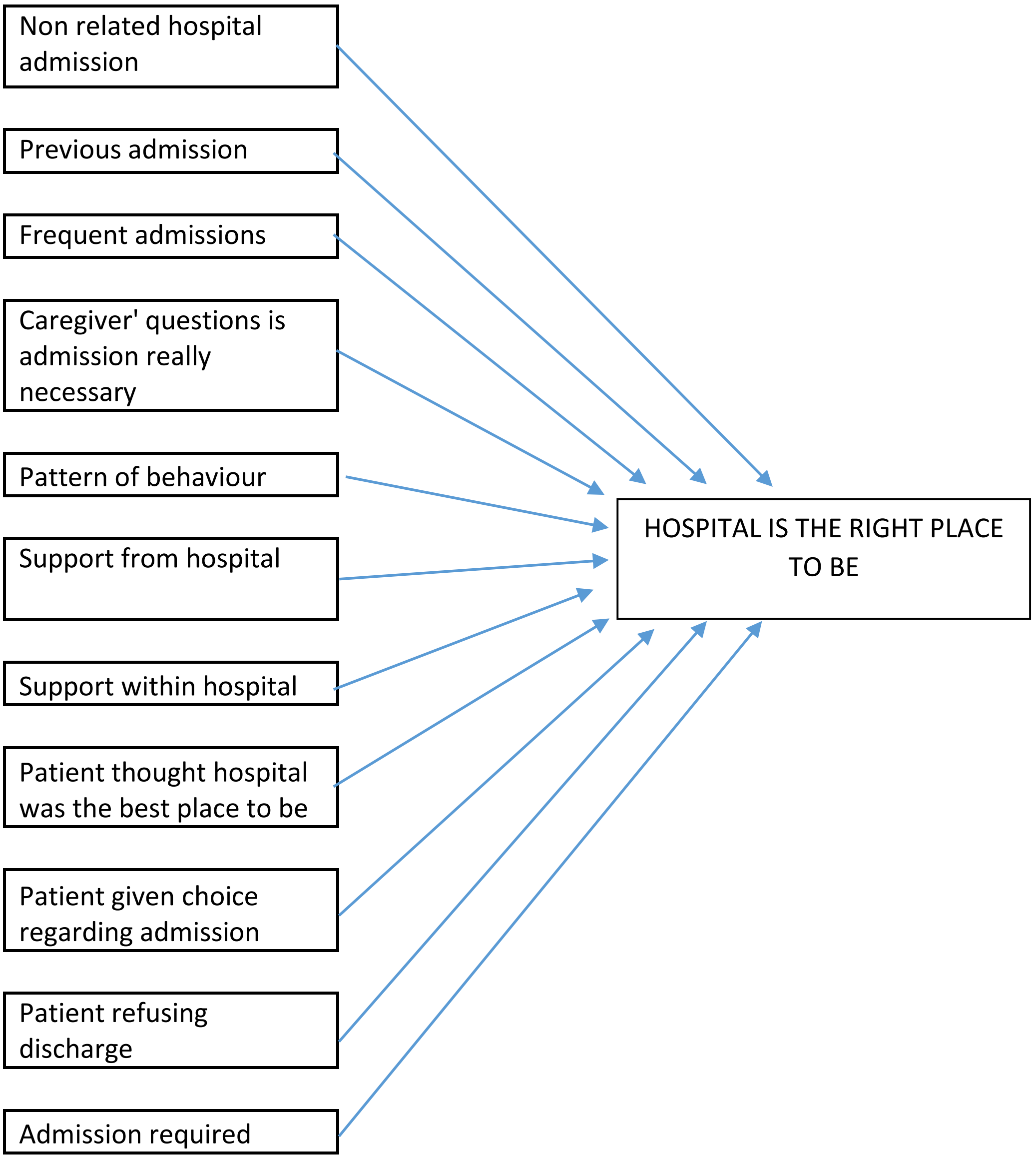
APPENDIX NINE – Nodes, Codes and Themes

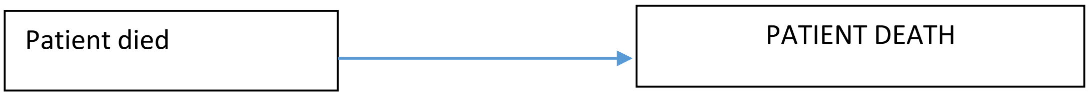
Nodes and Codes

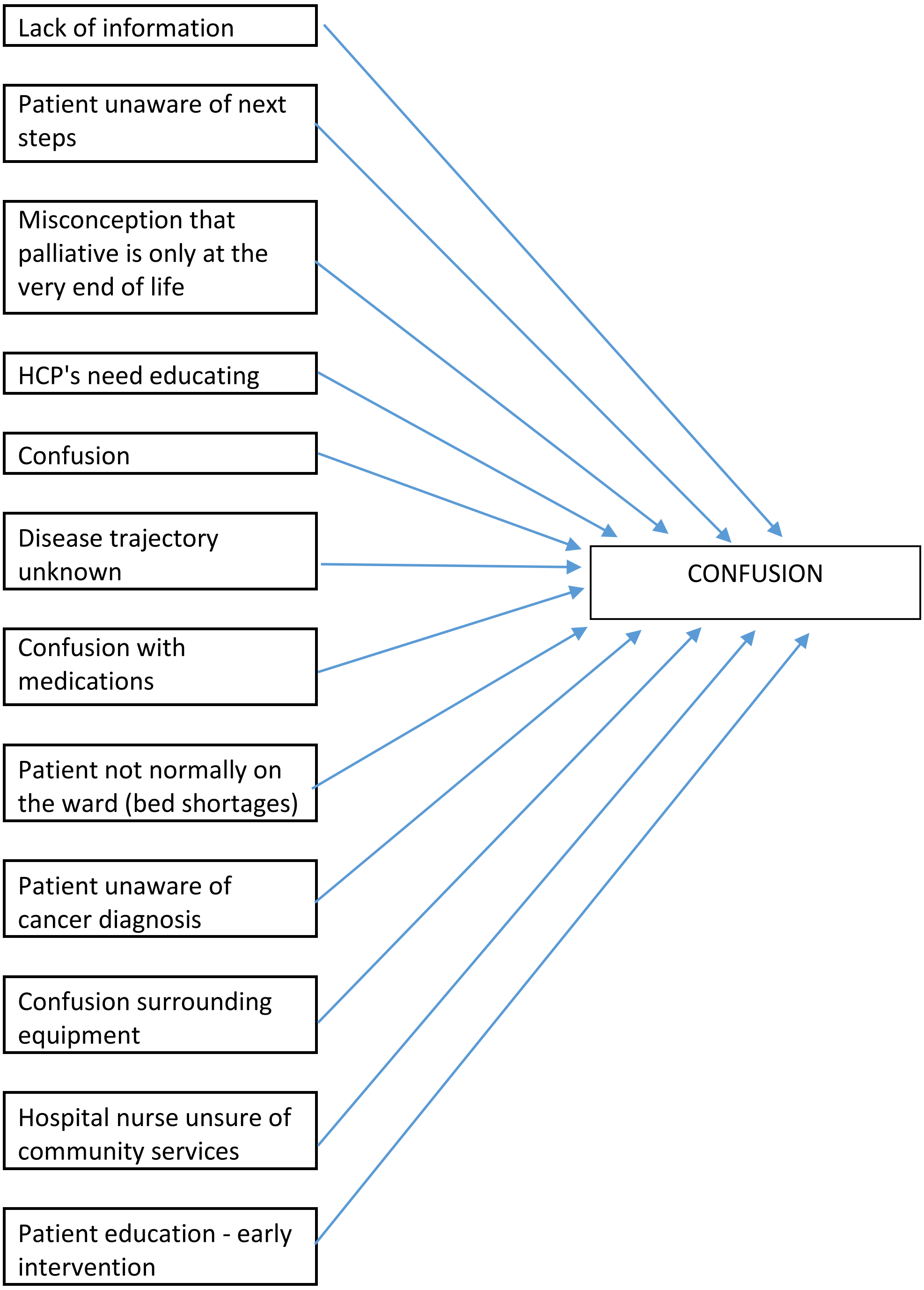


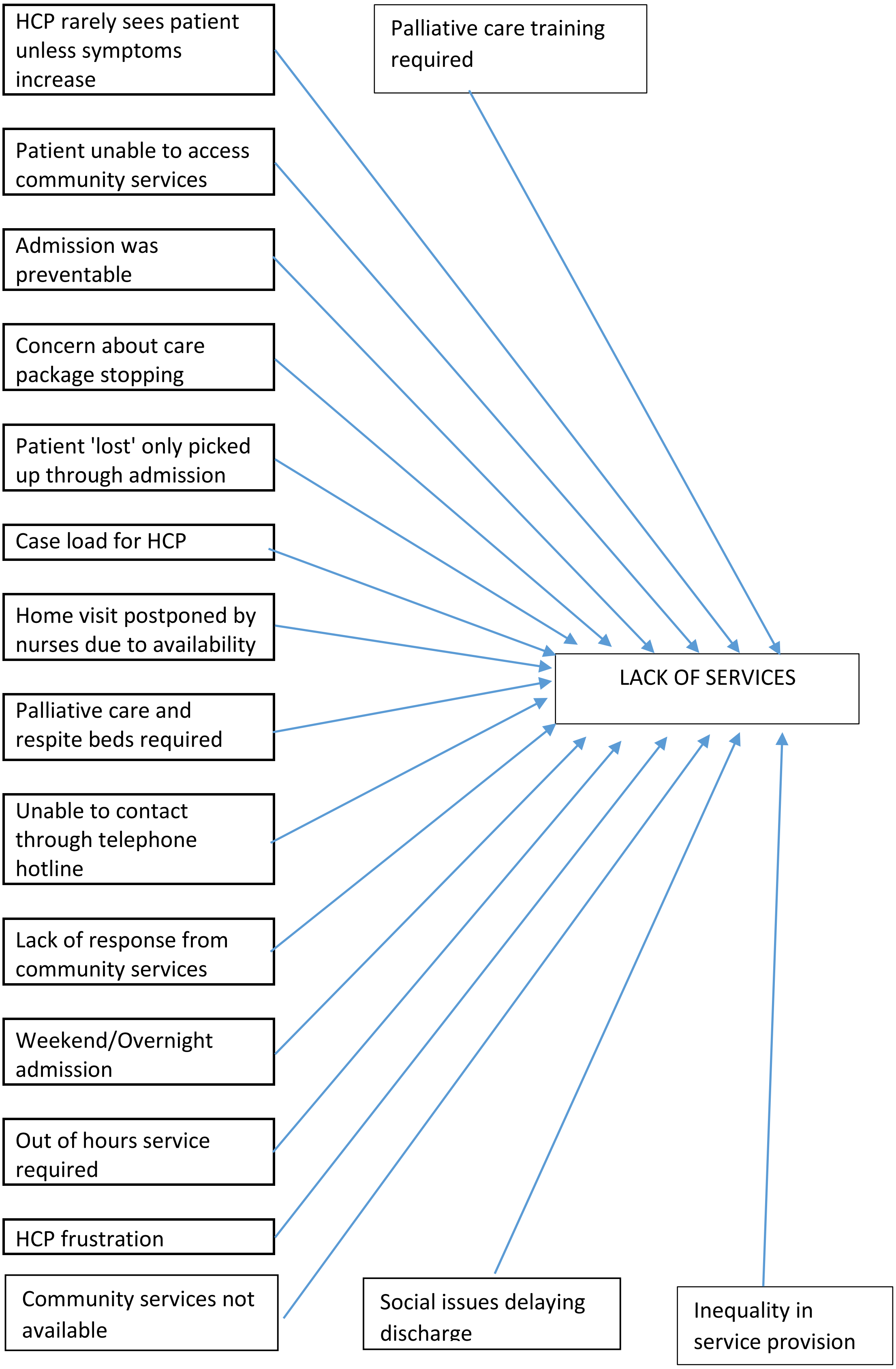

Patient not accessing community services
Unexpected admission
Patient disengaged with services
Inappropriate patient use of services
Smoking – patient continues
Communication with patient is bad
Patient feeling depressed sorry for themselves
DISENGAGMENT
Refusal to admit severity
Communication with family is important
Patient instructed by another HCP to call 999 / be admitted to hospital
DISCONNECTION
Caregiver’ on holiday or off duty
Unsupported patient
Patient alone
Disagreement with ‘caregiver
ABSENCE OF CAREGIVER

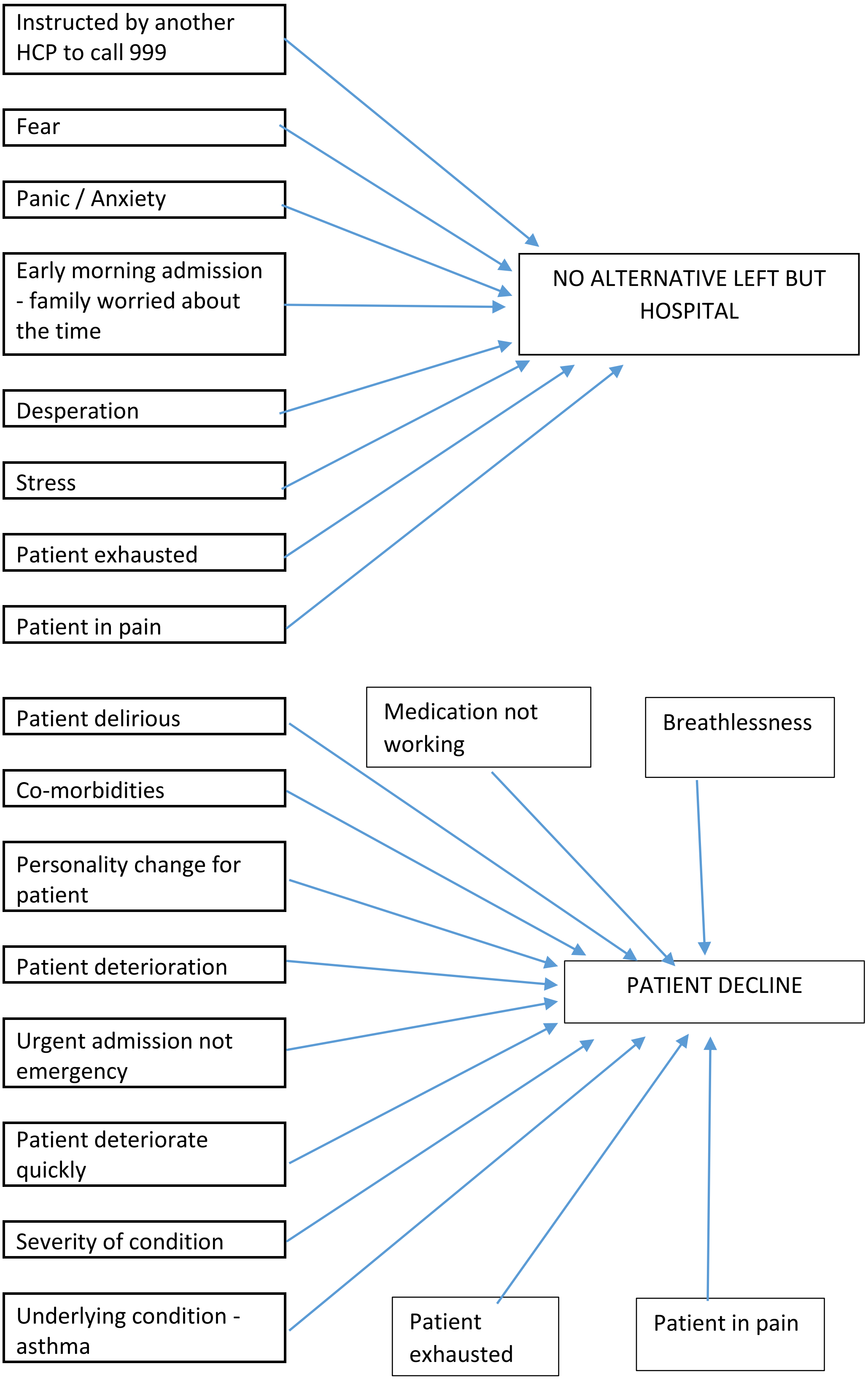

Hospital pathway
Reason for patient admission
Duration of hospital stay
HOSPITAL PATHWAYS
Dissatisfied with ward environment
Lost confidence in HCP
No change in management
Dissatisfaction with community services
Communication bad between HCP's
Family unhappy with services
Patient feels left out
Disappointed with the 'system'
DISSATIFACTION
Patient feels a burden to their caregivers
Guilt
CARE GIVER BURDEN
Gender Influence
GENDER

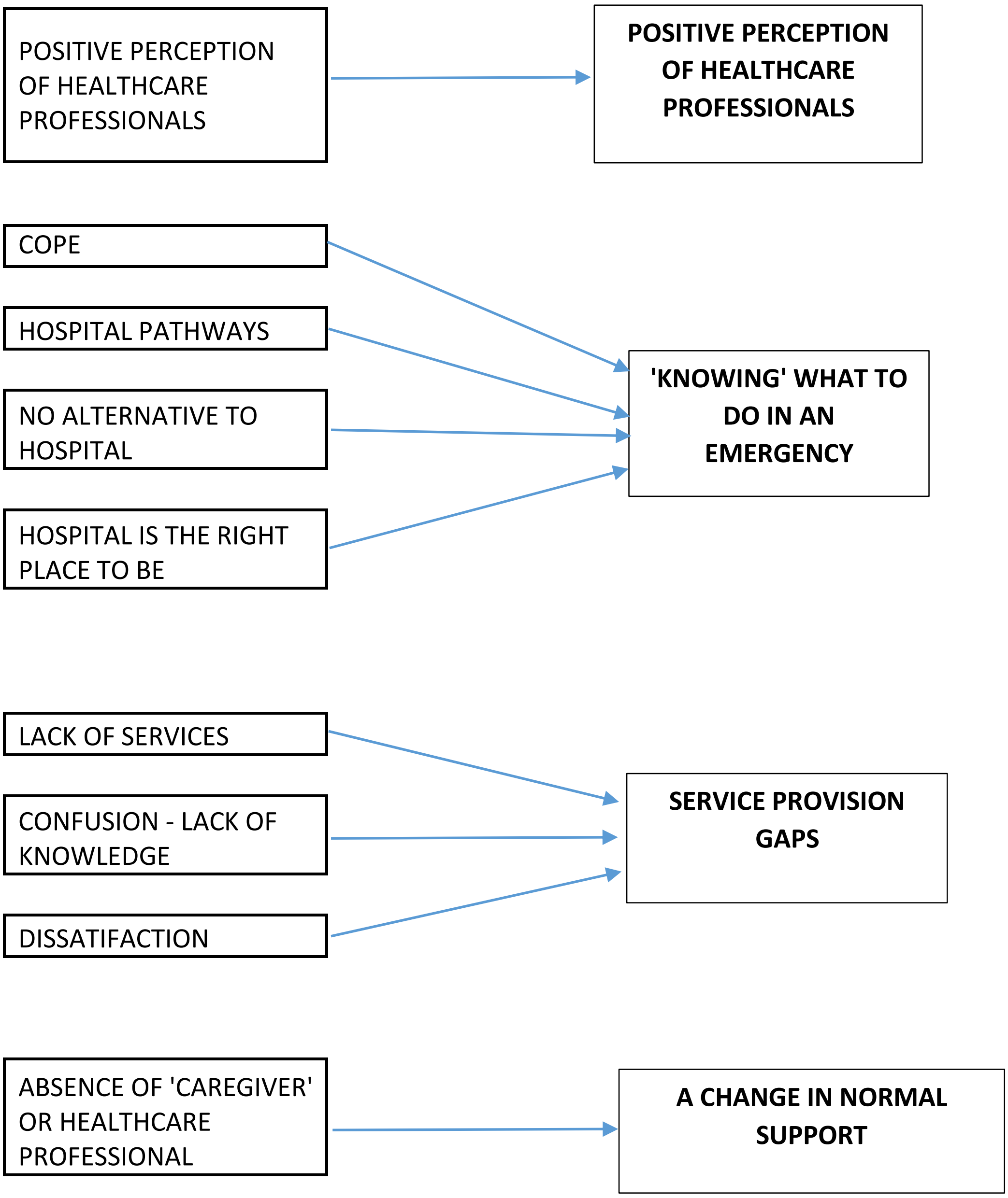

Non related hospital admission
Previous admission
Frequent admissions
Caregiver' questions is admission really necessary
Pattern of behaviour
Support from hospital
Support within hospital
Patient thought hospital was the best place to be
Patient given choice regarding admission
Patient refusing discharge
Admission required
HOSPITAL IS THE RIGHT PLACE TO BE


Patient died
PATIENT DEATH


Lack of information
Patient unaware of next steps
Misconception that palliative is only at the very end of life
HCP's need educating
Confusion
Disease trajectory unknown
Confusion with medications
Patient not normally on the ward (bed shortages)
Patient unaware of cancer diagnosis
Confusion surrounding equipment
Hospital nurse unsure of community services
Patient education - early intervention
CONFUSION


HCP rarely sees patient unless symptoms increase
Palliative care training required
Patient unable to access community services
Admission was preventable
Concern about care package stopping
Patient 'lost' only picked up through admission
Case load for HCP
Home visit postponed by nurses due to availability
LACK OF SERVICES
Palliative care and respite beds required
Unable to contact through telephone hotline
Lack of response from community services
Weekend/Overnight admission
Out of hours service required
HCP frustration
Community services not available
Social issues delaying discharge
Inequality in service provision


Instructed by another HCP to call 999
Fear
Panic / Anxiety
Early morning admission - family worried about the time
Desperation
Stress
Patient exhausted
Patient in pain
NO ALTERNATIVE LEFT BUT HOSPITAL
Patient delirious
Co-morbidities
Personality change for patient
Patient deterioration
Urgent admission not emergency
Patient deteriorate quickly
Severity of condition
Underlying condition - asthma
Medication not working
Breathlessness
PATIENT DECLINE
Patient exhausted
Patient in pain


POSITIVE PERCEPTION OF HEALTHCARE PROFESSIONALS
POSITIVE PERCEPTION OF HEALTHCARE PROFESSIONALS
COPE
HOSPITAL PATHWAYS
NO ALTERNATIVE TO HOSPITAL
HOSPITAL IS THE RIGHT PLACE TO BE
'KNOWING' WHAT TO DO IN AN EMERGENCY
LACK OF SERVICES
CONFUSION - LACK OF KNOWLEDGE
DISSATIFACTION
SERVICE PROVISION GAPS
ABSENCE OF 'CAREGIVER' OR HEALTHCARE PROFESSIONAL
A CHANGE IN NORMAL SUPPORT