

**Healthcare Professionals' Perceptions of  
Pulmonary Rehabilitation as a Management  
Strategy for Patients with Chronic Obstructive  
Pulmonary Disease (COPD): An Interpretive  
Phenomenological Analysis**

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requirements for the degree of Doctor of Philosophy.

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Declaration:

This thesis is entirely my own work and has not been submitted in full or part for the award of a higher degree at any other educational institution. Parts of the PhD have been discussed and presented prior to submission of the thesis and these are detailed below:

### **Invited Speaker:**

June 2018: *British Lung Foundation Health Care Professional Study Day, The Hilton Hotel, Blackpool, UK: Healthcare Professionals' Perceptions of Pulmonary Rehabilitation for Patients with COPD.*

July 2017: *Round Table Discussion on Improving Uptake to Pulmonary Rehabilitation, British Lung Foundation Head Office, London, UK: Invited to provide views on healthcare professionals' perceptions of pulmonary rehabilitation, and ways to change policy and improve practice.*

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**2017:** *Invited to a dance taster event for patients with COPD, by Professor Ann Caress, University of Manchester, in association with the British Lung Foundation: Held a meet the researcher stand and spoke with patients, relatives and carers.*

**2017:** *Attended Ormskirk Breathe Easy, British Lung Foundation patient support group: Spoke to patients and carers about living with COPD, the support available, and communication with healthcare professionals.*

**2015:** *Attended a pulmonary rehabilitation session: Consulted with physiotherapists and patients to assist with the design of the PhD project.*

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## PREFACE:

I would like to begin this thesis by explaining how I arrived at this study as it helps to situate the research and my prior experiences. I embarked upon my PhD after studying for an undergraduate degree and an MRes, both in psychology. I have always been fascinated by human behaviour, and how knowledge and individual perceptions are formed. I find it intriguing how individuals perceive phenomena differently, whether this be as a result of personal experience, beliefs or education. Furthermore, I have always been interested in conducting research in the healthcare sector and working with healthcare professionals to try to initiate positive change within the NHS. This was fostered during research from my MRes, interviewing General Practitioners regarding their perceptions of family and friend involvement in consultations surrounding a persistent cough. Although not a registered healthcare professional myself, and not claiming to have any depth of medical knowledge, I am passionate about the role psychology can have within health research.

When my Grandad was diagnosed with COPD in 2014, it came as a huge shock to all the family, as he had always been very active. He owned a local bicycle shop, and in later life was a gardener and a member of a crown green bowling team. As a result, he was well-known in his local community, with many friends, and a real family man. In reality, he had probably had COPD for a number of years prior to his diagnosis, however as many patients do, only went to see his General Practitioner when his breathlessness became quite severe.

At the time of diagnosis my Grandad was 77, and I was 21 and in the final year of my Psychology BSc Hons degree at the University of Salford. His symptoms progressed quite rapidly, and as a result he was provided with 24 hour oxygen therapy. Grandad was always upbeat, caring and the joker of the family, however the oxygen was something which he never came to terms with, nor accepted. He felt that it took away his independence, he no longer wanted to do the things he once loved, such as socialising with friends, going on days out, and on holiday. COPD had taken the fun out of life.

Myself, my Mum and Nanna accompanied Grandad to all of his appointments, and pushed his wheelchair down the long hospital corridors which he no longer felt he could manage. It was upsetting to see this once active and healthy man so deflated and anxious of becoming breathless, that he refrained from any form of activity. As a family we looked for anything to try to improve his quality of life. After searching on the internet we encountered a programme called '*pulmonary rehabilitation*'. We asked a nurse who introduced herself as a respiratory nurse, if Grandad could attend pulmonary rehabilitation, as we believed that

he would gain a lot in terms of confidence from socialising with others with COPD, and the educational components of the programme. The nurse replied with '*what's that, do you mean when they go away for a few days for respite?*'. Her response came as a shock, as someone who cared for patients with respiratory conditions she was unaware of the programme. This made me question how many other healthcare professionals may also lack this knowledge, and why they may have this lack of awareness.

I applied for a PhD studentship at Edge Hill University in 2015 and was successful in obtaining the position. I was told that I would be required to complete a research proposal surrounding an aspect of COPD in the first six months. Grandad was thrilled, and he told everyone that he came into contact with that his granddaughter was going to conduct research into his condition; he was so proud. Unfortunately, seven weeks before commencing the PhD, Grandad passed away. He never got the opportunity to attend pulmonary rehabilitation, and after telling my PhD supervisors about our experiences regarding pulmonary rehabilitation, they suggested it would be a good idea to establish an understanding of the current literature surrounding healthcare professionals' knowledge and perceptions of the programme. It seemed as though it was perfect timing, as the National PR Audit (2015) had just been published, highlighting a lack of referrals from healthcare professionals to pulmonary rehabilitation. The audit concluded that the reasons for this were unknown, and there appeared to be a lack of literature to establish this. Although Grandad did not know it, he had helped me to identify a real world issue, and a gap in the literature, thus my PhD project was decided upon.

These prior personal experiences therefore informed the undertaking of the critical interpretive synthesis, and as a result of insufficient literature focusing purely on healthcare professionals' perceptions of pulmonary rehabilitation, contributed to the formation of the research question for the empirical research. Due to adopting an interpretive phenomenological approach these experiences can be embraced, as long as correctly acknowledged, rather than acting as a bias. These personal experiences will be drawn upon further in the reflections chapter (Chapter 6). However, it was considered important to provide an overview at the start of the thesis, to evidence why as a non-healthcare professional this project was important on a personal level.

## **ABSTRACT:**

### **Background:**

Sound evidence supports pulmonary rehabilitation (PR) as an effective management strategy for patients with respiratory disease, in particular chronic obstructive pulmonary disease (COPD). A multi-disciplinary programme, PR encompasses exercise training, education, nutritional advice, self-management and psychological support. Following PR patients often experience an increase in exercise capacity and quality of life, but a lack of referrals suggests that healthcare professionals (HCPs) are not 'selling' PR to patients. However, no evidence exists to fully substantiate this claim; a missing piece of the jigsaw.

### **Objectives:**

1. To explore HCPs' perceptions regarding referral of COPD patients to PR in primary and secondary care settings.
2. To establish HCPs' understanding of PR.
3. To explore barriers and facilitators to referral to PR.

### **Methods:**

Interpretive phenomenological analysis (IPA) was adopted to establish HCPs' perceptions of PR. Purposeful recruitment of general practitioners and practice nurses, and doctors and nurses working on general medical wards yielded a total of 27 participants. Informed consent preceded semi-structured interviews which were digitally recorded and transcribed verbatim.

### **Findings:**

Three super-ordinate themes were identified: *COPD Illness Perceptions*, *Pulmonary Rehabilitation Beliefs*, and *Organisational and Referral Pathway Perceptions*. Commonalities and disparities were identified between primary and secondary care and amongst the different professional groups. HCPs held COPD illness perceptions; many held stigmatising beliefs in relation to the disease, which impacted upon referral practice. Pulmonary rehabilitation beliefs highlighted HCPs' views on patient suitability and the PR programme. A lack of knowledge of PR and the referral process was evident. Organisational and referral pathway perceptions revealed barriers and facilitators to referral.



**Conclusion:**

Referral to PR is as certain as spinning a wheel of fortune. Chance of referral appeared dependent upon individual HCPs, their perceptions of the programme, views of how COPD affects patients, and opinions of the referral process. All of these aspects, pieced together, could act as a predictor of referral practice. This is the first study to focus on HCPs' perceptions of PR as a management strategy for patients with COPD and as such is a valuable contribution to knowledge.

**Key Words:** Healthcare Professional, Perceptions, Pulmonary Rehabilitation, COPD, Exercise, Psychology.

## **ABBREVIATIONS:**

6 MWT	Six Minute Walk Test
A & E	Accident and Emergency
AB	Abstract
AMU	Acute Medical Unit
ANP	Advanced Nurse Practitioner
BLF	British Lung Foundation
BMI	Body Mass Index
BTS	British Thoracic Society
CBT	Cognitive Behavioural Therapy
CCG	Clinical Commissioning Group
CIS	Critical Interpretive Synthesis
COPD	Chronic Obstructive Pulmonary Disease
CRD	Centre for Reviews and Dissemination
CRN	Clinical Research Network
DESMOND	Diabetes Education and Self-Management for Ongoing and Newly Diagnosed
DNA	Did Not Attend
DR	Doctor
ERS	European Respiratory Society
ESWT	Endurance Shuttle Walk Test
FEV	Forced Expiratory Volume
FIRS	Forum of International Respiratory Societies
FREC	Faculty of Health and Social Care Research Ethics Committee
FVC	Forced Vital Capacity
FY1	Foundation Doctor Year 1
FY2	Foundation Doctor Year 2
GN	General Nurse
GOLD	Global Initiative for Chronic Obstructive Lung Disease
GP	General Practitioner
HCP	Healthcare Professional
HRA	Health Research Authority
IPA	Interpretive Phenomenological Analysis
ISWT	Incremental Shuttle Walk Test
ITU	Intensive Therapy Unit
LTOT	Long Term Oxygen Therapy

MAU	Medical Assessment Unit
MeSH	Medical Subject Heading
MRC	Medical Research Council
NHS	National Health Service
NICE	National Institute for Health Care Excellence
PN	Practice Nurse
PR	Pulmonary Rehabilitation
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
QALY	Quality Adjusted Life Year
QOF	Quality and Outcome Framework
TDF	Theoretical Domains Framework
TI	Title
UK	United Kingdom
USA	United States of America

# **CHAPTER 1: BACKGROUND**

## **1.1 INTRODUCTION:**

This chapter aims to introduce both chronic obstructive pulmonary disease (COPD) and pulmonary rehabilitation (PR), providing a definition and background to the context of the study. The incidence and prevalence of the disease are first explored before moving on to the symptoms and management of the condition. Subsequently, the history and effectiveness of PR is discussed, prior to exploring the literature on patients' perceptions of the programme. A rationale for the study will be provided, examining key guidelines, policy documents and literature, and thus providing a comprehensive overview upon which the research presented in the thesis is based.

## **1.2 OVERVIEW OF CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD):**

COPD is a chronic degenerative respiratory condition, caused by airflow obstruction which is not fully reversible and induced by abnormalities in the airways and/or alveoli (Global Strategy for the Diagnosis, Management and Prevention of Chronic Obstructive Pulmonary Disease [GOLD], 2018). COPD is an umbrella term which encompasses diagnoses of chronic bronchitis and emphysema with airways obstruction (narrowing of the airways), leading to airflow irregularities which is usually progressive (Celli et al., 2004; GOLD, 2018; National Institute for Health Care and Excellence [NICE], 2010).

Chronic bronchitis is identified as inflammation and narrowing of the airways, whereas emphysema is a destruction of the alveoli (air sacs) and blood vessels, resulting in less room for oxygen exchange (British Lung Foundation [BLF], 2016). In patients with COPD the two conditions can occur concurrently, and the inflammatory and obstructive changes make it more difficult for gas exchange to occur (BLF, 2016). Gas exchange within the lungs takes place between the alveoli and blood in the capillaries (small blood vessels), which provide a large surface for exchange to occur (Weibel, Sapoval & Filoche, 2005). Oxygen is absorbed into the blood, and carbon dioxide produced during respiration moves from the blood to the lungs where it is expelled, this is a vital function which enables the production of energy (Hsia, Hyde & Weibel, 2016).

COPD is associated with a number of symptoms which include breathlessness (also termed as dyspnoea) upon exertion, a persistent cough, wheezing and chest tightness, production of sputum and winter bronchitis (inflammation and infection of the bronchi). These

symptoms impact upon quality of life, and can lead to disability and reduced exercise tolerance (Kanervisto et al., 2010); this is often punctuated by recurrent exacerbations (Haplin et al., 2012). Symptoms are commonly managed using a combination of pharmacological and non-pharmacological interventions, with effectiveness variable from patient to patient (Price et al., 2011).

Early diagnosis and effective management is vital for slowing progression of the disease (Soriano, Zielinski & Price, 2009), decline in lung function (Csikesz & Gartman, 2014), improving health related quality of life (Welte, Vogelmeier & Papi, 2015) and enabling reduction of some of the risk factors associated with COPD exacerbations (Kaplan & Thomas, 2017). Risk factors, symptoms, diagnosis and treatments are subsequently discussed in further detail within the chapter.

### **1.2.1 Incidence and Prevalence:**

The incidence of COPD differs across nations and within different communities, however it is a leading cause of mortality worldwide (Adeloye et al., 2015; Csikesz & Gartman, 2014), and by 2030 is predicted to be the fourth major cause of death globally (Marthers & Loncar, 2006). Reduction in exercise capacity, deterioration of physical functioning and recurrent exacerbations are thought to be reliable predictors of mortality (Celli, 2010). Approximately 2- 4.5% of individuals aged over 40 in the United Kingdom (UK) have been diagnosed with COPD, and prevalence is increasing (BLF, 2017a). Although smoking rates have declined in the UK in recent years and are at their lowest since 1974 (Office for National Statistics, 2017a), the high prevalence of the disease can be attributed to the previous popularity of smoking, a growing aging society, and an increase in air pollution (López-Campos, Tan & Soriano, 2016). Traditionally, COPD was more common in males, however a recent systematic review identified that the gender gap is much narrower than previously thought (Ntritsos et al., 2018). This increase in the prevalence of COPD amongst women was identified in a study in 2000, and was attributed to an increase in smoking in the mid-twentieth century amongst women (Soriano et al., 2000). More recently discussion has also focused on exposure to indoor and outdoor air pollution affecting women in lower and middle income countries (Gordon et al., 2014), due to the use of biomass and fossil fuels used for cooking and heating (Gnatiuc & Caramori, 2014).

The Global Burden of Disease study highlighted that the prevalence of COPD was recorded at approximately 251 million cases worldwide during 2016 (Global Burden of Disease and Injury and Incidence Collaborators, 2016). In 2015, 3.2 million people died globally from the

disease, an 11.6% increase from the year 1999 (Soriano et al., 2017). This poses a significant burden in Europe with prevalence ranging from 5-10% of the population, increasing to 20% in those aged over 70 (European Whitebook, 2013). It is however proposed that the figures could be much larger than often predicted, with under diagnosis and misdiagnosis posing a significant issue in the management of COPD (Bastin et al., 2010; Jones et al., 2014; Llordes et al., 2015). The number of COPD related deaths in England and Wales is rising with 20,496 deaths recorded in 2010 in urban areas and 4,450 in rural, compared to 25,197 in urban locations, and 5,640 in rural areas in 2015 (Office for National Statistics, 2017b). This is confirmed in the BLF (2017b) report, which evidenced that COPD is the only major cause of mortality rising nationally, thus displaying the extent of those affected by the disease.

Within the UK, COPD is the second largest cause of emergency hospital admissions, due to its progressive deteriorating nature (Department of Health, 2012). Data collected from 182 hospitals in England and Wales displayed that between 1<sup>st</sup> February 2017 and 13<sup>th</sup> September 2017 there were 36,341 COPD related hospital admissions (National COPD Audit Programme, 2018). This equates to an average of 304.8 COPD related admissions per hospital during the seven month period, with 53.1% (19, 295) of admissions female, and the busiest day for arrival being Monday. Waiting times from arrival, to hospital admission during this period were on average 3.9 hours, with a further average of 27 hours before being reviewed by a member of the respiratory team (National COPD Audit Programme, 2018). As a result of an increased need for hospital care, COPD is therefore an expensive disease for the National Health Service (NHS) to manage (Department of Health, 2011), at an estimated cost of £1.9 billion per year (BLF, 2017b). In 2017 a continuous audit of COPD exacerbation admissions began in secondary care in England, with the need to minimise COPD related hospital admissions listed as a key priority (National COPD Audit Programme, 2018). Whilst undertaking this PhD, the NHS was experiencing added pressure on services during a period of austerity (NHS England, 2017; British Medical Association, 2018). The reported contribution to the increase in winter seasonal COPD hospital admissions, and the likelihood of patients experiencing a debilitating exacerbation (BLF, 2017c), offers potential for exploring preventative and alternative management strategies.

### **1.2.2 Associated Risk Factors:**

Identified risk factors for COPD include tobacco smoking, exposure to occupational chemicals, indoor and outdoor pollutants, genetics, diminished childhood lung development and socio-economic status (GOLD, 2018). Genetic factors can also be related to the incidence of COPD, with parents' respiratory function often being a predictor of a child's future respiratory health (Raheison & Girodet, 2009). Diminished lung development and severity of infections during childhood, also appear to be affiliated with future development of the disease (Raheison & Girodet, 2009). The risks of COPD can increase with the presence of asthma or bronchitis, and the likelihood of being diagnosed rises with age (Rennard & Drummond, 2015).

An individual's socio-economic status also has a considerable effect on the development of COPD, with those within the highest 10% of deprivation in the UK having a 50% greater chance of being diagnosed (BLF, 2017b). A possible explanation for this may be the correlation between low socio-economic status and poor health-related behaviours, for example smoking, poor diet and limited participation in exercise (Pampel, Krueger & Denney, 2010), with others suggesting that a decreased level of education is also a predictor of COPD (Kanervisto et al., 2011).

Smoking is recognised as a significant contributory factor in COPD, due to creating a pathological environment for the condition to progress, which results in a reduction of lung function (Cope, 2014). It is emphasised, however, that further attention needs to be paid to other risks such as chronic asthma, as it has significant potential to increase chances of developing COPD (De Marco et al, 2013; Gibson & Simpson, 2009). This is supported by the prediction that 25-45% of individuals with COPD have never smoked, therefore other factors such as exposure to biomass fuels, dust, chemicals, and having a low socioeconomic status and history of respiratory tract infections also play a large role (Salvi & Barnes, 2009). As substantiated above, there is considerable evidence available to highlight a number of associated risks, and as the general public may be exposed to a number of these, this makes it difficult to identify which have caused the condition in any given individual (Celli & Augusti, 2018). Thus, it is proposed that various factors can contribute to the development of the condition across different populations (Mannino & Buist, 2007), therefore a number of preventative methods are required (Rennard & Drummond, 2015).

In recent years cannabis use has increasingly been associated with COPD, as it is known to contain various carcinogenic chemicals which are inhaled more deeply than cigarettes; the effects on respiratory function however remain inconclusive (Gates, Jaffe & Copeland, 2014). A UK study by Macleod et al., (2015), established a connection between cannabis smoking (particularly smoking a resin form) and a greater self-reporting of respiratory symptoms, than those smoking traditional cigarettes. The presence of COPD was also more pronounced in younger individuals who smoked cannabis, compared to those smoking cigarettes. In spite of this, the authors noted that this was the first study in the UK to highlight the connection, and concluded that further research needs to be conducted to confirm the relationship.

### **1.2.3 Symptoms:**

Symptoms commonly associated with COPD are: dyspnoea (difficulty breathing), chest pain, wheezing, persistent chronic cough, production of sputum, and frequent winter bronchitis (NICE, 2010). During the early stages of the disease it is typical for symptoms to present sporadically, with patients most likely to experience a cough and 'rattling' of the chest, sputum production and episodes of breathlessness, with the infrequent nature leading to symptoms often going unnoticed (Arne et al., 2007).

In established COPD, a chronic cough and sputum production are often intensified, and most commonly appear alongside exertion-related breathlessness (Bednark et al., 2008; Smith & Claverley, 2004). Wheezing and tightness of the chest are variable and may be more severe for some on particular days or at certain times of the day. Thus, the presence or absence of a wheeze and chest pain does not confirm or reject a diagnosis of COPD (GOLD, 2018). A recent survey highlighted that healthcare professionals (HCPs) view a cough, breathlessness and sputum production as having the greatest impact upon a patients' quality of life, however conversely patients placed larger significance upon chest tightness and fatigue. The HCPs were able to appreciate the impact of the condition upon daily activities, such as ability to work and undertake exercise, yet found it difficult to comprehend and appreciate difficulties faced when undertaking leisure activities and socialising with friends (Celli et al., 2017). Thus, the findings expose a disparity of views between patients and HCPs with regards to the perceived impact of COPD.

Patients with COPD experience a variation of symptoms on a daily basis, with particular impact on morning routines and sleep quality (Kessler et al., 2011; Wu et al., 2017). Age also appears to have an impact upon symptoms, with younger patients experiencing greater



breathlessness, anxiety and sleep disturbances (Borge, Wahl & Moum, 2010). As the condition progresses it is often punctuated by frequent exacerbations, commonly elicited by a heightened number of lower respiratory tract infections (Sethi, 2010; Wedzicha & Seemungal, 2007). An exacerbation is defined as a worsening of respiratory symptoms which exceeds usual daily variations, and frequently results in hospital admission due to requiring additional treatment (Burge & Wedzicha et al., 2003; Criner et al., 2015). Exacerbations can manifest as either a sudden or gradual onset, however patients with gradual onset often take longer to recover (Aaron et al., 2012). Severe exacerbations are associated with a deterioration of the condition, acceleration of loss of lung function, functional ability, quality of life and poorer survival rates (Alcazar et al., 2016; Viniol & Vogelmeier, 2018). Exacerbations can have long term consequences for patients, as even after recovery the physical, psychological, social, and emotional effects can be present for some time (Anzueto, 2010). It is however possible to reduce the severity and long-term impact of an infection using preventative methods and timely treatment (Seemungal et al., 2001).

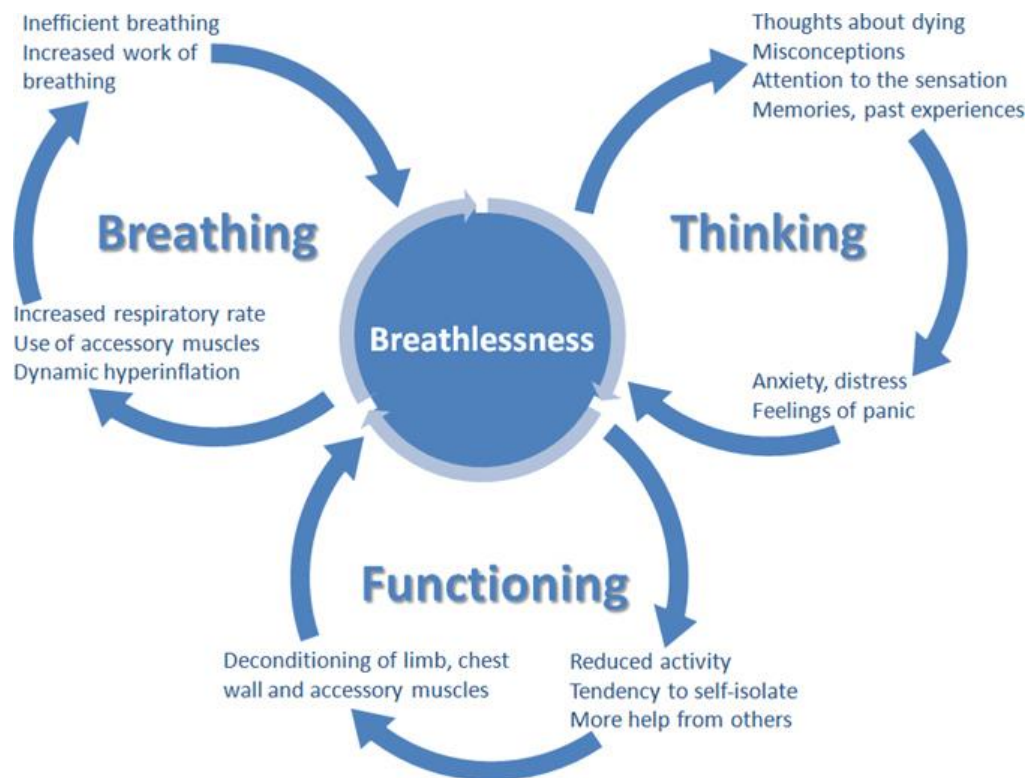
### *Breathlessness:*

Breathlessness has been focused upon as patients with COPD often describe it as the most disruptive symptom, and something that they have to learn to cope with on a daily basis (Jørgensen et al., 2012). Dyspnoea and breathlessness are terms often used interchangeably and are defined in an official American Thoracic Society Statement as '*a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity*' (Parshall et al., 2012, pg 436). The statement highlighted that breathlessness can be triggered by physical, psychological and environmental conditions, and that it is an individual experience, therefore perceived severity can be as a result of a patient's interpretation, and symptoms are therefore self-reported. Breathlessness is a dominant symptom for those with COPD (Kessler et al., 2011), and is considered the feature which usually initiates patients to seek medical advice (Pauwels & Rabe, 2004). It is typical for breathlessness to develop slowly, therefore a decline in health frequently goes unnoticed for some time; some patients enter a state of denial and guilt due to prior smoking history, and thus delay health seeking behaviours and engagement with healthcare services (Gysels & Higginson, 2010). Consequently, it is often only when symptoms become extremely troublesome for the patient, that they confront the issue and seek medical assistance (Gysels & Higginson, 2011).

Although, not always apparent to others, breathlessness evokes a physiological response, which psychologically triggers the patient to change their behaviour in order to attempt to reduce shortness of breath (Calverley, 2017). Despite leisure activities such as walking and participating in sport (Genoe & Zimmer, 2017), assisting patients to maintain a sense of independence, many decide to reduce activities, only doing those they perceive necessary to avoid breathlessness (Gysels & Higginson, 2011). The initial stages of the disease may have little impact upon breathlessness and physical ability, however as the disease progresses breathing can become laboured upon exertion; something which many patients try to conceal (Arne et al., 2007). Although it is evident that there is a decrease in physical activity, coupled with increased airflow obstruction throughout the course of the disease, reduction in activity results in the advancement of exercise intolerance and muscle wasting (Waschki et al., 2015). Recent research has highlighted that patients also often choose to reduce their physical activity after an exacerbation, which may cause diminished exercise capacity; a viscous cycle of inactivity ensues (Demeyer et al., 2018). Exercise limitation is however a counterproductive response, as exercise reduces increased ventilatory impairment and skeletal muscle dysfunction (Puhan et al., 2005).

Dyspnoea is a complex symptom and in addition to physical factors, psychosocial dimensions need to be considered (Carel, Macnaughton & Dodd, 2015). Many patients describe the psychological effects associated with breathlessness which, due to the unforeseeable and unstable nature of COPD, often results in a perceived lack of control, state of helplessness, and feeling the need to be hyper vigilant over the monitoring of symptoms (Harrison et al., 2014). The Breathing, Thinking, Functioning Clinical Model (figure 1), aims to illustrate the continuous vicious cycle associated with breathlessness (Spathis et al., 2017). The model provides personalised non-pharmacological management strategies for patients with COPD. There are three distinct stages: *Breathing*, *Thinking* and *Functioning*, which display how physical symptoms associated with breathlessness evoke psychological ones, such as feelings of anxiety, panic and a negative outlook. This is described as a sequential process associated with breathlessness, which results in a chain reaction. Some patients experience psychological symptoms, which then trigger physical ones, others encounter physical symptoms which activate a psychological response; the impact of which is detrimental to a patient's health and psychological wellbeing.

**Figure 1: The Breathing, Thinking, Functioning Clinical Model (Spathis et al., 2017)**



Included with permission from Dr Anna Spathis)

#### **1.2.4 Comorbidities:**

Previously, COPD was defined as a condition affecting the lungs, however due to increased understanding, the systematic consequences and comorbidities should also be taken into account (Fabbri et al., 2008). The disease often presents with, or intensifies other conditions, causing complications in management and requires attentive monitoring (Barnes & Celli, 2009). Comorbidities are mutual or causal relationships between two or more different diseases (Sethi, 2010,). COPD is often associated with a number of comorbidities which typically fit into one of four categories:

1. Cardiovascular (heart conditions, such as hypertension)
  2. Cachectic (muscle wasting, associated with weight loss)
  3. Metabolic (obesity and atherosclerosis)
  4. Psychological (anxiety and depression)
- (Vanfleteren et al., 2013).

Comorbidities often present due to having similar associated risk factors, such as smoking and holding similar pathogenetic pathways; thus, for example, COPD patients have a heightened chance of later being diagnosed with lung cancer (Hillas et al., 2015). Cardiovascular comorbidities, such as arterial hypertension and heart failure are commonly associated with COPD (Crisafulli et al., 2008). Shared risk factors are held between COPD and cardiovascular disease, with smoking, inactivity and lower socio-economic status contributing to both conditions (Maclay & MacNee, 2013). The presence of cardiovascular disease in conjunction with COPD is therefore associated with increased patient mortality (Cavaillès et al., 2013). Other systematic effects associated with COPD include skeletal muscle wasting and weight loss (American Thoracic Society & European Respiratory Society, 1999; Augusti & Soriano, 2008; Barnes & Celli, 2009). Patients with COPD often lose muscle mass in their thighs and upper arms, and upon progression this results in fatigue and breathlessness (Sin & Mann, 2006). In comparison to healthy individuals, patients with COPD experience a greater reduction in quadriceps endurance (Allaire et al., 2004). The reduction in lower limb strength, in particular the quadriceps, impacts upon exercise capacity and increases mortality (Swallow et al., 2007). These effects can however, be reduced via strength and endurance training (Casaburi, 2001).

Metabolic comorbidities are often high in patients with COPD, such as diabetes, osteoporosis (bone weakness) (Hillas et al., 2015), and atherosclerosis (the formation of plaque in arteries), due to sharing many similar inflammatory characteristics with COPD (Bäck, 2008). Obesity also now has a recognised presence in the disease, and as a result can lead to reduced physical activity (Franssen et al., 2008; Ten Hacken, 2009). Patients frequently report night time symptoms causing sleep disturbances, difficulty returning to sleep, and a shorter sleep duration; typical night time symptoms include a tightness of the chest and wheezing (Augusti et al., 2011). Although this is a less researched comorbidity of COPD, a study including 2,807 patients highlighted the significance of the issue, with 78% experiencing waking and sleep disturbance. The effects of night time waking impacted upon patients' morning wakening, with these patients reporting greater levels of daytime dyspnoea compared to those with good sleep quality (Price et al., 2013).

As discussed previously in relation to breathlessness, many patients with COPD experience psychological symptoms. The most common are depression and anxiety (Yohannes & Alexopoulos, 2014), which consequently impacts quality of life, heightens risk of exacerbation, prolongs hospital admissions and increases mortality (Pumar et al., 2014). It is predicted that over one third of patients have depression or anxiety, which negatively

impacts upon health related quality of life, and can generate heightened rates of mortality (Panagioti et al., 2014). A systematic review however, highlighted the disparity in reporting of the prevalence of depressive symptoms in COPD patients, with figures varying between 15.5 – 35.7%, in eight included studies (Matte et al., 2016). Although estimates of the prevalence of anxiety and depression in the COPD population differ significantly, it is accepted that rates are typically greater than patients with other chronic diseases (Maurer et al., 2008). It is proposed that estimated prevalence is variable, due to a number of different measures being used, methodological approaches and sample sizes (Hill et al., 2008; Matte et al., 2016). The principle correlates of depressive symptoms in COPD are reported as breathlessness and troublesome walking; other factors consist of being female, a current smoker, single, being diagnosed with cancer, diabetes or arthritis alongside their COPD, (Schane et al., 2008), a younger patient (Maurer et al., 2008; Schane et al., 2008), and a worsening of symptoms or exacerbations (Maurer et al., 2008).

The symptoms discussed earlier highlight both the physical and psychological comorbidities experienced with COPD, which can often impact upon daily routine and associated activities (Kessler et al., 2011). Those with COPD can also become frail, and when compared to matched individuals without a respiratory condition, they score higher on the frailty index (Gale et al., 2018). Patients recount '*fighting for their breath*', and as a result feel the need to limit activities; some are unable to work and maintain an active social life, which ultimately has negative consequences upon independence (Seamark, Blake & Seamark, 2004, pg 621). Fatigue is a contributory factor in the reduction of activity, and when coupled with breathlessness can become intolerable and overbearing, resulting in patients entering a state of helplessness (Stridsman, Lindberg & Skär, 2014). As a result of the worry associated with any aspect of their condition worsening, patients regularly undertake lifestyle changes such as: quitting smoking, eating healthily, taking life at a slower pace, avoiding prolonged exposure to extreme weather conditions, and reducing contact with individuals with infections (Harb, Foster & Dobler, 2017).

As a result of the physical and psychological symptoms, COPD patients often report requiring additional assistance with daily activities, and emotional reassurance from family and friends, which often leads them to experience a sense of guilt (Harb, Foster & Dobler, 2017). Depressive symptoms also occur regularly in caregivers (Bernabeu-Mora et al., 2016), as the psychological impact of caring for a family member can evoke worry, anxiety, stress and frustration and, as a consequence many describe developing a coping strategy of taking life one day at a time (Simpson et al., 2010). A narrative review of the literature highlighted many influences with the potential to impact upon the psychological well-being

of the carer (Grant, Cavanagh & Yorke, 2012). Within the review aspects which attributed to caregiver psychological distress was the burden associated with the caring role, the strain of the relationship between patient and carer, and the perceived helpfulness of the support provided for carers. Hence, a diagnosis of COPD has the ability to have a significant impact upon the wider network of family and friends (Gardiner et al., 2010).

### **1.2.5 Diagnosis:**

Many patients, especially those in primary care, go undiagnosed or misdiagnosed for many years (Bednarek et al., 2008; Løkke et al., 2012). This is often due to early stage COPD not being identified and symptoms only recognised in those with moderate COPD and worsening symptoms (Pauwels & Rabe, 2004). As a result of symptoms often progressing slowly over time, diagnosis is therefore more likely in those aged over 40 – 50 (World Health Organisation, 2016). Currently, there is no test available to provide a conclusive diagnosis, however it is suggested that diagnosis should be based on clinical history and symptoms, and confirmed by spirometry (NICE, 2010). Therefore, patients over 35 presenting with dyspnoea, a chronic cough and sputum production, in particular those who have been exposed to any of the risk factors previously discussed, should be considered for a diagnosis of COPD (NICE, 2010). The presence of a persistent cough is often overlooked in the diagnosis of COPD, by both HCPs and patients, as it is frequently attributed to smoking, developed from smoke inhalation irritating the airways, or an increase in mucus (Caverley, 2013). This has also been evidenced in the Netherlands, where 29% of patients (n=353) over 50 who had previously attended a doctor's appointment with a chronic cough were later, when re-assessed, diagnosed with COPD (Broekhuizen et al., 2010).

Spirometry is considered as the only accurate way to confirm the clinical diagnosis of COPD and to monitor disease progression, therefore it is imperative that it is used in both diagnosis and management of the condition (GOLD, 2018; NICE, 2010). At present, it is believed that the quality of spirometry recordings obtained in primary care is high, however accuracy in interpretation is low (Rothnie et al., 2017), resulting in issues surrounding diagnosis (Bolton et al., 2005; Poels et al., 2007). In a review of the global burden of COPD, López-Campos, Tan and Soriano (2016) suggested three key aspects to address in order to increase accurate diagnosis. The first highlighted the low level awareness of COPD and its symptoms amongst the general public. The second indicated low level knowledge amongst doctors in how to recognise COPD and, finally, insufficient use of spirometry, particularly within primary care was discussed.

Spirometry measures lung function by recording volumes of air and so determines lung capacity. The essential objective measurements made are FEV<sub>1</sub> (Forced Expiratory Volume in 1 second) and FVC (Forced Vital Capacity). Obstruction is defined by a reduced ratio between FEV<sub>1</sub> and FVC, expressed as the FEV<sub>1</sub>/FVC ratio. A ratio below 70% indicates narrow airways and defines obstructive lung disease (GOLD, 2018; NICE, 2010). World-wide classification of the severity of airflow obstruction differs based upon the guidance followed (Celli et al., 2004; GOLD, 2018; NICE 2010). In the UK NICE (2010) recommend that Stage 1 mild COPD should be confirmed if the FEV<sub>1</sub>% of predicted is  $\geq 80\%$ , with symptoms of COPD also confirmed. Stage 2 moderate COPD would be confirmed if the FEV<sub>1</sub>% of predicted is 50-79%, stage 3 severe COPD is classified as a 30-49% FEV<sub>1</sub>% of predicted level, with very severe COPD identified at  $<30\%$ , or at  $<50\%$  with confirmation of respiratory failure. In addition to lung function the GOLD (2018) classification also takes into consideration the frequency of exacerbations and the severity of symptoms, helping to identify more vulnerable subsets of patients.

The impact that breathlessness has upon an individual's life can be measured using the Medical Research Council (MRC) dyspnoea scale, which was developed in 1959 (Fletcher et al., 1959; MRC 2018) (see appendix 1). The scale is commonly used in conjunction with FEV<sub>1</sub> scores at the time of diagnosis to grade breathlessness in relation to the amount of activity needed to trigger a response (NICE, 2010). It is important to refer to the MRC breathlessness scale, as spirometry readings are often not correlated with severity of symptoms or COPD related disability (Bestall et al., 1999). Although the MRC scale has been shown to be quick and simplistic for clinicians to administer (Stenton, 2008), it is criticised by some for being short and only providing limited information (Banzett & O'Donnell, 2014). A restriction of the MRC breathlessness scale is that the different grades are unable to identify deterioration over a short period, with significant change needed before grading alters (Stenton, 2008). There are a number of alternative scales available which are considered to have greater comprehensiveness, such as the St George's Respiratory Questionnaire and Chronic Respiratory Disease Questionnaire, however these are often more time consuming and complicated to use (Jones, et al., 2009). Other tools, such as the Borg scale may be considered more effective as they are able to accurately measure breathlessness (American Thoracic Society, 1999), however it has long been deemed by clinicians as time consuming (Skinner et al., 1973). During diagnosis of COPD, NICE (2010) also recommend that additional tests should be arranged for all patients. These include a chest x-ray, a blood test to identify anaemia or polycythaemia (a rare condition affecting bone marrow), and calculation of body mass index (BMI), to assess for related comorbidities.

Information given to a patient at the time of diagnosis can have a significant impact upon how they manage their condition and their perception of it (Arne et al., 2007). Many patients are informed that they have COPD and will need to use an inhaler, and are advised to quit smoking, however some are provided with no further context to the condition (Gysels & Higginson, 2010). As a result, many patients view the word *chronic* as being long term, although do not comprehend and recognise the potential worsening of symptoms, which therefore can cause shock and distress when their health deteriorates (Gysels & Higginson, 2010). A COPD diagnosis evokes a multitude of emotions, with many feeling disconcerted and refuting a diagnosis, whereas others have a reasoned acceptance (Bragadottir et al., 2017). Patients with a pre-existing lung condition at the time of diagnosis find it difficult to understand how COPD differentiates, and this is often as a result of poor communication between HCPs and patients (Ansari et al., 2014). Diagnosis of COPD is commonly protracted, however patients place greater significance on a chest x-ray than spirometry, due to the spirometry results often being difficult for patients to understand (Arne et al., 2007). This uncertainty surrounding the information received, results in some believing their condition is worse than it actually is, and others not comprehending the severity; therefore patients highlight the need for greater explanation and communication at the time of diagnosis (Arne et al., 2007). Thus, a strong relationship between the HCP and patient, coupled with effective communication, aids acceptance of the diagnosis of COPD and understanding of the prognosis (Seamark, Blake & Seamark, 2004).

### **1.2.6 Management:**

COPD symptoms can significantly improve when appropriately managed, therefore the Quality and Outcomes Framework (QOF) recommends that all COPD patients should be invited to an annual review where lung function, history of exacerbations, levels of breathlessness and medication are evaluated (NICE, 2018). In addition to defining COPD and providing diagnostic criteria, the NICE (2010) guidelines include recommendations for HCPs regarding management of the condition. These suggestions are formed after considering systematic reviews of the evidence, and the associated costs and effectiveness of treatments. In instances where evidence is diminished, the guideline development group are consulted to provide their opinion on good practice (O'Reilly et al., 2010).

Recently there has been a shift in opinion from defining COPD as a disease which causes airflow obstruction, to understanding it as a multifaceted and heterogeneous condition, requiring a personalised approach to its management (Augsti, 2014). Due to the complex



and degenerative nature of the condition, COPD is often managed using a combination of pharmacological and non-pharmacological interventions, alongside patient education and smoking cessation programmes (Viniol & Vogelmeier, 2018). Smoking cessation is proven as the most successful management strategy in reducing disease development and prolonging life (Tønnesen, 2013). Smoking cessation should be the primary recommendation for any patient with COPD, and initially may be the only suggestion for those with mild COPD until symptoms progress (O'Reilly et al., 2010). It should be promoted at every opportunity, with patients of all ages advised to cease smoking and offered appropriate support (NICE, 2010).

Within recent years electronic cigarettes (e-cigs) have become a popular replacement for cigarettes and, although some do contain nicotine, the vapours produced are thought to be less harmful (Celli et al., 2014). As a result of the rise in popularity Public Health England (2015) published a report which accentuated that electronic cigarettes are 95% safer than traditional nicotine based cigarettes, and are successful in aiding some to quit. A position statement produced by the Forum of International Respiratory Societies (FIRS) however draws caution to such claims, suggesting that findings have shown the effectiveness of e-cigarettes in smoking cessation to be variable. Thus, the statement warned about their use until a greater body of research regarding their safety has been established (Schraufnagel et al., 2014). This is consistent with the view of GOLD (2018), who add that the integrity and dependability of the use of e-cigarettes in smoking cessation is incalculable, although the effectiveness of pharmacotherapy and nicotine replacement is proven and supported.

Pharmacological treatments should be assessed on an individual basis with symptoms, severity of the condition, exacerbation history, other comorbidities, availability and effectiveness, and patient preference of treatments all taken into consideration (GOLD, 2018). Frequently used pharmaceutical medications available include bronchodilators to open the airways, and corticosteroids and steroids to reduce inflammation. Medication is often administered using inhalers, nebulisers, tablets or a combination of both oral and inhaled therapies, with antibiotics commonly used for infective exacerbations (NICE, 2010). It is recommended that HCPs follow the NICE (2010) COPD Guidelines and GOLD (2018) recommendations when prescribing medication for patients.

In some instances, oxygen therapy and non-invasive ventilation is also required, however the needs of each patient are assessed on an individual basis (GOLD, 2018; NICE, 2010). The BTS guideline (2015) for the use of oxygen in adults provides HCPs with details of different approaches to oxygen therapy, and recommendations for use. Long term oxygen

therapy (LTOT) is advised for patients with chronic hypoxaemia (a severely diminished concentration of oxygen in the blood) and is used for 15 hours or more per day, however its use should be carefully considered following a thorough assessment of the patient, and not prescribed as standard (BTS, 2015). LTOT is advocated for those with chronic hypoxaemia in order to reduce mortality; patients on oxygen therapy may also be offered portable ambulatory oxygen cylinders to assist daily activities and exercise, and enable them to maintain a good quality of life (Ambrosino, 2008; GOLD, 2018). For those admitted to hospital with respiratory failure, long-term non-invasive ventilation is advocated to improve survival and reduce admission rates (BTS, 2016)

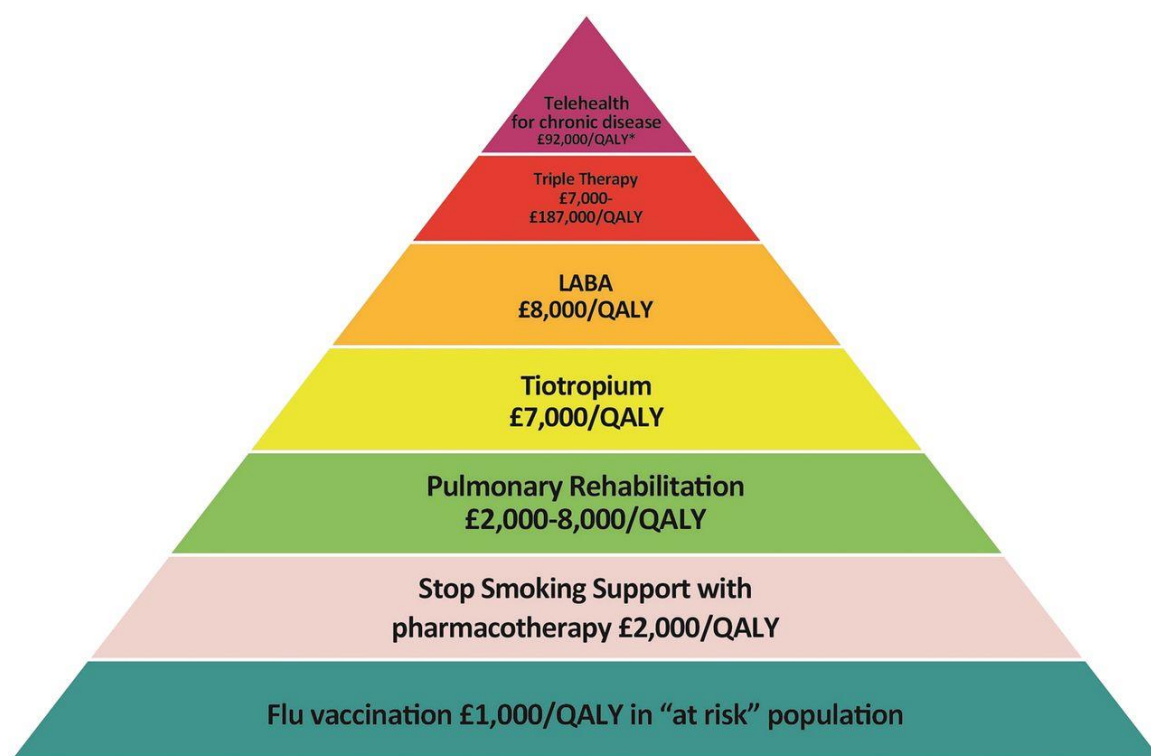
It is advised that all COPD patients receive a pneumococcal vaccination and annual influenza vaccination, to reduce the number of infections developed and the debilitating effects they can cause to the patient's health (GOLD, 2018; NICE, 2010). Lung surgery is considered for those who have received maximised medical treatment, yet dyspnoea continues to significantly impact their daily life. Surgery often consists of either lung volume reduction or lung transplantation, however upon consideration of a transplant, other comorbidities, the individual's age and condition should be carefully evaluated (NICE, 2010).

Non-pharmaceutical interventions should be used alongside pharmaceutical treatments to assist with the management of COPD. A multidisciplinary approach should be adopted using a combination of smoking cessation, with nicotine replacement therapy and behavioural support, pulmonary rehabilitation (PR), breathing retraining, education, and self-management (Morgan & Britton, 2003). This advice is reinforced by the findings of a narrative literature review, which highlighted that patients require advice on maintaining a healthy lifestyle, which encompasses how to remain physically and socially active, alongside receiving emotional and psychological support (Gardener et al., 2018).

It is recommended that PR should be provided to all patients who meet the criteria defined in both the BTS (2013) PR guidelines and NICE (2010) COPD guidelines (see section 1.3.4 Patient Suitability for PR, for details of criteria), along with those admitted to hospital with an exacerbation of their COPD (European Respiratory Society, 2013; British Thoracic Society [BTS], 2013; GOLD, 2018; NICE, 2010). PR is a programme which aims to improve the well-being of individuals with COPD, incorporating exercise, education, breathing techniques, psychological support and medication advice (BTS, 2013). This integrated multidisciplinary approach provides individualised care and management, regardless of where a patient is placed on the disease trajectory (Meshe et al., 2017; Morgan, 2017).

HCP engagement with referral is important to clinical practice (GOLD, 2017), as PR is recognised as one of the most cost effective management strategies for COPD, at an approximate quality adjusted life year (QALY) of £2,000-£8,000 (Vogiatzis et al., 2016). Only two strategies have a lesser QALY than PR, which are smoking cessation with pharmacotherapy at £2000 per QALY, and flu vaccinations at £1000 per QALY (Vogiatzis et al., 2016) (See Figure 2). PR will be discussed in further detail in section 1.2.

**Figure 2: COPD Value Pyramid (London Respiratory Network, 2015)**



\*Not specific to COPD

(Included with permission from Dr Noel Baxter on behalf of the London Respiratory Team and London Respiratory Network)

### 1.2.7 Self-management:

It is recommended that all COPD patients are actively engaged in self-management, with particular attention paid to the development of early signs of an exacerbation (GOLD, 2018; NICE, 2010). Self-management can be defined as patients taking responsibility for, and having an active role in the management of symptoms, with patients' health behaviours (such as smoking) reflecting their management style and motivation to change (Lenferink et al., 2017; Lorig & Holman, 2003). To assist patients with this process HCPs should endeavour to increase patient self-efficacy, due to its large influence upon which health

behaviours an individual will adopt or reject (Borbeau et al., 2004). Within primary care it is acknowledged that self-management support often focuses upon exacerbations and usually takes place during an annual review (Ogunbayo et al., 2017). It is however of equal importance for HCPs to draw upon techniques used in motivational interviewing and cognitive behavioral therapy (CBT), to assist with behavior change, goal setting and psychological needs (Ogunbayo et al., 2017). Self-management interventions should therefore aim to inspire and facilitate positive modification of health behaviors via comprehensive education, which equips patients to better manage their COPD (Effing et al., 2016). In order to achieve the best results, self-management should be delivered by HCPs who are enthusiastic and confident in its use, and should be driven by:

1. Recognising requirements, health beliefs and strengthening intrinsic motivations (an individual completing an activity because they find it rewarding and enjoyable)
  2. Obtaining individualised goals
  3. Devising suitable plans (for example exacerbation management) to accomplish goals
  4. If necessary, assessing and adapting plans
- (Effing et al., 2016)

Patients can self-manage their condition by monitoring and recording symptoms on a daily basis, paying attention to differentiation in breathlessness and sputum production, or using medical equipment such as a pulse-oximetry or peak-flow device (Harb, Foster & Dobler, 2017). This personal monitoring of health enables patients to better understand their condition and seek early intervention if they suspect an infection or exacerbation (Frei et al., 2016). Many patients do not modify their treatment during periods of symptom intensity, however the reasons why are unclear (Kessler et al., 2011). Self-management within the NICE (2010) COPD Guidelines focuses on being able to identify an exacerbation and symptom management. Often however self-management encompasses much more than this, consisting of life-style changes such as quitting smoking and adopting a healthy balanced diet, regulating emotions to maintain a positive and realistic outlook, and moving household objects to make certain tasks easier (Chen et al., 2008).

The self-management medicalised approach discussed above can be defined as providing education or information to patients. It is however viewed that purely providing patients with knowledge of their condition does not alter illness behaviours, and to increase quality of life and coping strategies, cognitions (perceptions and views of the condition), and the associated emotions (shame, fear and frustration), need to be targeted (Kaptein, Fischer &

Scharloo, 2014). The associated beliefs surrounding a diagnosis are referred to as illness perceptions; these are internal beliefs which individuals develop to try to make sense of their condition (Petrie & Weinman, 2006). Illness perceptions originate from the common sense model; this is popular within the psychology discipline, as it establishes the behavioural and cognitive processes which surround illness and self-management (Leventhal, Phillips & Burns, 2016). It is proposed that although many patients have the same condition, each forms very different illness perceptions; this ultimately impacts upon the course of the disease, and can affect management (Petrie & Weinman, 2006). There are five aspects which contribute to the formation of an illness perception, and these are:

1. The *identity* or name given to the condition.
2. The perceived *cause* of the condition.
3. The *time line* of the condition (how long it will last), which depends on perceived severity.
4. The *consequences* of the condition. This encompasses thoughts about how it will impact upon their life, however these perceptions may only develop after some time.
5. How *controllable* or curable the condition is.

(Hale, Treharne & Kitas, 2007; Petrie & Weinman, 2006)

Patients with COPD form illness perceptions, which can be an accurate predictor of a health related quality of life, ability to cope (Scharloo et al., 2007; Vaske et al., 2017), and ability to carry out tasks (Kaptein et al., 2008). In order to exemplify how illness perceptions vary, it is highlighted that COPD patients who experience panic attacks have significantly different illness perceptions than those who do not. Those experiencing panic attacks do not differ in respect of disease severity, however perceive their illness as more long lasting, have higher levels of anxiety and believe their condition has a greater impact upon daily activities (Howard et al., 2009). It is therefore imperative that HCPs place high regard upon the psychosocial needs of the patient, alongside management of medication and exacerbations, with patients' COPD illness perceptions monitored regularly to promote and facilitate positive behavior change (Russell, et al., 2018). Self-management therefore needs to adopt a blended multidisciplinary approach, combining disease related education, with reinforcement and promotion of behaviour change (Bourbeau, Nault & Dang-Tan, 2004), and this can be achieved via attendance at PR (Bourbeau, Alsowayan & Wald, 2018).

## 1.3 HISTORY AND BACKGROUND TO PULMONARY REHABILITATION:

### 1.3.1 History and Definition:

The concept which pulmonary rehabilitation is based upon dates back to 1895 when Dr Charles Denison published his revolutionary book entitled '*Exercise and Food for Pulmonary Invalids*' (Spruit et al., 2016). Denison was the first to recommend that supervised exercise should be used in the recovery of respiratory patients, with bed rest confined to periods of acute ill-health (Celli & Goldstein, 2018). It was these observations and pioneering suggestions which today's pulmonary rehabilitation descends from (Celli & Goldstein, 2018). Fifty-seven years subsequent to Denison's initial proposal, Barach, Bickerman and Beck (1952), built upon this knowledge and investigated how to reduce dyspnoea in patients with pulmonary emphysema. In order to examine this they assessed two patients whose breathlessness improved when administered with oxygen, and then provided them with a programme of exercise. During the exercise programme they observed that the patients improved daily, and whilst on oxygen the distance walked each day doubled; they also noted that without oxygen patients improved significantly, with minimal breathlessness experienced.

Almost 20 years later, in 1969, Thomas Petty published a seminal piece, which was the first to discuss an extensive programme of rehabilitation, providing both long and short term benefits for patients with COPD (Spruit & Clini, 2013). Initially, there was reluctance during the 1980's surrounding the effectiveness of an exercise programme to improve COPD patients' health, and at a time when PR was trying to establish itself, it was referred to as the '*dark ages*' of PR (Casaburi, 2008, pg 1187). During this time it was difficult to convince some individuals of the benefits of PR, particularly those who believed that COPD patients had insufficient lung capacity to exercise to a threshold where they could improve their skeletal muscle function (Belman & Kendregan, 1981). However, the first international report was produced by the European Respiratory Journal Working Group in 1992, which compellingly advocated the use of PR to HCPs, describing it as an effective management strategy for those with COPD, (Donner et al., 1992). The report detailed the three primary aims of the programme:

*'1) a decrease of physical and psychological impairment due to the disease, 2) an increase in physical and mental fitness and performance and 3) maximal social re-integration of the patient to lower the handicap.'* (Donner et al., 1992, pg 266).

Spruit et al., (2013), on behalf of The European Respiratory Society and American Thoracic Society, developed a consensus statement which still adheres to the aims first reported in 1992. Given the strong evidence base the consensus statement advocated the referral of COPD patients to the programme. Although, there are a number of guidelines and definitions internationally for PR, they formed a collective and universal definition, describing PR as:

*“a comprehensive intervention based on a thorough patient assessment followed by patient-tailored therapies that include, but are not limited to, exercise training, education, and behavior change, designed to improve the physical and psychological condition of people with chronic respiratory disease and to promote the long-term adherence to health-enhancing behaviors.”* (Spruit et al., 2013, pg e16).

### **1.3.2 Aims and Effectiveness of PR:**

PR is a proven evidence based intervention which is effective in reducing COPD related hospital admissions (Moore et al., 2016) and the associated financial costs (Vogiatzis et al., 2016). It is a non-pharmacological therapeutic management strategy used in the care of patients with COPD (Arnold, Bruton & Ellis-Hill, 2006), and has been successful in enhancing health related quality of life (Janssens et al., 2011; McCarthy et al., 2015), exercise tolerance (McCarthy et al., 2015; Rochester et al., 2015), ability to carry out daily activities (Paz-Diaz et al., 2007), and reducing depression and anxiety (Coventry & Hind, 2007; Harrison et al., 2012; Paz-Diaz, 2007). The key aim is to assist patients with reduced exercise capacity caused by breathlessness and enable them to become actively engaged in their health (Steiner & Roberts, 2016). It is important to distinguish the difference between exercise capacity and physical activity. Exercise capacity is associated with an individual's ability and capability to exercise, whereas physical activity is associated with the exercise undertaken to enhance fitness levels (Troosters et al., 2013). It is therefore recommended that PR programmes should encompass an appropriate exercise regime to increase exercise capacity, education, breathing techniques, medication advice, behaviour change techniques and psychological support (BTS, 2013). Therefore the programme is multidisciplinary providing individualised care for each patient regardless of where they are placed on the disease trajectory (Nici et al., 2009); with the view of helping patients to self-manage their symptoms (Carlin, 2009).

Assessments are often carried out to evaluate patients' exercise capacity at the start of PR, and any potential improvement throughout the duration of the programme (Jenkins, 2007;

Singh et al., 2008; Singh 2018). The most common are the six minute walk test (6MWT) and the incremental shuttle walk test (ISWT) (Singh, 2018), performed to assess potential disease severity, exercise tolerance and an individual's performance (Rennard & Drummond, 2015). The 6MWT is a simplistic patient paced assessment in which patients are asked to walk up and down a 30 metre corridor, and the distance walked over a six minute period is recorded and can be used to assess patients pre and post PR (American Thoracic Society, 2002). Conversely, the ISWT is pre-paced along a 10 metre corridor, with the speed which patients are required to walk between two cones determined by a pre-recorded audio bleep, with the speed increasing over the 20 minute test period (Holland et al., 2014). The endurance shuttle walk test (ESWT) is conducted on the same 10 metre corridor and, although externally paced, it is not incremental and therefore walking remains at a steady pace (Singh, 2018). Oxygen saturation, heart rate, breathlessness and blood pressure should be measured both prior and subsequent to any of the tests, to determine impact (Singh, 2018). Both the 6MWT and the ISWT display good test-retest reliability, with a poor 6MWT an accurate predictor of hospital admission and patient mortality (Holland et al., 2014).

It is acknowledged that conducting a programme of PR, subsequent to hospitalisation for COPD, dramatically reduces the rate of re-admission and mortality (Puhan et al., 2016; Revitt et al., 2013); thus lessening the financial costs associated with frequent hospital admissions (Spruit et al., 2013). PR enables patients to separate themselves from the vicious cycle of inactivity they enter through modifying their behaviour in a safe multidisciplinary exercise programme (Troosters et al., 2013). The programme has been effective in reducing some of the exercise related fear discussed previously, and has the ability to change how patients perceive breathlessness (Williams et al., 2010). If high intensity exercise is carried out, it can decrease oxygen demand through muscle reconditioning (Troosters et al., 2010). Patients in the study by Williams et al., (2010), believed that PR had changed their attitude to breathlessness, which had a positive impact upon their quality of life. The increase in mobility enabled patients to walk further than they previously could, carry out household tasks such as hoovering, and reduce social isolation enabling them to partake in activities they once loved. PR allows patients to adapt to a life with COPD, and often provides a rare chance to meet others whose experiences bear a close resemblance to their own, as prior to this they may have never met anyone else with the condition (Cooke & Thackray, 2012; Halding, Wahl & Heggdal, 2010). The programme therefore has the ability to increase quality of life and assist psychologically (McCarthy et al., 2015).



The effectiveness of PR is therefore proven, with a reduction in the likelihood of increased ventilatory impairment and skeletal muscle dysfunction for up to two years after participation (McCarthy et al., 2015). It is not always possible to maintain the benefits of PR, with the duration of the benefits experienced variable (Morgan, 2017; Reis et al., 2007; Rochester & Spruit, 2017). Those, however, who experience benefits from the programme may be more likely to continue to exercise, and therefore would be ideal candidates for follow up PR (Rochester & Spruit, 2017). Patients who are referred to PR for a second time often experience similar positive benefits (Morgan, 2017). As a result, PR maintenance programmes are increasing in popularity, and have the ability to provide patients with a further 3-12 months of benefits (Busby, Reese & Simon, 2014). As the benefits of PR vary it is therefore proposed that PR should be used in conjunction with other treatments and management strategies, to allow patients to have the best quality of life possible (Evans & Steiner, 2017).

### **1.3.3. Structure and Content of PR:**

Although PR is effective in improving patients' health (McCarthy et al., 2015; Revitt, Sewell & Singh, 2008), the availability and content differs globally dependant on geographical location (Mallia et al., 2008; Spruit et al., 2013). Similar variations can be observed throughout England and Wales, with varying group sizes and session lengths, often due to individual programmes or trusts being responsible for the organisation and delivery of their programme (National PR Audit, 2015). The National PR Audit (2015), highlighted that location, HCPs delivering the content, dropout rates, reimbursement for attendance, patient referral criteria and referral processes all differed significantly across the country. There are also discrepancies in patient referral criteria and the referral process, with some accepting self-referral, re-referral, and attendance after hospital admission, whilst others do not. Many have access to physiotherapists, nurses, dieticians and occupational therapists, to deliver programme content, however availability of respiratory physicians, pharmacists, psychologists and social workers is limited. The location where PR is delivered also differs, with community halls and leisure centres most commonly used, and other sites noted as hospitals, health centres, general practice surgeries or prisons (National PR Audit, 2015).

The National PR Audit (2015) also highlighted differences between services and which patients they would consider suitable for the programme, with only 19% accepting patients who are towards the severe end of the disease trajectory (MRC scale 5). In addition, although it is recommended that patients should receive PR following an exacerbation

resulting in a hospital stay, only 66% of services were able to offer this, and only 22% of these services had the provision for patients to commence the programme in less than a month of discharge. Thus, a number of key recommendations were made, which included PR providers and commissioners ensuring there is a clear referral pathway in place, and availability on programmes for patients discharged from hospital following an exacerbation. Moreover, it was advocated that patients should have the opportunity to attend PR regardless of the severity of their disease (MRC scale 2-5), or their current exercise capacity, with a focus on commissioners guaranteeing long term funding.

National UK PR guidelines (BTS, 2013) highlight the components required to deliver an effective programme; this is due for review in 2018. Similar to the National PR Audit (2015), the guidance acknowledged that programmes vary nationally in the content and delivery, however suggested that PR should be delivered twice weekly, as frequent contact increases chances of improvement in a patient's condition. The guideline states that patients with mild to severe COPD should be considered for PR, and advises that all patients admitted to hospital with an exacerbation should be referred. In a review of the literature regarding PR and severe exacerbations by Mann et al., (2015), it was concluded that exacerbations have a great impact upon both physical symptoms and psychological wellbeing. They added that although attendance at PR following an exacerbation is recommended worldwide, many patients and possibly HCPs do not value it. These findings are reiterated by the BTS (2013), who suggest that the success of PR is restricted by poor patient uptake and adherence.

In order to develop an effective programme and increase adherence, the multi-disciplinary nature of PR should be embraced, encompassing exercise training, education, nutritional advice, self-management and psychological support. The effectiveness of PR increases when these aspects combine and are delivered by experts in the field; each component is successful individually, however when amalgamated surpass the singular elements (Spruit & Nici, 2018).

#### **1.3.4 Patient Suitability for PR:**

The NICE guidelines (2010), state that PR should be offered to patients who define themselves as *functionally disabled*; these are individuals who would typically have an MRC score of three or above. They add that any COPD patient whose condition is stable, and who has exercise limitation as a result of breathlessness, should be referred to PR. The BTS (2013) agree with the NICE (2010) guidelines and reinforce that PR should be offered to those recently admitted to hospital with an exacerbation of their COPD, and commence

within four weeks of discharge. It is also emphasised that PR should be delivered in a location and at a time suitable for the patient's needs, with a timely admittance to the programme after referral (NICE, 2010). The MRC breathlessness scale, discussed previously, is often used to assess patient suitability for PR (Stenton, 2008). It is however proposed that the MRC breathlessness scale should not be used in isolation to exclude a patient from PR, as patient exercise capacity has been shown to improve regardless of the breathlessness score (Evans et al., 2009). The BTS (2013), add that HCPs who refer patients to PR should have an adequate level of understanding of the components of the programme, allowing them to educate the patient of the benefits.

### **1.3.5 Referrals and Engagement with PR:**

The focus of discussion here will predominantly concentrate on the pulmonary rehabilitation workstream audits. The first national PR audit entitled 'Pulmonary Rehabilitation: Time to breathe better', was the first to be published worldwide, and to release details of the information gathered from 224 PR programmes in England and Wales (National PR Audit, 2015). The findings of the PR audit were of particular relevance to the thesis, and greatly assisted in the development of the project, research question and aims. It highlighted that even though referral practice was not included in the audit, it is evident that many COPD patients suitable for PR are not referred. This was identified after assessing the prevalence of COPD, and then estimating those who would be potentially eligible, and comparing this to the number currently attending the programme. The audit revealed that between 2013 and 2014 approximately 68,000 patients in England and Wales were referred to PR. When compared to the 446,000 patients during this period estimated to be eligible for PR, with an MRC score of 3-5, this highlights that the number of referrals was significantly lacking, with patients not being given the opportunity of an effective evidence based management strategy.

Since the PR audit was published in 2015, a historical/retrospective cohort study of UK general practice data has been undertaken by Moore et al., (2017). The study sought to assess the numbers of patients who were admitted to hospital or treated in primary care with an acute exacerbation of COPD, one year before attending PR and one year after. They concluded that attending PR did not result in fewer exacerbations in the following year. It was however interesting to note that their findings support the notion that there are a lack of referrals to PR in the UK, with 69,089 patients in the study deemed as eligible, and only 6,436 (9.3%) recorded as being referred to the programme. They summarised that referrals were not made for 62,019 patients (89.8%), and a further 634 (0.98%) were offered PR,

however refused to attend. This study was critiqued by Evans and Steiner (2017) in an editorial, who suggest that the number of patients with COPD may be much greater than predicted, due to primary care data recording, on occasion, being imprecise. The editorial further identified that part of the inclusion criteria consisted of patients who experience frequent exacerbations, and as these individuals are more prone to developing infections, this is something which PR cannot account for nor reduce, therefore their conclusions regarding the effectiveness of PR should be approached with caution.

Due to the known benefits achieved from attendance at PR, increasing patient uptake is a key priority for a number of services (Williams, 2011). The National PR Audit (2015), unveiled that a large proportion of patients referred subsequently do not attend. It is also recognised that patients who live in deprived areas and have a low socio-economic status are not as likely to finish a programme of PR, although those who complete gain the same benefits, and do not differ in terms of outcomes achieved (Steiner et al., 2017). Possible explanations for low attendance and referral rates were offered within the National PR Audit (2015), suggesting that HCPs may lack knowledge of the programme's benefits, and as a result may not 'sell' it to patients. These however are merely assumptions, and no specific evidence is available to support the claims. This highlights current issues surrounding referral and attendance at PR, however the reasons why still remain unclear, hence further clarification is required. The audit stressed the importance of HCPs in both primary and secondary care engaging in conversation of PR, when discussing COPD management with eligible patients, and that this should be a prime concern.

The same issues regarding referral to PR in primary care appear to be apparent in secondary care, however there is less evidence available to support this. The National COPD Audit Programme (2017) did however conduct a secondary care organisational audit, which concluded that only 46% (82) of hospitals included, reported availability in PR within 4 weeks of discharge. In addition, the findings revealed that regardless of being recommended by NICE (2010) that patients admitted to hospital with an exacerbation of their COPD are referred to PR upon discharge, 44% of patients still return home without being assessed for referral. Although this has improved from 38% in 2014, it still does not meet patient needs, thus it was concluded that access to PR requires improvement in secondary care. Overall, it is evident that referral rates to PR could be improved in both primary and secondary care (Spruit et al., 2013). Following the audit it was recommended as a requisite that more research should be conducted, to establish a clearer understanding of aspects which influence accessibility to PR (Steiner & Roberts, 2016), and that PR should

be accessible and offered to all eligible patients, with a focus also on those with a lower socio-economic status (Johnston & Williams, 2017).

## **1.4 PATIENTS' PERCEPTIONS OF PULMONARY REHABILITATION:**

### **1.4.1 Patients' Experiences and Views of PR:**

A vast range of literature has been published in relation to patients' perceptions and experiences of PR, therefore selected key papers have been drawn upon to provide an overview. It is well documented that patients experience an increased benefit from attending PR after a diagnosis of COPD; in particular patients are less apprehensive about symptoms and have an improved exercise capacity (Williams et al., 2010). Patients' views of attending PR are mostly positive, with only a small minority not adapting well to the programme, finding it difficult to adjust to the exercise component (Zakrisson, Theander & Anderzén-Carlsson, 2014). A systematic review of the qualitative literature highlighted that patients experience many benefits from attendance at PR (De Sousa Pinto et al., 2013). Within the review, focus was primarily placed upon the psychological benefits patients experience, with the group setting increasing confidence, forming friendships and reducing loneliness. Studies included in the review also highlighted other advantages discussed by patients, which encompassed the education that equips them to better manage their condition, the positive health transitions which occur, such as encouraging patients to make health-related behaviour changes, and setting goals and providing hope. The new knowledge gained from PR was described as providing '*a new way of life*' (pg 149). Perceived patient disadvantages were described in the review as, difficulties in attendance due to transportation issues, the return of isolation after PR due to a lack of continued support and the duration of the programme not being long enough. It is evident that patient experiences of PR are both positive and negative, therefore all of the issues introduced will be explored in further detail below.

Prior to PR, patients can often feel as though they are dealing with the illness alone and receiving very little guidance from HCPs, however during the programme patients report a sense of inclusion from other patients, and HCPs delivering the sessions (Halding, Wahl & Heggdal, 2010). This sense of inclusion culminates from receiving exercise information and personalised medical and emotional support, with patients feeling that the programme equips them to live with the condition (Halding, Wahl & Heggdal, 2010). Other patients have reported finding the group setting reassuring and motivating, knowing that others are experiencing the same symptoms, and that there are some with a condition as severe as

their own (Sinnerton & Gillen, 2009). The benefits of attendance at PR therefore appeared to be much greater than just improved exercise capacity (Sinnerton & Gillen, 2009). Before attending PR some patients report feeling different to those without COPD, and feel stigmatised for having a condition which others perceive is self-inflicted, thus there is a perceived lack of sympathy from others (Toms & Harrison, 2002). The group setting of PR however has been found to dispel some of these thoughts and patients find comfort in the fact that they no longer feel that they are dealing with the condition alone (Toms & Harrison, 2002). This change in perceptions and the increase in knowledge provided by the programme allows patients to take back control and live life to the full, and not to become worried by breathlessness (Zakrisson, Theander & Anderzen-Carlsson, 2014). Much of this new found confidence is attributed to the multidisciplinary nature of the programme, providing a comprehensive package of exercise, education, psychological support and peer and HCP reassurance and guidance (Sinnerton & Gillen, 2009; Vincent et al., 2017; Zakrisson, Theander & Anderzen-Carlsson, 2014).

Some patients refuse the offer of PR (Mathar et al., 2017), believing that COPD is self-inflicted, due to many years of smoking, and therefore perceive that they do not deserve any additional treatment (Harrison et al., 2015). Feelings of self-blame and stigmatisation, from both HCPs and the general public, are present after diagnosis (Harrison et al., 2015). These patients often describe feeling unworthy of PR, due to prior unpleasant experiences with HCPs who focus upon smoking during consultations, making them reluctant to return for advice (Halting, Heggdal & Wahl, 2011). Insufficient knowledge of PR is also a contributory factor to non-attendance, believing the programme focuses upon exercise which they would be incapable of performing (Harrison et al., 2015). Others are anxious about attendance, due to holding the perception that exercise induces breathlessness (Thorpe, Kumar & Johnston, 2014).

As previously discussed, many patients are unaware of the help available to them, and when asked about PR do not remember being offered referral (Mathar et al., 2017). Some patients do however have an understanding of PR, although are unsure of how to access the programme due to a lack of information provided by HCPs (Mathar et al., 2017; Thorpe, Kumar & Johnston, 2014). Other patients perceive that accessing further help from healthcare services is futile, as they believe nothing more can be done after being told by a HCP that their lungs will never improve; information that seems to leave a lasting impression (Habracken et al. 2008). Reasons for non-compliance and withdrawal from PR include issues with transportation and living a distance from where the service is delivered (Keating, Lee & Holland, 2016; Sabit et al., 2008), suffering from an exacerbation, and the perception that

their condition is too serious or conversely too mild to gain benefit from attendance (Hayton et al., 2013; Marthar et al., 2017). Some patients, in particular those who are younger, comment on the difficulty of PR taking place during working hours (Fischer et al., 2007; Marthar et al., 2017), and many patients have other commitments which they decide to prioritise (Marthar et al., 2017). Patients also report having other health conditions and perceive that exercise could worsen these, alongside the misconception that they are too old to participate in PR (Keating, Lee & Holland, 2011). Additional reasons for non-completion range from worsening of respiratory related symptoms (Fischer et al., 2009, Johnston et al., 2013), not observing a benefit, and the illness of a family member (Johnston et al., 2013). Evidently some patients place little importance and value on PR, and do not perceive that attendance will be of benefit (Keating, Lee & Holland, 2011). For those that decide to attend, progression is not solely reliant upon the programme's content, but dependent on patient views and perceptions of COPD (Zoeckler et al., 2014).

The barriers highlighted above, especially perceived severity of COPD, highlight the important role that illness perceptions play in participation and completion of PR, as time since diagnosis has a significant effect on perceptions of the disease, as being long-term and chronic, and therefore affecting perceived ability (Fischer et al., 2010). Similarly, uncertainty experienced throughout the course of COPD impacts upon patients' illness perceptions and is heightened via the perceived decline in their condition whilst waiting to attend PR (Fischer et al., 2010). Waiting for treatment therefore increases anxiety, and although many attend PR, they lack devotion and discontinue with the programme if perceived ineffective (Lewis, Bruton & Donovan-Hall, 2014). Conversely, those who attend PR and believe that it has been beneficial, and have achieved what they wished from the programme, are often less worried about disease progression and feel in greater control of their condition (Fischer et al., 2010). This therefore reaffirms that if patients believe PR is useful in the management of COPD, they are more likely to achieve their full potential from the programme, and have a positive outlook on life (Fischer et al., 2010).

#### **1.4.2 The Impact of HCPs on the Effectiveness of PR:**

A limited amount of literature has sought to explore the impact of HCPs on the effectiveness of PR as a management strategy for COPD. It is proposed that patient expectations of PR are highly variable, and this is often dependant on whether the HCP who referred them informed them of the benefits (Bulley et al., 2009). This study highlighted that many patients are given very little information about PR, and the benefits of the programme are not discussed at the time of referral, which leads to uncertainty as to how useful the programme

will be. A key aspect highlighted in the paper by Bulley et al., (2009) was that patient attendance at PR did not appear to be associated with the level of information provided at the time of referral, however it was linked to how passionate the HCP appeared about the programme. Furthermore, COPD patients who complete PR, indicate that they feel most helpless immediately after the COPD diagnosis, and the information which resonated with them the most upon diagnosis, was that there is no cure (Halting & Heggdal, 2012). Thus, it is evident that the way HCPs communicate with COPD patients can leave a lasting impression and have a great psychological impact.

Patients with COPD discuss how they want to obtain an increased level of knowledge, not be spoken to in complex terminology, and to build a relationship with a HCP who is approachable (Sadeghi, Brooks & Goldstein, 2013). The authors indicate that without following these points, there is the potential for the patient to leave unsatisfied, lacking understanding, and reluctant to return with any further issues or questions. This provides a clear example of how the delivery of the diagnosis and information to patients with COPD, can have lasting negative effects. It is therefore recommended that HCPs who have the ability to refer to PR should promote the programme to patients, yet approach conversations with compassion, being conscious of the insecurities and guilt previously discussed (Harrison et al., 2015).

On average more referrals are made to PR from primary care than secondary care, however patient attendance rates at PR assessment do not differ based upon the referrer, although those referred by a general practitioner (GP) are less likely to complete the programme (Hogg et al., 2012). Lack of referral within primary care is displayed within the literature, however no current research focuses on the perceptions of HCPs in secondary care. It is evident however that HCPs are *not referring* patients as frequently as they should, but the reasons for this are unclear (National PR Audit, 2015). Patients are more likely to accept referrals to PR from a HCP they trust and who understands their condition (Arnold, Bruton & Ellis-Hill, 2006), hence, it is important for those who refer to have an adequate level of knowledge regarding the programme (BTS, 2013).

## **1.5 CHAPTER SUMMARY:**

This initial chapter aimed to provide a comprehensive introduction and background to the thesis, and formulate a rationale for the research. An overview to COPD was provided, and the history and current literature surrounding PR explored. Insight has been provided into



the aims, structure and content of PR, along with patient suitability. Current literature, as evidenced in this chapter focuses upon patients' perceptions of PR and the barriers and facilitators which could impact upon uptake, attrition and completion. Given that the effectiveness of PR is proven, this chapter placed emphasis upon a lack of HCP referrals, as highlighted by the National PR Audit (2015). The reason for a poor referral rate to the programme is unknown, however the audit suggests that HCPs may not be advocating PR to patients. It is therefore evident that there is a need for further research to identify HCPs perceptions of PR, if they refer, and their beliefs of the barriers and facilitators to referral. This chapter does not attempt to be definitive, as there is a wealth of literature available which could have been drawn upon; it merely serves to provide an overview to both COPD and PR. The following chapter takes the form of a Critical Interpretive Synthesis (CIS) and aims to identify pre-existing literature surrounding HCPs perceptions of the programme, in an attempt to increase understanding surrounding why referrals to PR are low, and if HCPs perceptions may be a contributory factor to low referral rates.

## **CHAPTER 2: CRITICAL INTERPRETIVE SYNTHESIS: HEALTHCARE PROFESSIONALS' PERCEPTIONS OF PULMONARY REHABILITATION AS A MANAGEMENT STRATEGY FOR PATIENTS WITH CHRONIC OBSTRUCTIVE PULMONARY DISEASE**

### **2.1. INTRODUCTION:**

This chapter aims to display the available literature regarding HCPs' perceptions of PR as a management strategy for patients with COPD, and will take the form of a Critical Interpretive Synthesis (CIS). A background to systematic review methodology and CIS is provided, prior to justification of why this form of review has been chosen. The aims, review question and methods undertaken are provided. The findings are displayed in a narrative which was formed after synthesis of qualitative, quantitative and mixed-methods research included in the review. The narrative encompasses the views of HCPs with the ability to refer to PR, and those who deliver the programme. This chapter therefore aims to establish the current literature surrounding HCPs perceptions of PR and the gaps in evidence in the current evidence base. The literature identified within this chapter was used to inform and guide the design and conduct of the main study discussed in Chapter 3.

### **2.2. BACKGROUND TO SYSTEMATIC REVIEW METHODOLOGY AND CRITICAL INTERPRETIVE SYNTHESIS (CIS):**

Recently there has been an acceleration in the popularity of systematic reviews within the healthcare sector; the rise has occurred due to this type of review providing a detailed summary and analysis of current literature, with the ability to influence policy and practice (McGowan, 2012). A systematic review in its most simplistic form is essentially defined by its two components; '*systematic*', being carried out with a specified plan (Oxford Dictionary, 2017a), and '*review*' described as '*a formal assessment*' (Oxford Dictionary, 2017b). Systematic reviews such as Cochrane Reviews, which only assess randomised control trials, have been acclaimed as the gold standard of research (Kowalczyk & Truluck, 2013). Prior to systematic reviews, narrative reviews were previously the method of choice, as they allow researchers to give an accessible broad overview of the literature in relation to a specified review question (Green, Johnson & Adams, 2006). Narrative reviews however do not comprise of a detailed method or review procedure, nor contain defined inclusion or exclusion criteria for selected studies (Dixon-Woods et al., 2006a; Popay et al., 2006). It was considered that this could be perceived as subjective and potentially lead to selection

bias, resulting in the inability to replicate findings (McGowan, 2012), as a result narrative reviews are becoming less popular amongst some journal editors (Green, Johnston & Adams, 2006). The most notable difference between the two approaches is that systematic reviews provide a rigorous evaluation of the literature to date, and can, by means of transparency in methods, be updated to encapsulate new findings. Narrative reviews on the other hand produce a snap shot of the literature attainable to the researcher at the time of the review (Booth, Papaioannou & Sutton, 2012).

A form of systematic review methodology, known as critical interpretive synthesis (CIS) (Dixon-Woods et al., 2006b) was chosen for the current review question: 'What are the perceptions of healthcare professionals in both primary and secondary care regarding pulmonary rehabilitation as a management strategy for patients with Chronic Obstructive Pulmonary Disease?'. CIS is a method developed by Dixon-Woods et al., (2006b), who took the formal structure of meta-ethnography, which only includes qualitative papers, and modified it to include a number of methodological approaches, including quantitative, qualitative and mixed methods. This enables integration of data extracted from different research methodologies to produce a synthesising narrative (Dixon-Woods et al., 2005).

A systematic review approach was favoured as it allowed a clear methodology to be followed, enabling replication and appraisal of the literature and synthesis, in order to produce a clear and coherent representation of the research area under question (Halcomb & Fernandez, 2015). It therefore allows the researcher to confidently state, to the best of their knowledge, that all literature pertinent to the review question has been identified and included.

Due to the nature of the review question, studies previously conducted in the area have encompassed a range of methodologies including quantitative, qualitative and mixed methods. It became apparent that a traditional systematic review, such as meta-analysis used to display evidence from only quantitative statistical research (Borenstein et al., 2009), or a meta-synthesis used to integrate and synthesise purely qualitative studies (Walsh & Downe, 2005), would not be appropriate for this review. Therefore, it was evident that an integrative review which allows for the synthesis of both quantitative and qualitative data, would be required (Whittemore & Knaf, 2005). Integrative reviews are effective in gathering and summarising the literature in the area of focus, whilst following a detailed methodology similar to that carried out in primary research studies; this increases rigour in comparison to narrative reviews (Cooper, 1982; Torraco, 2005). It should however be noted that there is a key difference between a strict integrative synthesis that compiles and summarises the

literature, and an interpretive synthesis where focus is paid to synthesising and interpreting the data, in order to draw conclusions and offer suggestions (Pope, Mays & Popay, 2007).

Although it was clear this review required a technique that enabled integration of different research methodologies, an approach was sought that also allowed for interpretation of the literature. This was determined after it became evident there was very little literature to directly address the review question, and a large proportion of this literature was qualitative in nature, with a few quantitative and mixed methods papers. Hence, it was apparent that qualitative research would be a dominating factor within the review, and an approach that allows the researcher to dissect relevant parts of a study to form a synthesising argument would be required. Although, an integrative approach, rather than an aggregated approach was sought, a method was also required to permit findings to be analysed in a way that complements qualitative data (Dixon-Woods et al., 2005). Therefore, initial consideration was paid to meta-ethnography, whereby qualitative studies are synthesised and interpreted by the researcher; the method relies heavily on holism, whereby studies are transformed and translated into one another, rather than described separately (Noblit & Hare, 1988). This approach sits within the interpretive paradigm, and has the ability to compile findings from a number of qualitative studies into a narrative; providing new insight and highlighting research previously conducted in the area under review (Atkins, et al., 2008). A limitation of meta-ethnography however, is that it does not accommodate the integration of quantitative studies into the review (Pope et al., 2007), thus attention was shifted to CIS.

CIS promotes the creation of a synthesising argument, which provides a narrative to display new understanding gained from the existing literature (Flemming, 2010). The synthesising argument is structured using synthetic constructs, which take form after interpreting the literature as a whole, and displaying it in a representative, yet new conceptual form (Dixon-Woods et al., 2006b). CIS is novel in its approach as it encompasses the authorial voice, and interpretation of the literature yielded in the search (Gough & Thomas, 2012). Having previously cared for a close relative with COPD, this brought a unique perspective as an author to the review. CIS acknowledges that different accounts may be formed dependent on author insight, however this is promoted on the basis that interpretations are grounded in extracted data and reflection is included (Dixon-Woods et al., 2006a). During the review, literature was analysed using a technique similar to thematic analysis. Emergent codes were first identified throughout the data, before establishing commonalities and potential themes, enabling the formation of a rich and coherent narrative (Braun & Clarke, 2006). This ordered process assisted with the development of synthesising arguments, as the themes and codes contributed to the formation of synthetic constructs.

### **2.3. AIMS OF THE REVIEW:**

This CIS aimed to identify and synthesise the literature exploring HCPs' perceptions of PR as a management strategy for patients with COPD. The review aims to be inclusive of a diverse range of HCPs' beliefs and opinions, therefore the synthesis will incorporate the perceptions of those who refer to PR, those who deliver it, and other HCPs who have provided their views about PR.

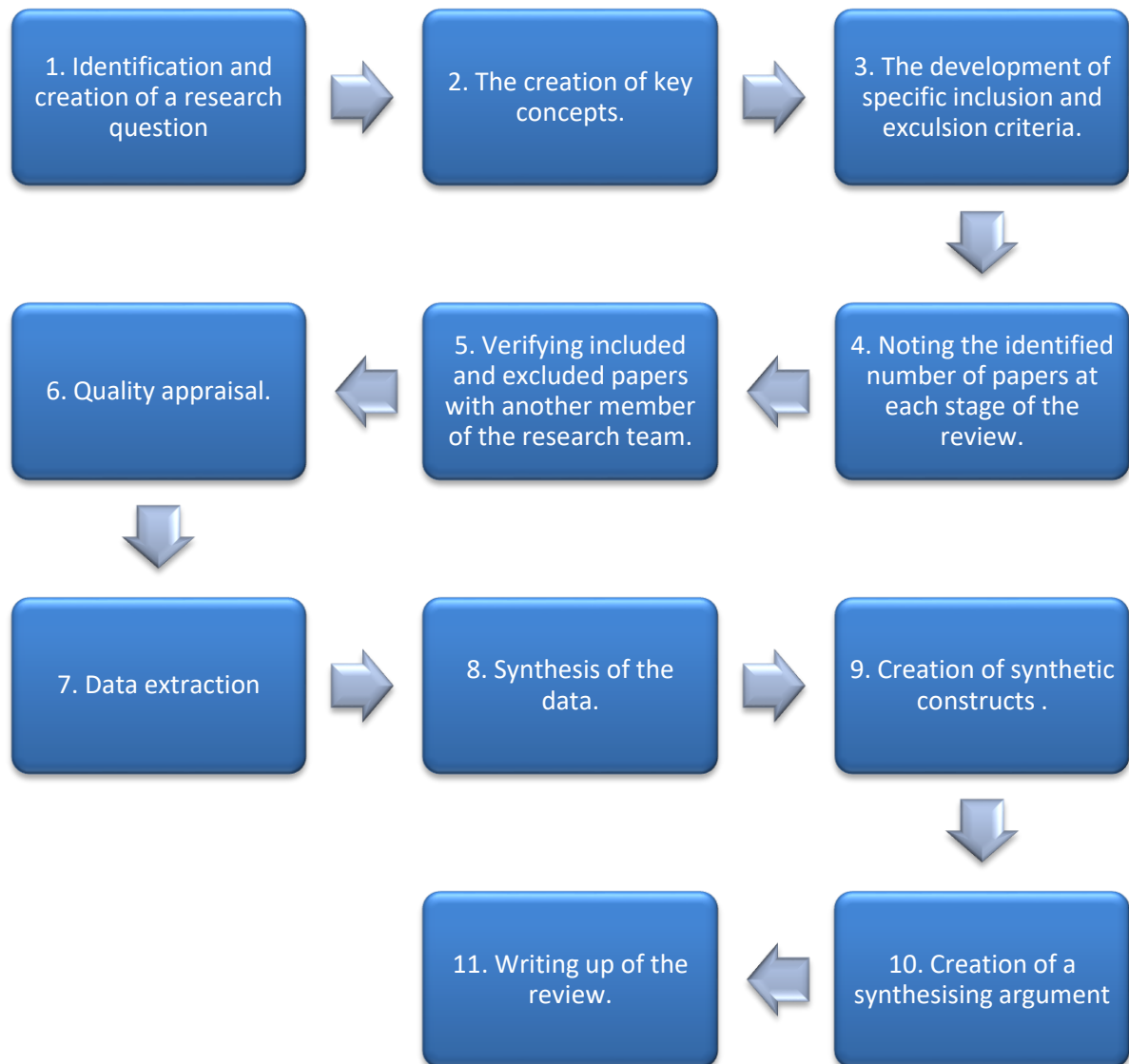
### **2.4. REVIEW QUESTION**

What are the perceptions of healthcare professionals in both primary and secondary care regarding pulmonary rehabilitation as a management strategy for patients with chronic obstructive pulmonary disease?

### **2.5. REVIEW METHOD:**

The method undertaken when carrying out the systematic review followed the key components of CIS outlined in Figure 3.

**Figure 3 Method undertaken when carrying out the CIS, adapted from the methodology proposed by Dixon-Woods et al., (2006)**



### **2.5.1 Study Selection; Inclusion and Exclusion Criteria:**

The inclusion and exclusion criteria were carefully considered to gather papers of the highest significance to the review question. It is recommended that criteria should be well defined yet comprehensive in order to establish a detailed overview of the phenomenon in question (Jensen & Allen, 1996). Therefore, the inclusion and exclusion criteria were reviewed and agreed by the supervisory team prior to conducting the search. Papers included in the CIS were required to meet all of the inclusion criteria. Please see table 1 for details of the criteria that papers were compared against.

**Table 1: Inclusion and Exclusion Criteria**

<b>Inclusion Criteria:</b>	<b>Exclusion Criteria:</b>
The study establishes HCPs' perceptions of PR as a management strategy for patients with COPD; in full or as part of a larger study.	Does not include HCPs' perceptions of PR as a management strategy for COPD, or only includes patient perceptions.
Written in English.	Paper unavailable in English.
Conducted between 1988-2018.	Any research conducted prior to 1988.
Primary research study with a clear and detailed method.	Discussion or review papers, or studies without a clearly stated methodology.

**2.5.2 Search Strategy:**

Papers were identified using a systematic search strategy (see appendix 2). Advice and guidance for the initial search strategy was sought from a clinical information specialist who had expertise in creating advanced searches for systematic reviews. An information specialist from Cochrane Airways Group also confirmed that search terms and filters used complemented their searches for COPD. When undertaking a systematic review, the details of each stage of study selection are documented with enough detail to allow the search to be replicated, which in turn reduces selection bias (Centre for Reviews and Dissemination (CRD) (2009).

Three databases were selected, which included: CINAHL, MEDLINE and PsychINFO. Searches were refined by restricting results to the last 30 years (1988-2018), as this is the approximate period of time PR has been used in the management of COPD (Casaburi, 2008). The databases were chosen due to their emphasis on either general healthcare or medicine (EBSCO, 2016a), nursing and allied healthcare professionals (EBSCO, 2016b), or psychological and behavioural aspects (American Psychological Association, 2016). The initial search of CINAHL was conducted on 9<sup>th</sup> June 2016, MEDLINE on 18<sup>th</sup> August 2016, and PsychINFO on 10<sup>th</sup> June 2016. Each search was then re-run on 12<sup>th</sup> January 2018, to encompass any new literature published whilst conducting data synthesis and writing the review. A hand search was also carried out in key respiratory journals, and reference lists of included papers. It was anticipated these databases, along with hand searching key respiratory journals, would encompass all of the factors related to the review question, including: respiratory, health, and psychological.

### 2.5.3 Key Concepts Defined:

The key concepts used to search all databases were *chronic obstructive pulmonary disease*, *pulmonary rehabilitation*, *healthcare professional* and *perception*. For each concept a definition has been provided in table 2, to exemplify how the term was utilised in relation to the review question.

**Table 2: Key Concepts Defined**

<b>Chronic Obstructive Pulmonary Disease (COPD):</b>	COPD is an umbrella term for a number of conditions which feature airflow obstruction, or narrowing of the airways, including bronchitis and emphysema (GOLD, 2018). Symptoms suggestive of COPD include: dyspnoea (difficulty breathing), a persistent chronic cough, production of sputum with no other known cause, chest pain and wheezing (NICE, 2010)
<b>Pulmonary Rehabilitation:</b>	PR is led by a multidisciplinary team, and is a programme that provides personalised care for patients with respiratory diseases. This review however only focused on PR for patients with COPD. It encompasses an appropriate exercise programme, education, advice on breathing techniques, medication and psychological support (Spruit et al., 2013).
<b>Healthcare Professional:</b>	Any HCP working in either primary or secondary care who provided their perceptions of the use of PR as a management strategy for patients with COPD.
<b>Perception of PR:</b>	Perception is a diverse term that encompasses HCPs' beliefs, views, opinions, attitudes or satisfaction with PR, as a management strategy for patients with COPD.

Databases have slightly different features, and each requires the user to become familiar with the individual system, for example some use medical subject headings (MeSH) rather than thesaurus terms (Barroso et al., 2003). Where available, thesaurus or MeSH terms



were utilised (e.g. 'attitude of health personnel'), this was a term used in both MEDLINE and CINAHL, and these were exploded to encompass a wide range of other terms. Variants of search terms were also included, for example, perception\*: belief\*, view\*, opinion\*, attitude\*, satisf\*, and were searched for separately. Each term when input into the separate databases was searched for in both the title (TI) and the abstract (AB) of papers.

Phrases were grouped with the use of quotation marks, for instance 'chronic respiratory disease'. Truncation was added using an asterisk mid-word to encompass different spellings or word endings, for example 'pulmonary rehab\*'. Each word variant was linked with the Boolean Operator 'OR', and key concepts with 'AND'. Where available an advanced search strategy was implemented through the use of proximity searching, this allowed words to be searched for in relation to how close they were to one another. In this instance phrases were searched for if they were three or less words away from each other, in either the title or abstract. This was utilised when searching with variants of the word 'healthcare professional', for example the following was entered: AB belief\* OR perception\* OR view\* OR opinion\* OR attitude\* OR satis\* N3 nurse\*. The aim therefore, was to establish papers which had published abstracts with any of the variants of the word 'belief' as provided in the example, no more than three words away from 'nurse'. This was replicated using alternative words for 'healthcare professional'. For a detailed search history of each of the three databases, with the number of recorded hits at each stage, see appendix 2. The techniques discussed allowed for a broad and in-depth search, and ensured as far as possible no relevant literature was overlooked. The search strategy was designed and implemented for each database.

#### **2.5.4 Data Extraction and Quality Appraisal:**

Data extraction is an important aspect of any systematic review, however it is particularly important in CIS, as it allows appropriate data to be extracted in relation to the review question (Dixon-Woods et al., 2006b). For each study that met the inclusion criteria (n=18), a data extraction form and quality appraisal was completed (see appendix 3). The data extraction form was created after consideration of what information would be important to contribute to the synthesis (see appendix 4 for an example of a completed data extraction form and quality appraisal).

Quality appraisals are used within systematic reviews to minimise bias (Dixon-Woods et al., 2006a), however the effectiveness of quality appraisal for systematic reviews, particularly those that incorporate qualitative research comes under much debate (Pawson, 2006).

Some view the use of quality appraisals within systematic reviews as distorted, with many guides and potential oversimplification due to assigning a numerical value to each paper (Littlewood, Chance-Larson & McLean, 2010). Others view them as essential, deeming it an important aspect of the review which enhances findings (Hayden, Cote & Bombardier 2006). Furthermore, it is argued that gaining an overall score may lose important aspects conducted well within the study (Voss & Rehfuess, 2013). It is acknowledged that some quality appraisals, especially for qualitative research, do not allow for the diversity of different methodological approaches, however it is advised that quality appraisals should include questions comprehensive of any method (Dixon-Woods et al., 2004). This suggestion was noted when searching for a quality appraisal tool, as it was a requirement that it encompassed differing qualitative methodologies, and also needed to assess quantitative and mixed methods research.

The quality appraisal tool by Hawker et al., (2002) was used and recommended by Flemming (2010) when carrying out a CIS. It was designed to appraise literature from various research methods, therefore questions are inclusive of different methodologies, and as a result was deemed most suitable for the review. Hence, the quality appraisal for this CIS was conducted in accordance with the guidance provided by Hawker et al., (2002). The protocol for scoring and appraising the quality of the literature was marginally adapted by adding an extra question (question 10), to assess the relevance of the study in relation to the review question (see appendix 5).

The quality appraisal used 10 screening questions, with scores between one (poor) and four (good) for each question. Therefore, the total quality appraisal score given, could be positioned between 10 and 40. The lowest quality appraisal score given was 23 (Yawn & Wollan, 2008) and the highest was 37 (Harris, Hayter & Allender, 2008). Although quality appraisal is important when conducting a CIS, Dixon-Woods et al., (2006b) recommend that the focus should be on including papers of relevance to the review question, therefore, unless the paper is methodologically unsound, it should be included. This approach is promoted, as quality appraisal complements the synthesis (Pawson, 2006), thus when the findings are written they are critically analysed, and consequently any issues identified in the quality appraisal are discussed. For the purpose of this CIS, papers were appraised to assess where they fitted on the quality scale; this has been used as a discussion point in the findings section of the review. It was decided that some data extracted from the lower quality papers provided essential insight and new knowledge to the area in focus, and as a result has been incorporated into the review. It should however be noted that no study was found to be of very poor quality.

### **2.5.5 Data Synthesis:**

Some CIS publications have a broad review question and synthesise data from a purposeful sample, therefore using a subset of papers from a larger sample (Dixon-Woods, 2006b). As the current search yielded a manageable number of papers, each study that met the inclusion criteria (n=18), was included in the analysis. This is consistent with the approach used by Flemming (2010), who recommends not to use a purposeful sample when the topic is of a specific focus and a plausible number of papers are obtained, as inclusion of all enhances the synthesis.

A synthesising argument is formed within a CIS when the data set has been reviewed in detail, and is used to give a representative overview of the information (Dixon-Woods et al., 2006b). Synthetic constructs are developed after consideration of all of the data, allowing for interpretation and exploration of various aspects of the phenomenon. Interpretation is promoted, encompassing the authorial voice, yet all conclusions should be grounded in the data (Dixon-Woods et al., 2006b). Two key themes were formed: Barriers to PR and General Perceptions of PR. The data was analysed by hand, initially annotating hard copies of included papers, and then transferring thoughts on to flip chart paper using post-it-notes. Transferring supporting quotes or extracts on to post-it-notes allowed for manoeuvrability between different synthetic constructs during the decision making process. It would have been possible to use NVivo 11® (QSR International, 2015), a software package which assists with the organisation of qualitative data for this process, however as a manageable number of papers (n=18) were obtained and only data relevant to the review question was extracted, a pen and paper approach was adopted.

During analysis, synthesising arguments were displayed on the left hand side of the flip chart paper, with synthetic constructs in the middle, and supporting quotes or extracts on the right. An example of how synthesising arguments and synthetic constructs took form, is provided in appendix 6. This analysis was used to assist with the formation of the narrative.

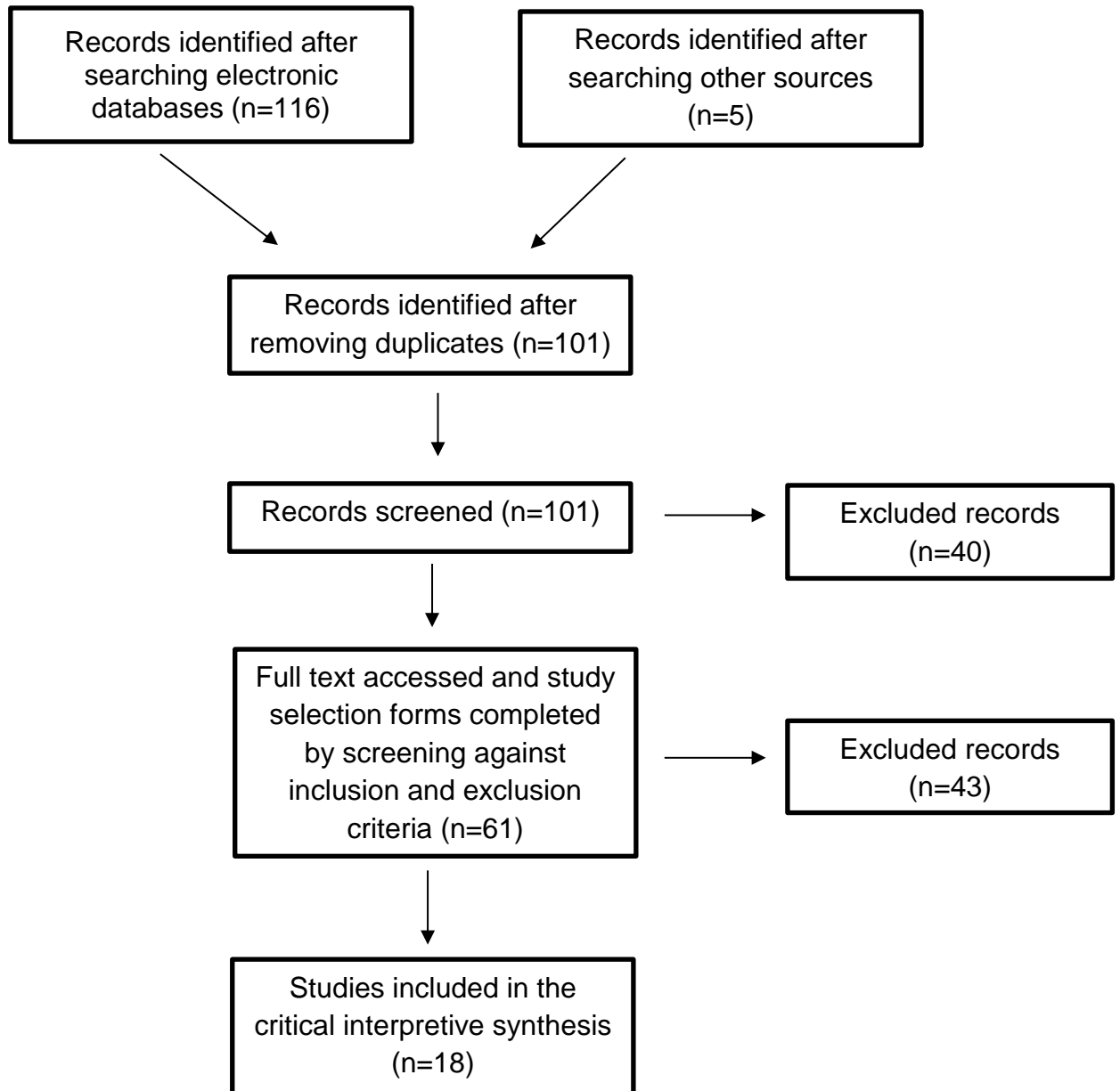
### **2.6 REVIEW FINDINGS:**

The review process was carried out in two stages following guidance from the Centre for Reviews and Dissemination (2009). Initially 121 records were identified; removal of duplicates resulted in 101 papers. Each paper was screened by reading the title and abstract against the inclusion criteria, resulting in 61 papers. Stage two involved reviewing the full text of the remaining papers using the study selection form (See appendix 7). The

initial screening process was conducted by the primary researcher (ES), and at stage two the remaining 61 were independently reviewed by the director of studies (CK); agreement was 100%. It is good practice when conducting a systematic review to have all papers checked independently by another researcher, to verify decisions and increase reliability (Centre for Reviews and Dissemination (CRD), 2009). Therefore, as the search yielded a manageable number it was decided to verify the whole sample.

Eighteen papers met the inclusion criteria and were incorporated into the review (See Figure 4, for the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram (Moher et al., 2009). The reason for exclusion (n=43) was either they did not include HCPs' perceptions of PR (n=36), or it was a discussion or review paper (n=7). The 18 studies included in the review encompassed a range of qualitative (n=10) and quantitative (n=5) methodologies, along with mixed methods (n=2), and action research (n=1). One paper by Yawn and Wollan (2008), was assessed in greater detail as the primary researcher (ES) was unsure that it met all the inclusion criteria. This paper was discussed at length with the director of studies (CK), and it was decided that although the study was not as pertinent to the review question as others included, there was still sufficient data in relation to HCPs' perceptions of PR. As no papers, in their entirety, directly answered the review question, relevant data was extracted to form the synthesis.

**Figure 4: Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Moher et al., 2009) flow diagram of records identified at each stage.**



### **2.6.1 Demographic Information of the Synthesised Research:**

All included papers provided data related to HCPs' perceptions of PR, however the views were sometimes from HCPs who had the ability to refer, and from others who delivered the programme. HCPs participating in the included studies ranged from: physiotherapists who ran PR, GPs, practice nurses, nurse practitioners, community matrons, pulmonologists and

respiratory physicians, therefore a wide range of views will be discussed. The studies also originated from a number of geographical locations: Australia (n=6), United Kingdom (UK): (n=4), United States of America (USA) (n=2), Canada (n= 2), Denmark (n=1), Japan (n=1), Saudi Arabia (n=1) and The Netherlands (n=1). Included papers (n=18) were published between 2005-2017, and used a range of data collection approaches. The qualitative studies encompassed: interviews (n=7) (this was inclusive of mixed methods studies by Cochrane et al., 2016 and Johnston (K) et al., 2012, where quantitative analysis was conducted on patient data), interviews combined with survey comments (n=1), focus groups (n=3), and focus groups with semi-structured interviews (n=1). Quantitative data collection included: surveys (n=4), and questionnaires (n=2) (this was inclusive of the action research study by Foster et al., 2016). For further information on each study, please see table 3 for study summaries.

It should be noted that if the study included both HCPs and patients, this information was listed in the study summary table, however only data extracted in relation to HCPs' perceptions of PR was included in the '*main data extraction elements relevant to the review question*' column.

**Table 3: Study Summaries**

Authors/ Year	Location	Methodology	Participants	Emphasis of Study	Quality Appraisal	Main Data Extraction Elements Relevant to the Review Question
Alsubaiei et al., (2016)	Saudi Arabia	Cross-sectional questionnaire	123 participants: 44 physicians, 49 nurses, 30 respiratory therapists/ technicians.	To establish HCPs' views of barriers in establishing a PR programme in Saudi Arabia.	34	<p>Data largely from HCPs unfamiliar with PR (n=119).</p> <p><b>General perceptions of PR:</b></p> <ul style="list-style-type: none"> <li>- 4.5% of physicians, 36.7% of nurses, and 3.3% of respiratory therapists/ technicians believed standard management is more beneficial than PR (<math>p &lt; 0.0001</math>).</li> <li>- 91% believed COPD patients would attend.</li> </ul> <p><b>HCPs' perceived barriers to establishing a PR programme:</b></p> <ul style="list-style-type: none"> <li>- 75.6% 'the capacity of the hospital does not allow us to set up a PR programme'.</li> <li>- 72.4% did not have trained staff to deliver PR.</li> <li>- Costs more than traditional management (<math>p &lt; 0.032</math>); small population of COPD patients (<math>p &lt; 0.005</math>); PR not appealing to HCPs (<math>p &lt; 0.0001</math>).</li> </ul> <p><b>Perceived patient barriers to PR:</b></p> <ul style="list-style-type: none"> <li>- Smoking status (76.2%)</li> <li>- Affecting routine (59.8%)</li> <li>- Accessibility/ transportation (59%)</li> <li>- Dropout rates (55.7%)</li> <li>- Patient disinterest (45.9%)</li> <li>- Limited support from family and friends (41.8%)</li> <li>- Patients not perceiving PR helpful (38.5%)</li> <li>- Dislike group setting (30.3%)</li> <li>- Lack of persuasion from HCPs (23%)</li> </ul>

<b>Barr et al., (2005)</b>	USA	Quantitative: Survey	523 primary care physicians and 528 pulmonologists. Patients with COPD.	To identify HCPs and patients' perceptions of the care involved with COPD.	28	<p><b>Beliefs about PR:</b></p> <ul style="list-style-type: none"> <li>- 63% of HCPs expressed PR would benefit patients with moderate COPD, 76% of primary care physicians and 77% of pulmonologists viewed it would benefit severe COPD patients.</li> <li>- 19% of primary care clinicians and 54% of pulmonologists referred regularly.</li> </ul> <p><b>Perceived barriers to PR:</b></p> <ul style="list-style-type: none"> <li>- Costs and poor insurance coverage.</li> <li>- Availability of the programme.</li> </ul>
<b>Cochrane et al., (2016)</b>	Australia	Mixed Methods: COPD algorithm created, intervention carried out. Interviews with HCPs/stakeholders on barriers and viability of the intervention.	Qualitative: 7 participants: specialist respiration physician, registered nurse, case co-ordinator, GP and three patients. Quantitative: 12 COPD patients.	To explore the views of stakeholders, HCPs and patients on a multidisciplinary PR based intervention.	31	<p><b>Perceived barriers surrounding PR:</b></p> <ul style="list-style-type: none"> <li>- HCPs highlighted GPs were unfamiliar with making referrals.</li> <li>- Healthcare team perceived it challenging to convince patients of benefits; better patient education required.</li> <li>- Respiratory nurses perceived the referral process demanding.</li> <li>- Waiting times.</li> </ul>



<b>Foster et al., (2016)</b>	UK	Participatory Action Research: Semi-structured questionnaire followed by actionable changes. Also questionnaires for COPD patients.	9 GPs, 13 practice nurses and 126 patients.	To identify and create strategies to increase referrals to PR.	34	<b>Poor knowledge of PR, especially from GPs:</b> Suggested and implemented strategies to increase referrals. This included: running sessions at the GP practice to increase awareness, memory aids, prompts on yearly review forms, and development of a PR referral practice specific protocol.
<b>Guo and Bruce (2014)</b>	Canada	Qualitative: Focus group. Also separate focus groups with COPD patients.	7 HCPs involved in the delivery of PR, and 25 patients.	To establish the perceptions of attendance and completion of PR.	32	<b>Benefits of PR:</b> <ul style="list-style-type: none"> <li>- Increased socialisation and group setting reinforces inclusion, increases confidence and self-belief.</li> <li>- Increases patient knowledge.</li> </ul> <b>Barriers to PR:</b> <ul style="list-style-type: none"> <li>- Programme accessibility and expensive parking. Limited patient knowledge of transport options.</li> </ul> <b>General perceptions:</b> <ul style="list-style-type: none"> <li>- Patients most in need lack confidence to improve their quality of life, and are less active.</li> <li>- Motivated patients initiate referral.</li> <li>- If patients are provided with tips, and convinced of benefits in PR assessment, it provides hope and they are more likely to attend sessions.</li> </ul>

<b>Harris, Hayter and Allender (2008)</b>	UK	Qualitative: 5 focus groups conducted.	21 HCPs: 9 GPs, 2 GP registrars, 7 practice nurses, 2 community matrons and one healthcare assistant.	To establish barriers and facilitators to referring COPD patients to PR.	37	<b>Perceived barriers surrounding PR:</b> <ul style="list-style-type: none"> <li>- Lack of clarity, whose role it was to refer.</li> <li>- Lack of knowledge about PR and the referral process.</li> <li>- Long wait times.</li> <li>- Communication issues when introducing PR, and time associated with discussion.</li> </ul>
<b>Johnston et al., (2011)</b>	Australia	Qualitative: Interviews	16 participants: 9 hospital medical practitioners and 7 GPs.	To identify HCPs experience of evidence-based care recommendations for COPD.	31	<b>Perceived barriers surrounding PR:</b> <ul style="list-style-type: none"> <li>- Not their role to refer.</li> <li>- Unclear on eligibility criteria, referral process and waiting lists.</li> <li>- PR is not publicised well enough, resulting in less referrals.</li> </ul>
<b>Johnston (C) et al., (2012)</b>	Australia	Descriptive cross-sectional, observational survey design (anonymous questionnaire).	31 HCPs completed a pre-workshop questionnaire, before a Breathe Easy, Walk Easy training session.	To assess confidence levels and knowledge of HCPs providing management strategies for patients with COPD.	33	<b>General perceptions of PR:</b> <ul style="list-style-type: none"> <li>- 77% viewed PR as important by their health service.</li> <li>- Unconfident in COPD management.</li> <li>- Lack of staff.</li> <li>- Financial difficulties.</li> <li>- Deficiency in knowledge and training.</li> </ul>

<b>Johnston (K) et al., (2012)</b>	Australia	Mixed methods: Semi-structured interviews with HCPs. Quantitative analysis on patient data, which included adherence to COPD recommendations	9 hospital doctors (General medical registrars and interns), and 15 patients.	To establish the implementation of COPD management recommendations, what was expected in comparison to what was implemented. If expected practices differed to those carried out, views were sought to establish the perceived barriers/facilitators to implementation.	26	<b>General perceptions of PR:</b> <ul style="list-style-type: none"> <li>- Doctors admitted they infrequently referred patients, and were more likely to refer those with severe COPD, on maximal therapy.</li> <li>- Those who referred to PR, highlighted the significance of communicating programme benefits at referral.</li> <li>- PR needs publicity. A lack of awareness resulted in forgetting to refer.</li> </ul>
<b>Johnston et al., (2013)</b>	Australia	Qualitative: Semi-structured interviews	12 GPs.	To explore GPs perceptions of the barriers and facilitators to referral to PR.	34	<b>Barriers to referral:</b> <ul style="list-style-type: none"> <li>- Lack of knowledge about PR, COPD and the referral process.</li> <li>- Issues with transportation.</li> <li>- Long waiting lists.</li> <li>- Uncertain of benefits gained.</li> <li>- Difficulty selling the programme.</li> <li>-</li> </ul> <b>Perceived facilitators to referral:</b> <ul style="list-style-type: none"> <li>- Knowledgeable of the benefits.</li> <li>- Suggested making PR part of COPD patients standardised care plan, and issuing incentives.</li> <li>- Raising HCP, patients and public awareness.</li> <li>- Information regarding PR services.</li> </ul>

<b>Johnston, Maxwell and Alison (2016)</b>	Australia	Qualitative: Interviews and survey comments.	25 HCPs who attended a session on PR completed a survey. 16 completed the survey at three month follow up and seven at the 12 month. 11 HCPs participated in interviews.	To explore the opinions, attitudes, and beliefs of HCPs regarding the establishment and delivery of PR.	31	<b>The HCPs perceived:</b> <ul style="list-style-type: none"> <li>- They lacked PR knowledge.</li> <li>- Considered COPD patients challenging. Required HCP's to have a specific skill set, rather than a generalised one.</li> <li>- Patients do not want to attend. Worried about asking a COPD patient to exercise.</li> </ul>
<b>Meis et al., (2014)</b>	The Netherlands	Qualitative: Focus groups and semi-structured interviews.	14 HCPs in associated disciplines. Also, 7 patients starting PR and 6 patients at the end of the programme.	To establish the perceptions of patients attending or who have attended in-patient PR, and the support provided by HCPs.	35	<b>General perceptions of PR:</b> <ul style="list-style-type: none"> <li>- Patients need to be motivated to increase activity; it is their goal.</li> <li>- Sense of accomplishment when patients can do more.</li> <li>- Bonds and friendship are created with others in a similar situation.</li> <li>- PR should incorporate partners.</li> </ul>
<b>Molin et al., (2016)</b>	Denmark	Qualitative: Semi-structured interviews.	8 GPs.	To establish GPs' perceptions of their role in rehabilitation, and how patients manage their COPD.	36	<b>Beliefs surrounding PR:</b> <ul style="list-style-type: none"> <li>- Some GPs would not discuss PR if the patient seemed healthy and did not discuss referral themselves.</li> <li>- Many believed it was not their role.</li> </ul> <b>Perceived barriers to PR:</b> <ul style="list-style-type: none"> <li>- Patients lack motivation to attend.</li> <li>- Distance to the programme.</li> <li>- Those who have attended once, should not be offered again.</li> <li>- The focus of COPD consultations is on medical treatments.</li> </ul>

<b>Motegi et al., (2012)</b>	Japan	Quantitative: Postal survey.	176 surveys were returned from 131 general hospitals, 29 university hospitals and 16 community hospitals. Primarily the survey was completed by the doctor with responsible for the pulmonary department.	To evaluate the implementation of PR in Japan, and to assess communication regarding management strategies between those in primary care and respiratory physicians.	26	<p><b>79 of the hospitals did not run a programme.</b></p> <p><b>General perceptions of PR:</b></p> <ul style="list-style-type: none"> <li>- Lack of service was due to: inadequate work force (90%), not providing revenue (35%), some hospitals not meeting pre-requisites of insurance companies (25%).</li> <li>- Small clinics should provide the service (35%).</li> <li>- 22.4% of respiratory physicians from specialist hospitals believed it was the GP's role to carry out PR.</li> </ul>
<b>Summers et al., (2017)</b>	UK	Qualitative: Interview study	17 physiotherapists	To establish physiotherapists views of goal setting within PR.	35	<p><b>Perceptions of goal setting in PR:</b></p> <ul style="list-style-type: none"> <li>- Need to establish individualised goals at the beginning of PR.</li> <li>- Difficult for patients to begin exercising.</li> <li>- Assessing goals can assist motivation.</li> <li>- Focus on exercise goals, however patients may want to achieve something different.</li> <li>- Realistic goals need to be set.</li> <li>- Some believed goals need to be failed in order to be re-assessed.</li> </ul> <p><b>Perceived service issues:</b></p> <ul style="list-style-type: none"> <li>- Differences in services.</li> <li>- Funding issues, and less input from other disciplines.</li> <li>- Time constraints.</li> <li>- Cost effective, however need to justify the service</li> </ul>

<b>Wilson et al., (2007)</b>	UK (Northern Ireland)	Qualitative: Focus groups.	8 HCPs and 32 patients with COPD.	To assess patients perceptions of the aspects which should be included in the educational component of PR, and compare to the views of HCPs.	32	<b>General perceptions of PR:</b> <ul style="list-style-type: none"> <li>- Patients need better understanding of COPD, to reduce exercise anxiety.</li> <li>- Educates patients and their relatives about exacerbations.</li> <li>- Psychological effects as important as physical.</li> <li>- Assists with depression, low self-esteem and smoking related remorse</li> <li>- Concerns for patients following completion of PR, including the psychological impact.</li> <li>- Location is important</li> <li>- Additional information needed such as leaflets and DVD's.</li> </ul>
<b>Witcher et al., (2015)</b>	Canada	Qualitative: Interviews	26 participants in total: 11 PR staff, 3 community stakeholders and 8 patients with COPD and 4 family members.	To explore perceptions of PR and what affects participation in exercise.	34	<b>General perceptions of PR:</b> <ul style="list-style-type: none"> <li>- Gender differences of how exercise is approached, which can impact HCPs behaviour when delivering PR.</li> <li>- Anxiety and fear amongst patients in relation to exercise.</li> <li>- Motivating patients was key to the HCPs role.</li> <li>- Community aspect of PR is motivating for patients.</li> <li>- Increases confidence and self -efficacy.</li> </ul>
<b>Yawn &amp; Wollan (2008)</b>	USA	Quantitative: Survey	178 physicians and 100 nurse practitioners/ physician assistants.	To assess the knowledge, attitudes and beliefs in relation to the diagnosis and treatment of COPD.	23	<b>Beliefs surrounding PR:</b> <ul style="list-style-type: none"> <li>- 16% expressed that they were indifferent about the benefits of PR.</li> <li>- Only 3% perceived PR as useful or very useful.</li> </ul>

## 2.6.2 Presentation of the Data:

Extracted data has been grouped into two themes: 'Barriers to PR' and 'General perceptions of PR'. Within these overarching themes the data is displayed within synthesising arguments and synthetic constructs, in the form of a narrative. See table 4 and 5 for details of established themes, synthesising arguments and synthetic constructs, with the number of papers each appear in.

**Table 4: Synthesising Arguments and Synthetic Constructs in Theme One**

<b>Theme One: Barriers to PR</b>		
<b>Synthesising Argument:</b>	<b>Synthetic Construct:</b>	<b>Number of Papers it Appears in:</b>
Lack of Knowledge	Lacked understanding	<b>8</b> Alsubaiei et al., (2016) Foster et al., (2016) Harris, Hayter and Allender (2008) Johnston et al., (2011) Johnston (C) et al., (2012) Johnston (K) et al., (2012) Johnston et al., (2013) Johnston, Maxwell and Alison (2016)
	Lack of patient knowledge	<b>4</b> Cochrane et al., (2016) Harris, Hayter and Allender (2008) Johnston et al., (2011) Summers et al., (2017)
Lack of Resources	Time	<b>5</b> Cochrane et al., (2016) Harris, Hayter and Allender (2008) Johnston et al., (2011) Johnston, Maxwell and Alison (2016) Molin et al., (2016)
	Uncertainty of how to approach discussion of PR.	<b>6</b> Cochrane et al., (2016) Harris, Hayter and Allender (2008) Johnston et al., (2011) Johnston et al., (2013) Johnston, Maxwell and Alison., (2016) Molin et al., (2016)

	Lack of services	<b>9</b> Alsubaiei et al., (2016) Barr et al., (2005) Cochrane et al., (2016) Harris, Hayter and Allender (2008) Johnston (C) et al., (2012) Molin et al., (2016) Motegi et al., (2012) Wilson et al., (2007) Yawn and Wollan (2008)
Practical Barriers	Transport and location	<b>8</b> Alsubaiei et al., (2016) Cochrane et al., (2016) Guo and Bruce (2014) Johnston et al., (2011) Johnston et al., (2013) Johnston, Maxwell and Alison (2016) Molin et al., (2016) Wilson et al., (2007)
	Long waiting lists	<b>4</b> Cochrane et al., (2016) Harris, Hayter and Allender (2008) Johnston et al., (2011) Johnston et al., (2013)
	Complicated referral process	<b>6</b> Cochrane et al., (2016) Foster et al., (2016) Harris, Hayter and Allender (2008) Johnston et al., (2011) Johnston (K) et al., (2012) Johnston et al., (2013)
Patient Barriers	Dislike group setting	<b>1</b> Alsubaiei et al (2016)
	Current smoking status	<b>2</b> Alsubaiei et al (2016) Barr et al., (2005)
	Affects an established routine	<b>1</b> Alsubaiei et al (2016)
	Limited support from family and friends	<b>1</b> Alsubaiei et al (2016)
	Too depressed to attend	<b>1</b> Molin et al., (2016)
	Not wanting to attend	<b>2</b> Cochrane et al., (2016) Johnston, Maxwell and Alison (2016)



Unsure it is their role	Not considered their job	<b>5</b> Foster et al., (2016) Harris, Hayter and Allender (2008) Johnston et al., (2011) Molin et al., (2016) Motegi et al (2012)
	Overlook the role of referral	<b>3</b> Harris, Hayter and Allender (2008) Johnston et al., (2011) Molin et al., (2016)

**Table 5: Synthesising Arguments and Synthetic Constructs in Theme Two.**

<b>Theme 2: General Perceptions of PR</b>		
<b>Synthesising Argument:</b>	<b>Synthetic Construct:</b>	<b>Number of Papers it Appears in:</b>
Improving PR	Programme change	<b>4</b> Johnston et al., (2013) Meis at al., (2014) Molin et al., (2016) Wilson et al., (2007)
	Suggestions for increasing referrals	<b>5</b> Cochrane et al., (2016) Foster et al., (2016) Harris, Hayter and Allender (2008) Johnston (K) et al., (2012) Johnston et al., (2013)
Unsure of the benefit	Negative attitude	<b>8</b> Alsubaiei et al., (2016) Cochrane et al., (2016) Guo and Bruce (2014) Johnston et al., (2013) Johnston (K) et al., (2012) Molin et al., (2016) Summers et al., (2017) Yawn and Wollan (2008)
The programme is positive	Increase in patient confidence	<b>6</b> Guo and Bruce (2014) Johnston et al., (2013) Meis et al., (2014) Molin et al., (2016) Wilson et al., (2007) Witcher et al., (2015)
	Increases patient knowledge	<b>3</b> Guo and Bruce (2014) Meis et al., (2014) Wilson et al., (2007)

Perception of patients who are referred to PR	Need motivation and encouragement	<b>9</b> Alsubaiei et al., (2016) Guo and Bruce (2014) Johnston et al., (2011) Johnston (K) et al., (2012) Johnston, Maxwell and Alison (2016) Meis et al., (2014) Molin et al., (2016) Summers et al., (2017) Witcher et al., (2015)
Facilitators to referral	Knowledgeable about the benefits	<b>1</b> Johnston et al., (2013)
	Healthcare professional advising patients to attend	<b>1</b> Meis et al., (2014)
	Motivated patients	<b>1</b> Guo and Bruce (2014)

Before discussion of the findings it should be noted that four Australian studies have first authors with the same surname, with the references presented as Johnston et al. In order to avoid confusion, it should be highlighted that one paper is from Catherine Johnston et al., (2012), and the other three from Kylie Johnston et al., (2011; 2012; 2013). Each of these papers however are separate pieces of research and therefore can be viewed as different entities and included within the review. The paper from Catherine Johnston will be cited as Johnston (C) et al., (2012), and the 2012 paper from Kylie Johnston cited as Johnston (K) et al., (2012), for ease of identification due to the same year of publication.

### **2.6.3 Theme One: Barriers to Referral:**

Theme one comprises of five synthesising arguments: Lack of knowledge, lack of resources, practical barriers, patient barriers and unsure it is their role.

#### Lack of Knowledge:

##### *Lacked Understanding*

It became increasingly apparent that many HCPs lacked knowledge and understanding regarding PR (Alsubaiei et al., 2016; Foster et al., 2016; Harris, Hayter & Allender 2008; Johnston et al., 2011; Johnston (C) et al., 2012; Johnston (K) et al., 2012; Johnston et al., 2013; Johnston, Maxwell & Alison, 2016). A key theme within the qualitative study by Harris, Hayter and Allender (2008), who adopted a grounded theory approach, was a perceived scarcity of knowledge amongst HCPs in primary care with regards to the running and

content of the programme. This notion was consistent amongst both practice nurses and GPs. One practice nurse stated '*if we know what happens [in PR] then we can sell it better*' (p 284), and a GP added '*it's not exactly clear who we can and can't refer or even how to refer*' (p 284). This displayed a lack of clarity amongst HCPs regarding the programme, and it was evident that uncertainty surrounding referrals does not lie within just one sub-group of HCPs. The study was conducted in the UK (North Midlands) and recruited a purposeful sample of primary HCPs (n=21). A clear and detailed method was provided, with justification for a qualitative approach, alongside distinct details of data collection, and as a consequence scored highly on the quality appraisal (37). Although, the study provided rich insight into the perceptions of the barriers and facilitators to referral, the findings may not represent the views of those in secondary care. This apparent lack of knowledge in primary care was reinforced by Foster et al., (2016), however it appeared that practice nurses had a greater understanding of the content and patient suitability for the programme than GPs.

Similarly, in an Australian study by Johnston (K) et al., (2012), doctors in secondary care (n=9) concurred that this low-level awareness acted as a significant barrier to referral. The study adds insight into HCPs' perceptions of PR, although the main focus of the research was to assess a number of guideline recommended interventions such as smoking cessation, PR, influenza vaccinations, oxygen, and medication used in the management of COPD. Description was provided as to how thematic analysis was carried out, however there was limited discussion of how themes were derived, with the authors stating that 'semi-quantitative' analysis was conducted to assess the frequency of themes in relation to COPD guidelines. Although, Braun and Clarke (2006), advocate the use of a flexible approach, this was not in keeping with traditional components of thematic analysis. Furthermore, there was a scarcity of quotations provided to support the analysis of HCPs' perceptions. Only three HCP quotes were present in total, all representing the views of the registrars, with no intern (n=4) views displayed; thus a low quality appraisal score of 26 was awarded.

Additionally, a qualitative study by Johnston, Maxwell and Alison, (2016), carried out in rural and remote areas of Australia, highlighted that some HCPs believed that their role '*required them to be generalists*' (p110.). It was suggested that as COPD is a complex condition they therefore lacked knowledge regarding the intricacies and management of symptoms. One nurse highlighted that '*if they said run a pulmonary rehab program I would have thought – Oh God what do I do now? I don't really – I've never really been involved in pulmonary rehab*' (p110). This study collected survey data from participants via open written responses on four occasions, both immediately before and after a Breathe Easy, Walk Easy workshop (n=25), three months later (n=16) and again at 12 months (n=7). Face-to-face interviews

were also conducted, with attendees recognised as individuals who may be involved in the creation or delivery of a local PR service (n=11). Both the survey and interviews explored knowledge, confidence and attitudes towards running and establishing a PR programme. The study highlighted a shortage of knowledge, experience and understanding, coupled with concern in relation to involvement with PR. The findings may however, not be generalisable to a wider geographical area outside of rural and remote areas of Australia, as knowledge may be greater or incidents of COPD higher in cities. As a result some HCPs may have more exposure to COPD patients and PR services, dependent on location. Furthermore, findings may have also differed if the participants had not been recruited from a Breathe Easy, Walk Easy workshop, as the programme aims to increase awareness. Therefore, attendance may have impacted upon responses given during interviews after the workshop.

Johnston et al., (2013), emphasised a lack of understanding and knowledge amongst GPs with regards to PR. GPs (N=12) were interviewed to establish their thoughts of the referral process, including potential barriers and facilitators. This study, also conducted in Australia, highlights a dearth of familiarity with PR. One GP emphasised: *'Frankly, I didn't know that there were structured programmes available and that would probably be the main reason I wouldn't send anyone'* (p 321). It is evident that HCPs lack expertise surrounding PR and the management of COPD (Harris, Hayter & Allender 2008; Johnston et al., 2011; Johnson et al., 2016), however, it is also apparent that some are unaware that PR exists (Alsubaiei et al., 2016, Johnson et al., 2013).

In the cross-sectional questionnaire study by Alsubaiei et al., (2016) of 44 physicians, 49 nurses and 30 respiratory therapists/ technicians who had contact with COPD patients, and worked in one of 22 Saudi Arabian hospitals, only 4 were familiar with PR. Those aware of PR were given a full version of a questionnaire, to establish their views of the barriers to setting up a PR service. Those unfamiliar were provided with a shortened version, along with supplementary information to describe the programme. The shortened version only included four questions, which asked participants their views of barriers to establishing a PR programme and attendance. The physicians represented each of the 22 hospital sites included in the study, however there was less diversity amongst the nurses, who provided representation from eight hospitals and respiratory technicians only three. The transferability of this study may be limited due to different cultures and health care systems between Saudi Arabia and the UK, however it provides a vital insight into HCPs' perceptions of PR, in a location where prior research was lacking. This uncertainty was reiterated in primary care by GPs in Australia: *'One would assume that your local major public hospital*

would do it [PR] ... my guess is that there probably are some private providers doing it but blown if I know who they were' (Johnston et al., 2013, p321). The uncertainty and scarcity of knowledge in relation to where the programme is run, acts as a significant barrier to referral.

Similarly, a quantitative descriptive cross-sectional observational survey was conducted by Johnston (C) et al., (2012), in Australia. Participants consisted of health care practitioners (n=31), mostly nurses who had already enrolled on to Breathe Easy, Walk Easy training. Consistent with the previous studies discussed, a large proportion of HCPs '*lacked confidence in any area relating to pulmonary rehabilitation*' (p204). A deficiency in knowledge and training was a prominent barrier to PR, expressed by 58% of participants (n=18). It was not evident from the data collected why the participants lacked confidence and knowledge, however the authors suggested that further training was necessary to increase levels of understanding surrounding PR and COPD. Although, this study was derived from a larger project, attention focused upon HCPs' knowledge and confidence of providing management strategies for patients with COPD, with a focus on PR.

The findings surrounding the synthetic construct '*lacked understanding*' predominantly originated from the Australian studies (Johnston (C) et al., 2012; Johnston (K) et al., 2011; 2012; 2013; Johnston, Maxwell & Alison, 2016). The apparent shortfall of PR knowledge, displayed a diminished passion surrounding the importance of the programme. Justification however, was not provided as to why GPs had a poor awareness of the programme, and if this is possibly due to a shortage of information, or if personal beliefs inhibit them from seeking information about the service. The transferability to a UK setting could be questioned due to the different health care systems across both countries, and the geographical setting of some of the research sites (rural Australia). Nevertheless, this highlights an evident gap within the literature, with a scarcity of literature related specifically to this issue identified in the UK.

#### *Lack of Patient Knowledge:*

In contrast to a lack of HCP knowledge, there was brief mention to a lack of patient knowledge (Cochrane et al., 2016; Harris, Hayter & Allender, 2008; Johnston et al., 2011; Summers et al., 2017). It was perceived a challenge to convince patients of the benefits due to low-level awareness and knowledge surrounding COPD and PR (Cochrane et al., 2016; Harris, Hayter & Allender, 2008). A qualitative interview study of physiotherapists who

delivered PR (n=17), in various locations in the UK, reiterated that some patients arrive not knowing anything about PR or what they wish to achieve (Summers et al., 2017).

Johnston et al., (2011), highlighted that some HCPs perceive that patients do not have the understanding or health literacy to carry out self-management, thus it appeared that they used subjective judgement to decide which patients to refer. In this Australian qualitative interview study the views of primary and secondary care medical practitioners (n=16) were explored, regarding the implementation of evidence based recommendations to assist patients with the management of COPD. Although, the focus was not centred on PR, other management techniques such as long-term oxygen therapy, influenza vaccinations and smoking cessation were also discussed. This study was given a fair quality appraisal score of 31, due to the relevance of the extracted data to the review question. It was however, noted that limited detail was provided on the sample, only stating the number of participants and their occupation. It was deemed disappointing that further demographic details such as age, gender, number of years as a registered HCP, as well as a justification for the sample size, were not provided. Other HCPs suggested that they believed patients are unaware of the programme because they do not ask about it during appointments (Harris, Hayter & Allender, 2008). Again, this highlights an ignorance of some HCPs, perceiving that it is the role of the patient to initiate PR related discussion. It does however appear that if some patients do not mention PR, HCPs will refrain from discussion. Consequently, HCP perceptions of a lack of patient knowledge may ultimately deter or act as a barrier to referral.

### Lack of Resources:

A lack of resources was a pertinent synthesising argument, appearing in 13 of the 18 papers. Within this synthesising argument the synthetic construct *lack of services*, appeared in ten of the papers, which highlighted a recurrent issue.

### *Time:*

HCPs perceived that some patients are incapable of carrying out self-management, and stated that they do not have the time or resources to teach them these skills (Johnston et al., 2011). One of the most prominent issues raised by Harris, Hayter and Allender (2008), both by practice nurses and GPs, was that they did not feel a standard 10 minute consultation was sufficient to discuss the prospect of attending PR. One GP highlighted that *'if you get round to talking about pulmonary rehab you're doing very well and actually there doesn't seem to be a role for it in typical general practice'* (p285) (Harris, Hayter & Allender, 2008). A potential justification is offered in this paper, that although some HCPs may be in

favour of PR they may lack passion when communicating with patients, due to the demanding processes involved with referral. Hence, this emphasised time as a perceived barrier to referral, with the prioritisation of other aspects of COPD management. It also displayed a negativity towards the programme, which may provide insight to why some in primary care may not promote PR.

In support, HCPs in Australia perceived the length of time, *'about an hour and a half'* (p109) to assess patient eligibility, as a barrier to referral, due to the difficulty of combining with competing duties (Johnston, Maxell & Alison, 2016). GPs in Denmark also suggested that HCPs within health centres may possibly have a greater amount of time and success when discussing PR with patients (Molin et al., 2016), thus inferring that others may not be as busy as themselves. The time involved and the volume of work was also emphasised in four papers (Cochrane et al., 2016; Johnston, Maxwell & Alison, 2016; Harris, Hayter & Allender, 2008; Molin et al., 2016), with the paperwork and tests required to initiate a referral considered excessive by GPs and nurses (Cochrane et al., 2016; Johnston, Maxwell & Alison, 2016). This view was reiterated by a UK GP: *"there's too much information required ... There's a two sides of A4 form that they won't accept unless we complete it"* (Harris, Hayter & Allender, 2008, pg284); highlighting that the perceived demands of the referral process are too taxing.

#### *Uncertainty of How to Approach the Discussion of PR:*

HCPs also viewed the *uncertainty of how to approach the discussion of attending PR* with patients as a barrier to referral. Practice nurses found it difficult to discuss referral and perceived that if they were in good health themselves, without a respiratory condition, recommending exercise to patients may appear patronising (Harris, Hayter & Allender, 2008). There was the belief that patients may feel undermined when being told the best way to manage their COPD by a HCP who has no personal experience of the condition. Similarly, others worried about asking COPD patients to exercise (Johnston, Maxwell & Alison, 2016). This fear and uncertainty resulted in discussion of PR often being overlooked, via the sub-conscious aversion of discussion, resulting in patients potentially not receiving the most appropriate management strategy. This was also a concern amongst GPs in the previously identified study by Johnston et al., (2013), describing it as a *'hurdle'* to get the patient to *'co-operate and comply'* (pg 321) with the idea of PR and exercise. It could be perceived that these concerns and beliefs may be translated when proposing attendance at PR; *'it's not us knowing what has to be done, it's translating that into an outcome'* (Johnston et al., 2013, pg 321).

A tentative view of how to approach discussions with patients may be strongly associated with a *lack of patient knowledge*. It was considered that PR is not publicised well enough (Johnston et al., 2011; Johnston et al., 2013), which often results in HCPs finding the programme difficult to sell (Harris, Hayter & Allender, 2008; Cochrane et al., 2016). Others suggested they would not initiate discussion with a COPD patient attending an appointment for a different reason, as they '*don't want to listen to you talking about their chest or smoking*' (Harris, Hayter & Allender, 2008, pg 285). This fear of rejection may result in potentially missing a 'golden opportunity' to initiate a referral.

In Denmark eight GPs discussed their perceptions of COPD management, with an emphasis on PR (Molin et al., 2016). A key theme within this paper was the effort required to persuade a patient they would benefit from attending PR. Initiated discussions surrounding PR was a selective process, with GPs only raising it with patients they perceived would benefit, with most left to '*think about it*' (p1934), and no referral made. GPs believed patients were apathetic towards PR, and therefore did not encourage, nor promote referral. Although, this study as a whole did not establish HCPs' perceptions of PR, a large proportion of data provides a rich new insight and perspective on the topic, thus contributing to the high quality appraisal score of 36. The small sample size (n=8), and lack of demographic details however, were limiting factors. Nevertheless, it would be interesting to establish if these views are consistent throughout Europe and America, using a larger sample.

#### *Lack of Services:*

Lack of services was a prominent synthetic construct as a barrier to referral within nine of the 18 studies. Shortage of programmes, coupled with a difficult and time consuming referral process (Harris, Hayter & Allender, 2008), along with a lack of well-established programmes (Hayter & Allender, 2008; Alsubaiei et al., 2016; Motegi et al. 2012; Yawn & Wollan, 2008), were considered a deterrent to referral.

The issue associated with a lack of services was further reinforced in a quantitative national survey conducted in America, by Barr et al., (2005). Responses were gathered from primary care physicians (n=523), pulmonologists (n=528) and patients with COPD (n=1023). A significant barrier to referral reported by 60% of primary care physicians and 41% of pulmonologists was that although there was an established programme in the area, the availability was limited. A further 23% of primary care physicians and 8% of pulmonologists, reported a total absence of a service in their area. Although, there are locations which do not have a service available, others have highlighted that some programmes only run if enough patients are referred and enrolled, with services delayed if patients do not accept



referral (Cochrane et al., 2016). Consequently, this could have a significant impact upon patients who have been referred on to programmes with these associated thresholds.

Having staff with appropriate qualifications to deliver PR was also an inhibiting factor (Barr et al., 2005; Cochrane et al., 2016; Johnston (C) et al., 2012; Wilson et al., 2007). Strong opinions were held by one GP who perceived PR should be '*reserved for new patients*', and re-attendance not offered (Molin et al., 2016). This reinforces that some HCPs appear to abide by their own criteria for referral; depriving some patients from attendance or causing confusion via mixed messages.

### Practical Barriers:

#### *Transport and Location:*

A practical barrier raised in relation to PR referral, is the issue of *transport and location*. In a previously discussed Saudi Arabian study by Alsubaiei et al., (2016), 72% of a sample of HCPs (n=123) listed issues with transportation. This appeared consistent regardless of location, as it was also considered a challenge for patients to use public transport to attend PR in Australia (Cochrane et al., 2016); additionally many patients had limited knowledge of transport options available to them in Canada (Guo & Bruce, 2014).

Further reiterating these concerns, Wilson et al., (2007) conducted a focus group with UK HCPs (n=8), who believed that programmes should be established in locations accessible to patients who require the service. A grounded theory approach was adopted, and the views of patients were also incorporated (n=32). It was however, not apparent that any theory was generated at the end of the study, therefore it could be questioned as to how appropriate the method of analysis was. Nevertheless, rich data was provided in relation to HCPs' perceptions of PR. A clear statement of findings was displayed within the results section, with data organised under clear headings; triangulation was carried out, increasing the reliability of findings. Suggestions were also provided for future research, policy and practice, hence a quality appraisal score of 32 was achieved.

Others mentioned the added strain and commitments for family members, with the time required to drive relatives to PR, thought to impact on daily life (Johnston et al., 2013). The issue of distance and transportation was a concern for a large proportion of HCPs, and often had a considerable bearing on if they believed a patient would attend, and therefore if the HCP would consider referral (Johnston et al., 2011; Johnston, Maxwell & Alison, 2016; Molin et al 2016). These three studies discussed 'difficulty' in relation to transport to the PR

programme, however none acknowledged how HCPs were aware of transportation issues, and if they themselves had personal knowledge, or if the patients had communicated the difficulty. Thus, further research is required to establish this.

Within the synthetic construct of transport and location, one study previously identified by Johnston, Maxwell and Alison, (2016), who interviewed HCPs who delivered PR, drew attention to the suitability of where the programme was undertaken. Added concerns surrounding room size and unsuitability of the room temperature for exercise were raised.

It is evident that the issues surrounding transport and location have a significant impact upon attendance of patients at PR, with many HCPs holding negative views on this aspect. It should therefore be questioned whether this would have a heavy bearing on referral to the programme. It is also apparent that those delivering PR are under pressure due to unnecessary complications, such as the unsuitability of the room for exercise, adding further strain.

#### *Long Waiting Lists:*

An additional practical barrier to referrals mentioned by HCPs, was the long waiting lists (Cochrane et al., 2016; Harris, Hayter & Allender, 2008; Johnston et al., 2011; Johnston et al., 2013). Some perceived that due to extended waiting lists, patients may have lost motivation to attend once they reach their scheduled appointment (Johnston et al., 2013). Others believed that the wait times are too much for the patient (Cochrane et al., 2016), with some stating that it *'makes you think, is it worth telling them about it?'* (Harris, Hayter & Allender, 2008, p 284). It could be viewed on occasion that HCPs were withholding referral decisions from patients, due to perceiving considerable waiting lists as a barrier (Johnston et al., 2011). This was consistent throughout the literature, regardless of professional title or role.

#### *Complicated Referral Process:*

There was a consistency in opinion amongst HCPs that the referral process was problematic, convoluted and arduous (Cochrane et al., 2016; Johnston et al., 2011; Harris, Hayter & Allender, 2008). As discussed previously, in the study by Johnston et al., (2013), a recurring theme was that GPs would like more information on how to refer patients to the programme, or someone who they could contact to arrange the referral for them.

Cochrane et al., (2016) conducted a mixed-method pilot study to establish the opinions of HCPs and stakeholders, on a PR based intervention in Australia. Only HCPs (n=7) participated in the qualitative component, whereas COPD patients took part in the

quantitative arm of the research. The study highlighted that HCPs did not feel GPs were familiar with making referrals to the programme. Thus, a set of instructions was created, along with partially completed referral forms, in addition to providing contact details for assistance. This could suggest that GPs find the completion of referral forms complicated if not routinely done, however this conclusion has been interpreted from the data, rather than evidenced. The findings of this study provide an interesting insight into the beliefs of HCPs towards PR and potential barriers to referral. A limiting factor was that this pilot study ended early, as reliable conclusions could not be drawn from the data. As a result of the small sample there was the inability to reach saturation from the qualitative component, thus caution should be taken when interpreting the findings.

Some did not *'know how to access the programme'*, and were unaware they could as GPs (Johnston et al., 2013, pg 321), others forgot they could refer (Johnston (K) et al., 2012), highlighting an ignorance of the process. This was comparable with the notion that some were unsure how to make a referral (Harris, Hayter & Allender, 2008; Cochrane et al., 2016). The papers did not substantiate why HCPs were unacquainted with the referral process, however possible reasons have been provided elsewhere. Insufficient referrals was perceived as being due to an unfamiliarity with the eligibility criteria (Foster et al., 2016; Johnston et al., 2011). Although, it was believed that a considerable amount of work was required to make a referral, a respiratory nurse felt that the referral process was too demanding for patients: *'many forms, many things to do at the same time and [it] makes them overwhelmed ... a lot of patients are 65 or 70 and it is too much for them'* (Cochrane et al., 2016, pg 9). This was the nurse's personal perspective, however it is concerning that she believed the referral process would be *'too much'* for an individual aged 65-70. This apparent subconscious categorisation of all individuals over 65 being incapable, may consequently influence her referral practice.

### Patient Barriers:

In contrast to HCPs' perceived barriers to referral, five papers discussed HCPs' perceptions of patient barriers to PR. Disliking the group setting was a perceived barrier by Saudi Arabian HCPs (n=37, 30.3% of the total sample of n=123) (Alsubaiei et al., 2016). Similarly, this same group of HCPs viewed current smoking status as a potential barrier to PR, highlighted in 76.2% (n=93) of HCP responses. It would appear therefore, that HCPs in Saudi Arabia believe that smoking status has a greater impact upon attendance than patients disliking a group setting. Barr et al., (2005) reported that physicians in the USA had similar views with *'almost'* 9 out of 10 surveyed (N=523), believing that COPD was *'self-*

*inflicted*' (pg 1415.e13), due to a history of smoking. Of note, many also agreed with the survey statement: '*there is nothing that can be done for COPD patients who will not quit smoking*' (pg 1415.e13). This suggests that for some HCPs, current smoking behaviours influence referral practice; this may be due to a dissatisfaction that patients continue to smoke, or relating back to a lack of programme knowledge.

The programme affecting an established routine and having limited support from family and friends was also emphasised as reasons for non-attendance (Alsubaiei et al., 2016). It is interesting that both of the studies by Alsubaiei et al., (2016) and Barr et al., (2005), used surveys, and respondents only answered if they agreed with survey statements. Questions such as '*I do not believe a pulmonary rehabilitation programme will be a valuable addition to the management of patients with COPD*' (Alsubaiei et al., 2016, pg 124), or '*smoking is the cause of most cases of COPD*' (Barr et al., 2005, pg 145.e13), could therefore be perceived as leading. Thus, it is possible that respondents may have answered differently, if given an open text box to provide their perceptions of the effectiveness of PR.

In another instance, a GP highlighted that patients become too depressed to attend (Molin et al., 2016). The GP assumed that patients would be unable to attend PR, as their depression impacts upon their '*energy*' levels (pg 1933). This further reiterates the potential impact of personal views upon referral practice. Additional patient barriers perceived by HCPs were identified as patients not wanting to attend (Johnston, Maxwell & Alison, 2016), whereas others stated that they knew patients disliked the idea, because they refuse attendance at PR when offered (Cochrane et al., 2016).

#### Unsure it is their Role to Refer:

The synthesising argument that HCPs were unsure that it was their role to refer was evident in five of the 18 papers. This was a significant issue raised by HCPs in these papers. Two key concerns ran throughout, the first was that HCPs did not consider referral to PR as part of their job, and the second, that they often overlooked referral or passed the buck.

#### *Not Considered their Job:*

Motegi et al., (2012), distributed a quantitative postal survey to hospitals in Japan, which evaluated the implementation of PR. Surveys were completed by 176 hospitals, and this was primarily fulfilled by the doctor with responsibility for the pulmonary department. The results indicated that those in secondary care did not believe it was their role to be involved with PR, with 35% suggesting it should be conducted in clinics and settings away from the

hospital. This was reinforced by 86.9% of respondents believing that PR should be delivered by physiotherapists, thus further removing their involvement. This study adds further context to the views of HCPs from different cultures across the globe.

Similarly, both primary and secondary care practitioners emphasised they were unsure what their role should be within the referral process, and believed PR was not associated with their job (Johnston et al., 2011). Others reported uncertainty surrounding who should make referrals within primary care (Foster et al., 2016; Harris, Hayter & Allender, 2008). In a UK mixed methods participatory action research study by Foster et al., (2016), practice nurses (n=13) and GPs (n=13) felt that no structured practice guidelines were available to detail the referral process or whose role it is to initiate referral. The findings of this study were only collected from one clinical commissioning group (CCG), thus may not be transferable. As PR varies nationally, others working elsewhere may have different experiences, and therefore hold different perceptions of the programme. Hence, it cannot be assumed that the results represent the views of all NHS primary care HCPs.

A lack of certainty of roles and responsibilities was apparent in primary care. Practice nurses felt burdened, solely left to help COPD patients manage their condition (Harris, Hayter & Allender, 2008). GPs reinforced this view highlighting the belief that they should only see a COPD patient during an acute exacerbation, and that it is not their role, nor of high importance, to discuss '*preventative type measures*' with patients (Harris, Hayter & Allender, 2008, pg 283). Similarly, other GPs perceived that discussion of non-pharmacological management techniques should be a greater responsibility of HCPs working at health centres, as they are '*better*' at it (Molin et al., 2016, pg 1932). Hence, it is evident that some GPs place higher importance on the medical aspects of treatment and management, rather than lifestyle and psychological recommendations.

#### *Overlook the Role of Referral:*

Similar to those who believed that it was not their role, other HCPs decided to overlook the role of referral, and in certain cases pass the buck rather than adopt a pro-active attitude (Harris, Hayter & Allender 2008, Johnston et al., 2011; Molin et al., 2016). In primary and secondary care, Johnston et al., (2011) discussed how HCPs perceived that PR was easy to disregard, due to an unfamiliarity with the eligibility criteria, and a belief that it is not associated with their role. These findings are instrumental in highlighting the barriers associated with PR, and although some HCPs were aware of the benefits, the barriers dissuaded them from pursuing referral. These findings should be treated with caution as the data was collected from registrars (n=5) and interns (n=4) from secondary care, and GPs

(n=7), who had been involved in the care of patients admitted into a tertiary hospital with a diagnosis of COPD. Hence, participants may have been more aware of the management strategies available to patients with COPD, than the general HCP population. Furthermore, the authors concluded that as only a small number of participants (n=16) were recruited from one particular area, the findings could not be generalised outside of the geographical location.

Some HCPs were aware of the programme, however admitted that they had become '*lazy*' (p1932), and would have placed higher importance on PR, if there was no one else to refer (Molin et al., 2016). This dismissive attitude was a key theme amongst GPs within the paper by Molin et al., (2016), with others stating that they '*clearly do not want to deal with this [PR]*' (pg 1932). This view was consistent with those who would not consider using PR as a management strategy (Johnston et al., 2011), and may be due to some GPs not placing a high importance on non-pharmacological treatment options, and therefore overlooking referral (Johnston et al., 2011; Molin et al., 2016). These HCPs, in particular GPs, appeared happy to let others take on the role of referral and discussion of PR, seemingly due to favouring medicalised treatment options, or believing somebody else would be more appropriate to make the referral. It was evident that many HCPs deferred referral responsibility in some way, however these avenues require further exploration.

#### Summary of Theme One:

In summary, theme one: Barriers to PR, highlighted five synthesising arguments identified within the literature: Lack of knowledge, lack of resources, practical barriers, patient barriers, and unsure it is their role. *Lack of knowledge* evidenced that HCPs lacked understanding and awareness of the programme, and also brief mention was made to a lack of perceived patient knowledge surrounding PR and self-management. *Lack of resources*, such as having the time to complete a referral, not feeling equipped to approach discussions about PR with patients and a lack of services in the area, were also identified as barriers to referral. *Practical barriers* such as transportation or issues with location, long waiting lists and complicated referral processes were also emphasised in a number of papers. Although not as prominent, *patient barriers* were highlighted and these involved a dislike of the group setting, current smoking status, the programme affecting an established routine, having limited support from family and friends, being too depressed to attend, and not wanting to attend. Lastly, some HCPs were *unsure that it is their role* to refer to PR, and this resulted in them considering it is not their job, and therefore overlooking referral. This theme has displayed HCPs perceptions of the barriers to referral to PR, within the current literature

## **2.6.4 Theme Two: General Perceptions of Pulmonary Rehabilitation:**

Theme two comprises of five synthesising arguments: Improving PR, unsure of the benefit, the programme is positive, perceptions of patients who are referred to PR, and facilitators to referral.

### Improving Pulmonary Rehabilitation:

Improving pulmonary rehabilitation was a strong synthesising argument, running throughout nine papers. This was one of the most practical aspects to emerge from the literature, with HCPs providing positive and beneficial suggestions to enhance PR and the referral process. Within this synthesising argument, two synthetic constructs emerged: programme change and suggestions for increasing referrals.

#### *Programme Change:*

Some HCPs offered practical suggestions based upon their perceptions of how PR could be improved (Johnston et al., 2013; Meis et al., 2014; Molin et al., 2016; Wilson et al., 2007). Ideas involved providing supplementary support, such as DVDs, information, and community-based assistance to patients who have completed the programme (Wilson et al., 2007). Involving partners in the PR sessions was also discussed; this was consistent with the view that PR should be conducted in a cohort, to enable the creation of relationships and peer support (Meis et al., 2014). Disagreement did however occur, as some GPs believed it may be possible to substitute PR with home visits on a one to one personal basis, to monitor the condition and sustain good spirits (Molin et al., 2016). The practicalities given the high workload and staffing shortages in primary care was however not addressed within this paper.

Others however, offered less patient centred suggestions, such as incorporating PR into the COPD guidelines and providing financial enticements for those who refer (Johnston et al., 2013). It could be perceived that although there is an awareness of the programme, some do not believe in it strongly enough to refer if it is not currently part of their management plan, or if there is no financial benefit. Interestingly, PR has been part of the NICE COPD guidelines since 2004 (NICE, 2010), and advocated in the COPDX plan in Australia and New Zealand since 2003 (McKenzie & Frith, 2003), again highlighting a lack of knowledge of guidelines and evidence base for PR amongst HCPs.

### *Suggestions for Increasing Referrals:*

Incorporating PR into management plans supports suggestions made regarding how to increase referrals. Practice nurses advised that along with better incorporation into COPD management, it should be positively promoted to patients, and supported with evidence that it is beneficial (Harris, Hayter & Allender, 2008). Some therefore viewed that the profile of PR needs to be raised (Johnston (K) et al., 2012; Johnston et al., 2013), and perceived that attendance would increase if patients were able to appreciate the different components of the programme at the time of referral (Johnston et al., 2013). This relates to the synthetic construct of uncertainty of how to approach discussion of PR, and if the issues raised were rectified, this may facilitate the referral process. HCPs perceived this improved awareness would assist with the understanding of eligibility criteria (Foster et al., 2016; Johnston (K) et al., 2012), and could be aided by a simplified referral process (Johnston (K) et al., 2012). GPs in particular felt unsupported and wanted more information on how to refer, or details of someone they could contact to arrange a referral (Johnston et al., 2013).

The previously identified UK study by Foster et al., (2016), focused on GPs' and practice nurses' perceptions of how to increase referrals to PR. The interviews sought to seek knowledge of PR, and ideas of how to enhance and promote referrals to the programme. Actionable suggestions included a 30 minute session at the GP practice to assist HCPs with the discussion of PR, which may address some of the concerns raised around communication by Harris, Hayter and Allender (2008) and Johnston et al., (2013). Referral prompts on COPD review forms, specific in practice guidelines, and memory aids such as mouse mats and cups were also suggested. This reiterates the apparent lack of knowledge surrounding PR, however does emphasise that there is an awareness of the need for extra support. The request of memory aids reinforces the point raised by Johnston (K) et al., (2012), that HCPs forget they can refer. Similarly, Cochrane et al., (2016) created an intervention to assist GPs with referrals in Australia, which involved instructions and partially completed referral forms, and contact details for referral assistance. This further displays a lack of knowledge and confidence, and appears to be an issue not just constrained to one country, but recurrent globally.

### Unsure of the Benefit:

#### *Negative Attitude:*

A prominent synthesising argument within eight papers was that some HCPs held a negative attitude towards PR. Regardless of geographical location some were uncertain of



the benefits gained from attending the programme (Alsubaiei et al., 2016; Johnston et al., 2013; Yawn & Wollan., 2008), and thus held a diminished attitude as to how PR complemented the management of COPD (Johnston et al., 2013). Some HCPs commented that they would only be likely to refer patients who were on maximal COPD therapy, as a last resort (Johnston (K) et al., 2012). This reinforces a lack of understanding of the recommendations of using PR as an early intervention. Consequently, the potential lack of programme clarity appears to impact HCPs confidence in the programme. Others perceived it would be difficult for a COPD patient to begin exercise (Cochrane et al., 2016; Guo & Bruce, 2014; Summers et al., 2017), and viewed that *'for patients to participate they need more energy'*. This further emphasises a diminished confidence in the programme, patients' abilities, and lack of knowledge surrounding the evidence base (Molin et al., 2016, pg 1933).

A USA quantitative survey conducted by Yawn and Wollan (2008), with physicians (n=178) and nurse practitioners (n=100), assessed beliefs, knowledge and attitudes surrounding the identification, diagnosis and treatment of COPD. Specific questions focused upon perceptions of PR. Overall, low opinions of the usefulness of PR were highlighted, with only 3% (n=8) acknowledging the benefits, and another 16% (n=44) indifferent, therefore accentuating unfavourable views. A notable strength was that views of HCPs working in three different locations across the USA from a large sample (N=278), were represented. A limiting factor however, was that HCPs were recruited during attendance at a training programme for chronic conditions, with surveys collected within the first 15 minutes of a 70 minute COPD presentation. It was assumed responses represented HCPs' knowledge and attitudes prior to the presentation, and did not consider if information delivered within the first 15 minutes would have impacted; a similar limitation is seen in the study by Johnston, Maxwell and Alison (2016). A dearth of information was also provided as to whether the training was mandatory or voluntary, as this too could have impacted upon the findings. After consideration of limitations, a low quality appraisal score of 25 was assigned. This was as a result of failing to present a research question and aims, and limited information regarding data collection, such as survey content. It should, however, be noted that the study was included due the pertinence of the data extracted, in relation to the review question.

## The Programme is Positive:

### *Increase in Confidence:*

Conversely, HCPs in six papers viewed PR positively, as it allows patients to restore and *increase their confidence* (Johnston et al., 2013; Meis et al., 2014; Molin et al., 2016; Witcher et al., 2015). This confidence appeared in many forms. HCPs recognised that the group setting assists with social and psychological aspects, such as connecting and creating bonds with others whose circumstances bear a close resemblance to their own (Guo & Bruce, 2014; Meis et al., 2014; Witcher et al., 2015).

A Canadian qualitative interview study by Witcher et al., (2015) gathered views of those who delivered PR (n=11). It highlighted that patients were extremely anxious upon commencement of the programme, however HCPs felt a sense of achievement when they motivated patients to recognise that they can exercise and accomplish their goals. Similarly, Guo and Bruce (2014), conducted a focus group with HCPs (n=7) who delivered PR in Australia. These HCPs viewed the initial assessment as an opportunity to encourage, give hope and discuss useful tips, and a chance to improve adherence to PR. Others perceived the programme useful to increase patients' understanding of COPD and exacerbations (Wilson et al., 2007), providing confidence and the ability to recognise a worsening of symptoms and to seek help promptly (Johnston et al., 2013). Similarly, those working in primary care reported high levels of patient satisfaction with PR, with some GPs advising that it is advantageous to use in conjunction with support provided in the doctor's surgery (Molin at al., 2016). This positive attitude towards PR evidences that some GPs understand the benefits of the programme and the support that is required from primary care to complement and increase chances of programme success.

Meis et al., (2014), conducted a focus group and interview study, with HCPs (n=14) who worked at an inpatient PR facility in the Netherlands. Detailed perceptions were provided from a range of HCPs who delivered the programme, who suggested that PR increases confidence, belief in ability and raises spirits. One HCP stated that PR helps patients to not *'feel they're alone'* (p 506), and that it provides affirmation, offering *'reassurance'*, *'the way I react is not unusual'* (p506). The term *'reassurance'* emphasised the assistance some COPD patients require to increase confidence levels; a primary aim of the programme. The group situation however, assisted with feelings of isolation and not managing their condition by themselves. This study also incorporated the views of COPD patients (n=13), however the data provided via direct attributable quotes from HCPs was rich, and adds to the limited knowledge base. This is a positive factor of the study as it shows transparency in the reporting of information. Detailed documentation of the sampling strategy and response

rates, along with demographic information for each HCP was provided. The method and findings were clearly described along with the context and setting, allowing comparison of results to other contexts and areas. Although, the positive perceptions highlighted are the views of those running the programme, it accentuates the accomplishment and benefits that patients experience. These HCPs witness the patient's journey and improvements made throughout the programme: *'It makes me feel good when patients have become more independent at the end and their quality of life has improved'* (p506). This encapsulates that PR is a programme where both the patient and HCPs delivering the programme feel a sense of reward. Therefore, evidencing that those delivering PR also gain a sense of achievement and a boost to their own confidence when a patient has improved throughout the programme, whether this be physical, emotional or psychological.

#### *Increases Patient Knowledge:*

Although this synthesising argument was not mentioned frequently, it was a pertinent theme within three papers (Guo & Bruce, 2014; Meis et al., 2014; Wilson et al., 2007). HCPs who delivered PR highlighted that there is time dedicated during sessions to teach patients step by step, for example improving their inhaler technique; something which can be overlooked in the management of COPD, yet patients find beneficial (Guo & Bruce, 2014). Others perceived that patients often enter PR not understanding the importance of exercise, however believed that PR provides clear advice to increase exercise capacity and thus assists with the adoption of a more active lifestyle (Meis et al., 2014). Similarly, in the previously mentioned study by Wilson et al., (2007), HCPs (n=8) knowledgeable about COPD believed that PR increases patient and family members' knowledge of COPD exacerbations, and viewed that the group setting is appropriate to deliver this information.

#### Perception of Patients who are Referred to PR:

It was evident that HCPs' perceptions of COPD patients could significantly impact upon whether a referral would be made, or if it was viewed that the patient would succeed on the programme.

#### *Need Motivation and Encouragement:*

There was a consensus of opinion that patients need to be motivated to attend PR, and HCPs believed this should be a personal goal (Johnston et al., 2011; Molin et al., 2016). Many, however, felt the need to encourage patients (Alsubaiei et al., 2016; Guo & Bruce, 2014; Johnston (K) et al., 2012), and highlighted it would be beneficial to persuade those

who *'just keep coming in with acute exacerbation'* to attend (Johnston (K) et al., 2012, pg 4). Some perceived patients would rather have a *'magic pill that was just going to fix them'*, rather than exercise (Guo & Bruce, 2014, pg 5).

PR staff advised that some patients initially lack motivation, and need to be eased into the sessions, with encouragement that exercise is possible (Witcher et al., 2015), otherwise this could lead to high patient attrition rates (Johnston, Maxwell & Alison, 2016). Similarly, patients who were fearful and anxious when entering the course, learned that moderate exercise is achievable and they *'are not going to die'* or experience an exacerbation; the support provided by PR staff offered this reassurance (Witcher et al., 2015, pg 1628). Others however, admitted that they may lose interest with patients who are not motivated, willing to learn or modify their behaviour (Meis et al., 2014).

There was the perception that some patients are not motivated to try PR, and some have become depressed as a result of their condition, and would not cope (Molin et al, 2016). These negative perceptions could act as a barrier, as could the assumption that patients do not want to attend because they've *'got more important things than coming to an exercise programme'* (Johnston, Maxwell & Alison, 2016, pg 111), or that they will become bored and not complete PR (Alsubaiei et al., 2016). It is unclear if patients voiced these concerns about attendance, or if these are the personal views of the HCPs, due to a negative attitude towards the programme.

Depleted motivation was highlighted by PR staff in the study previously discussed, by Summers et al., (2017). They suggested that motivation should be controlled by reviewing goals, breaking large goals into manageable ones, and that providing a positive experience was key to maintaining interest in the programme. Other HCPs who delivered the programme discussed this aspect, setting each patient realistic goals and modifying them throughout the course if they became unachievable; encouragement was a significant requirement, along with praise and success (Meis et al., 2014; Witcher et al., 2015). Some PR staff believed it was their role to inspire and provide positive reinforcement, however felt that this should be coupled with group peer support (Witcher et al., 2015). This reiterates that with encouragement and effective communication, goals within PR can be reached, and although HCPs play a large role in this, it is equally important that patients support each other.

Those who delivered PR emphasised distinct differences in how exercise is approached between genders, this was a notable finding presented in the paper by Witcher et al., (2015). This disparity altered HCPs' behaviour when delivering PR. Some viewed strong social aspects to gender, and believed that women required firm bonds to motivate them

throughout. Others viewed gender differences physically: *'with the women, I found I had to kind of encourage them a little bit more, whereas with the men ... some guys would really bump up the treadmill... So I found that they really would need a bit more coaxing and a bit more support'* (p1628). This displays HCPs' categorisation of patients, due to their own perceptions of motivational gender differences. Ultimately, this could impact upon practice and displays the perceived clear distinction between the levels of encouragement required by males and females. Once again, the issue of subjectivity is raised due to the perceptions HCPs hold. Thus, it is apparent that stereotyping of patients may occur in the running of the programme, as well as during the referral process.

### Facilitators to Pulmonary Rehabilitation:

The papers included in this CIS most commonly discussed the perceived barriers to referral and attendance at PR, however three papers discussed aspects which HCPs believed would facilitate making a referral. Being knowledgeable about the benefits of PR facilitated Australian GPs to make a referral; this knowledge was often gained via mentoring from a respiratory physician, observing patient benefits first hand, or researching the programme themselves (Johnston et al., 2013). This highlights that being aware and having knowledge of how the programme can assist patients, acts as a motivation for HCPs to refer.

Two papers mentioned HCPs' perceptions of what facilitates referral from a patient's perspective. Meis et al., (2014) suggested that HCPs believed that if they promote PR and advise patients to attend, they would be more likely to accept referral. It was evident that positive reinforcement and effective communication from an individual that the patient trusts and respects, could increase uptake to PR. Others added that patients who are motivated to improve their quality of life will initiate a referral, asking if they can attend PR (Guo & Bruce, 2014). This is associated with the synthetic construct that patients need motivation to attend, and this opinion highlights that some HCPs believed that if patients were motivated enough, they themselves would ask to be referred. It does however raise the issue of those who may be unaware of the programme, and appears to be associated with HCPs deferring responsibility, this time on to the patient.

### Summary of Theme Two:

In summary, theme two evidenced five synthesising arguments in respect of HCPs general perceptions of PR, these included: Improving PR, unsure of the benefit, the programme is positive, perception of patients who are referred to PR, and facilitators to referral. Within

improving PR the literature highlighted aspects which HCPs believed could be changed in the programme, such as letting partners attend sessions, also evidenced were suggestions on how to increase referrals, such as better awareness amongst HCPs of PR, and referral memory aids. Being unsure of the benefit of PR was highlighted as a result of a negative attitude to the programme. Others however, believed the programme is positive as it increases confidence and patient knowledge, highlighting that there are those who believe the programme is advantageous, and others who are a little more reluctant about its benefits. The studies included in the review also offered insight into HCPs' perceptions of patients who had been referred to PR, with the view that patients need motivation and also encouragement from PR staff. Lastly facilitators to PR were briefly highlighted, as HCPs being knowledgeable about the benefits of PR, HCPs advising patients to attend, and patients who are motivated to improve their quality of life.

## **2.7 DISCUSSION:**

This is the first systematic review to establish HCPs' perceptions of PR as a management strategy for patients with COPD.

### **2.7.1 Summary of Evidence:**

Overall, there was limited evidence to directly answer the review question: What are healthcare professionals' perceptions of pulmonary rehabilitation as a management strategy for patients with chronic obstructive pulmonary disease? CIS was therefore chosen as the most appropriate method, as it allowed data to be extracted, as well as providing a synthesis of both qualitative and quantitative research, along with incorporation of the authorial voice.

The review highlighted literature with regards to HCPs' perceptions of PR, however most related to primary care. Overall, HCPs predominantly focused upon the perceived barriers to PR, and this was displayed in all papers except for that by Witcher et al., (2015). Discrepancies in opinion were evident, and although the literature did not provide justification for identified perceptions, it could be proposed that each issue caused a vicious cycle of events, leading to a barrier to referral. Communication appeared to contribute to the issues, displayed by a lack of communication between the service and referrers, resulting in diminished knowledge, or HCPs feeling less confident in how to discuss PR with patients.

A pertinent positive aspect of PR highlighted, appeared to be an increase in patient confidence and knowledge from attending the programme (Guo & Bruce, 2014, Meis et al., 2014); this may be due to HCPs receiving favourable patient feedback, and therefore altering their perceptions. Overall, practitioners held negative views towards the use of PR and many were non-adherent to guidelines. This may have been as a result of the apparent lack of knowledge in relation to PR (Johnston et al., 2013), or not believing in non-pharmaceutical management strategies (Harris, Hayter & Allender, 2008). Many did not perceive that it was their role to be involved in PR (Moteji et al., 2012), or would overlook referral (Harris, Hayter & Allender, 2008). This may be strongly associated with HCPs being unsure of the benefit (Yawn & Wollan, 2008; Molin et al., 2016); or patients' ability to exercise. If unconvinced of the benefits or patient capabilities, it is unlikely HCPs would promote and communicate PR effectively to patients. These findings appear to be consistent with the suggested reasons for insufficient referrals highlighted in the PR audit (National PR Audit, 2015), and reinforced by an American study, which assessed speciality referral decision making by physicians (n=142) in primary care (Forest et al., 2006). Psychological factors such as having to admit uncertainty to the patient, or another HCP, acted as a barrier to referral, suggesting that a lack of confidence or knowledge impacts upon referral practice.

Others discussed practical barriers such as transportation and location (Wilson et al., 2007), long waiting lists (Johnston et al., 2013), or personal barriers such as current smoking status (Barr et al., 2005), and a dislike of the group setting (Alsubaiei et al., 2016). Transport also appeared to be especially problematic for those living in rural areas (Cochrane et al., 2016). It is unclear however if patients voiced these concerns, or if they are the HCP's individual perceptions. These findings are consistent with literature surrounding patient barriers, in particular travel and current smoking status (Hayton et al., 2013; Keating, Lee & Holland, 2011). The view that patients need motivation and encouragement during PR (Guo & Bruce, 2014), with apparent gender differences in relation to exercise (Witcher et al., 2015), displays HCPs' categorisation of patients due to their own perceived gender differences, which could impact practice. Similar findings have been evidenced within referral practice in primary care, where gender impacts referral decision making, with physicians more likely to refer males for further tests (Forest et al., 2006).

Feeling deskilled in COPD management and unable to confidently communicate PR was an undercurrent to the literature, and may provide explanation for a lack of referrals. Deficiency in knowledge and training were listed as significant barriers; reiterating that many feel unequipped to manage COPD or refer to PR (Johnston et al., 2016; Johnston (C) et al., 2012, p204). This may be as a result of a lack of information provided in practice, or

exposure during training, however no explanation was offered in the literature. GPs in Denmark selected which patients to discuss PR with, and left patients to consider referral (Molin et al., 2016). This appeared to be as a result of perceiving that patients would be disinterested in attendance, and abiding by their own criteria for referral. It would be interesting to establish if these views are consistent across Europe and America. Perceived patient barriers to PR were also highlighted, and although not explicitly stated, these perceptions could also act as a deterrent to referral for HCPs.

Interestingly, there was variation in the quality appraisal scores given, with some papers lacking details regarding the review question and methodology, for example Barr et al., (2005) and Yawn & Wollan, (2008). No paper was deemed such poor quality that it was discarded as a result; papers were included due to their pertinence to the review question. This does however emphasise the need for research of high methodological rigour, using samples from larger geographical locations, and HCPs of differing backgrounds.

Some, such as Foster et al., (2016), aimed to provide justification that HCPs and patients attitudes to PR result in a lack of referral, however this was not substantiated by the findings. As these conclusions are not corroborated, this appears to be a view held by the researchers. The results therefore provided details of knowledge surrounding PR and suggestions for increasing referrals, however this information cannot be used to deduce that a lack of referrals are a consequence of opinions surrounding the programme. Thus, it is apparent that further research is required to increase knowledge surrounding HCPs' perceptions of the programme, and assess if such claims can be substantiated.

### **2.7.2 Strengths and Limitations of the Review:**

A strength of conducting a CIS, was that it allowed for the synthesis of the different methodological approaches. CIS also supports the extraction of data, rather than whole studies, alongside incorporating the authorial voice to interpret findings (Gough & Thomas, 2012). It may be considered a weakness that the authorial voice is focused on, as this could lead to the subjectivity of the individual conducting the review (Cherry et al., 2014). This however is promoted on the basis that interpretation is grounded in the extracted data (Dixon-Woods et al., 2006a). Furthermore, it could be considered a limitation when conducting a review using qualitative literature, as there is no hierarchy of methods in qualitative research, therefore it cannot be claimed that one approach is superior to another (Cherry et al., 2014). CIS however, was viewed as the most appropriate method, given the diversity in the literature and the depiction of a detailed methodology, along with



interpretation of the literature being sought over that of a narrative review (Popay et al., 2006).

A further strength is that all articles were screened after reading the full text (n=61), and assessed by two researchers, who agreed that 18 met the inclusion criteria. Assessing all papers rather than a percentage is preferable, as there can be confidence that all met the criteria, minimising subjectivity (Centre for Reviews and Dissemination, 2009). The added systematic, rigorous and documented nature of each stage of study selection gives a detailed overview of the literature, and allows for replication (Garg, Hackam & Tonelli, 2008).

Appraisal tools have been criticised as being too general and dismissive of key factors associated with the research (Voss & Rehfuss, 2013). A tool was therefore selected to encompass questions applicable to quantitative and qualitative methods, thus allowing a score to be calculated for any research type (Hawker et al., 2002). To ensure relevance to the review question was specifically addressed, an additional question was added. It could be viewed as an inherent weakness that no papers were excluded after obtaining a score (Littlewood, Chance-Larsen & McLean, 2010). It was proposed that papers would only be excluded if they were methodologically unsound, however no papers fell into this criterion. As there is currently very limited knowledge surrounding HCPs' perceptions of PR, it was viewed unjust to remove pertinent papers due to poor quality scores, as inclusion of all would assist with a clearer narrative. It is advised that quality appraisal scores should be incorporated into the analysis, to enable readers to understand methodological processes, and draw their own conclusions; this approach was therefore adopted (Hayden, Cote & Bombardier, 2006).

It could be considered a limitation of this review that only English language papers were included. Therefore, it is possible that some papers of pertinence to the review question may have been overlooked, however as funds were unavailable, translation could not be carried out. A large proportion of the studies (n=6) were conducted in Australia. This emphasises the need for further research within the UK, Europe and USA, as although healthcare systems are similar, they do differ. Furthermore, two of the Australian studies were carried out within rural and remote areas (Johnston et al (C)., 2012; Johnston, Maxwell & Alison, 2016), and therefore the results may not be transferable to different locations.

Overall, it is perceived that the aims of the review were achieved. The PR audit highlights that PR is unequivocally effective and recommended (National PR Audit, 2015). It was apparent that many HCPs acknowledged its importance in the literature, however due to a lack of knowledge and confidence it is evident that further training is required. Although, the

review does not endeavour to change practice, it highlights the main concerns prevalent amongst HCPs, and will inform future research requirements.

### **2.7.3 Conclusions:**

Overall the CIS found a scarcity of research available to directly answer the review question. There was a particular paucity of literature surrounding the views of those in secondary care. Although it was evident that HCPs held disparate views, which were often based upon role and location, overall they lacked knowledge surrounding PR and the referral process, and many barriers to referral were highlighted. HCPs offered suggestions regarding how to improve referral, and although some could appreciate the programme's value, many were unsure of the benefits gained from attendance. After extracting relevant data from available literature, it is evident that HCPs are not referring patients to PR as frequently as they should. Whether this is due to their own internal beliefs, lack of programme knowledge or communication skills, should be questioned.

These points and findings raised from the CIS were used to refine the interview schedule for the main study, drawing upon previous literature in order to explore certain aspects further. Based upon the current lack of quality surrounding the evidence base, it would be difficult to make recommendations for practice or increasing referral uptake. Therefore, there is an evident need for research of high methodological rigour, with a sole focus on HCPs' views of PR as a management strategy for patients with COPD, as the current evidence base surrounding patients' perceptions is strong. Particular attention should focus on the gaps in the literature, incorporating views of those working in primary and secondary care, and their perceptions of the barriers and facilitators to referral. COPD patients are frequently admitted to general medical wards with other comorbidities, however it was noted that the views of those working there are not represented, although they have the ability to refer. This therefore is another avenue for exploration.

## **2.8 RESEARCH QUESTION AND OBJECTIVES FOR EMPIRICAL STUDY:**

The first two chapters have provided an overview of the literature, detailing the importance of the use of PR in the management of COPD. This however, evidenced that many patients are not referred to PR, or complete the programme. The National PR Audit (2015) highlighted that between 2013-2014, 68,000 patients were referred to PR in England and Wales, yet it is estimated that approximately 446,000 patients could have been eligible to attend during this period, demonstrating that the number of referrals is currently insufficient.

The audit drew attention to the insufficient evidence regarding why there is a lack of referrals to the programme. This was reinforced by the findings of the CIS (Chapter 2), which found no previous studies focusing entirely on HCPs' perceptions of PR. Although some insight has been achieved via extraction of data from studies with different objectives, no published research has fully addressed this issue. In addition, despite COPD patients often being admitted to general medical wards in secondary care, as evidenced in Chapter 1, there is a paucity of research specifically establishing the views of HCPs working there in relation to PR. Thus, the importance of establishing HCPs' perceptions of PR has been emphasised and further reaffirmed by the findings from the National PR Audit (2015), and supports this study's focus and the research question. It is therefore believed that this is the first study to focus upon the perceptions of both those working in primary care and those working on general medical wards, thus it was hoped that recruiting from these groups would add to the limited knowledge base. As a result the following research question and objectives were created.

### **2.8.1 Research Question:**

What are the perceptions of healthcare professionals in both primary and secondary care regarding PR as a management strategy for patients with COPD?

### **2.8.2 Objectives:**

1. To explore the perceptions that healthcare professionals, both in primary and secondary care, have about referring COPD patients to PR.
2. To establish healthcare professionals' understanding of PR.
3. To explore barriers and facilitators to referral to PR.

## **2.9 CHAPTER SUMMARY:**

This chapter aimed to provide a comprehensive overview of the literature to date surrounding HCPs perceptions of PR. Overall, 18 papers were included within the CIS, and as no study in its entirety focused upon the review question, data was extracted to form a narrative. The review highlighted two main themes: *Barriers to PR* and *General Perceptions of PR*, and synthesis of the data allowed the narrative to be displayed under synthesising arguments and synthetic constructs. Overall, it was deemed that the CIS met the aims and review question and highlighted the current gaps within the literature. This assisted with the

development and refinement of the interview schedule and research question for the current research. The subsequent chapter will therefore discuss the methodology and methods adopted for the current study.

## **CHAPTER 3: METHODOLOGY AND METHODS**

### **3.1 INTRODUCTION:**

This chapter will provide an insight into the methodology, including the research paradigm, ontological and epistemological position, before detailing the theoretical position adhered to throughout the research, with justification provided for each. Details of the method including the qualitative approach, use of interviews to collect data and data analysis using interpretive phenomenological analysis (IPA) will be provided, together with the rationale for choices, prior to presenting analysis of the findings in the subsequent chapter.

### **3.2 METHODOLOGY:**

A qualitative approach was adopted for the current research due to a lack of knowledge in the topic area, thus an exploratory, inductive approach was adopted (Creswell, 2014). Qualitative research commonly favours a pragmatic approach and aims to explore views, perceptions and experiences of a phenomenon via detailed accounts from different individuals (Hale & Kitas, 2007). Qualitative researchers engage in understanding the meaning of an experience, and endeavour to establish this from the individuals' perspectives; therefore, focus is on obtaining an in-depth account, rather than trying to determine a cause and effect relationship (Willig, 2013). Hence, qualitative research encompasses a number of methodological and theoretical approaches, and each researcher is required to establish their individual position (Lee, 2012; Lincoln, Lynam & Guba, 2011). The position adopted for this research, including the theoretical perspective is discussed in further detailed below.

#### **3.2.1 Constructivist/ Interpretivist Research Paradigm:**

Social constructivism was chosen as the research paradigm. Within social constructivism, individuals' views are formed by social interaction with others, via a process of construction, and based upon the world in which they live (Creswell, 2013). Social constructivism is closely related to interpretivism (Denzin & Lincoln, 2011); this is a multidisciplinary approach drawing upon psychology, sociology and language (Burr, 2015). Constructivism diverges from the realms of positivism, as positivism proposes that there is one physical reality (Burr, 2015); constructivism promotes that multiple realities exist, with each having equivalent importance (Ponterotto, 2005). As a consequence, social constructivism argues that what

we perceive is never a direct reflection of the world in which we live, and views are based upon our experiences of language, history and culture (Willig, 2013). This position supports the notion of 'knowledges' as opposed to 'knowledge', and thus our views are constructed based upon prior experiences (Willig, 2013, pg 7). Constructivism and interpretivism believes that views and perceptions are therefore gathered and modified as a result of experiences in specific situations, and are based upon human action (Schwandt, 1998). This is referred to in the literature as 'verstehen', and translates as understanding of human behaviour (Schwandt, 1998).

Interpretivism involves the researcher interpreting individuals' perceptions within a particular social construct, for example within a specific workplace or profession (Schwandt, 1998). Interpretivism was drawn upon for this study as it relates to the nature of the research question, which aimed to establish individuals' perceptions from different professional groups within a healthcare setting. Interpretivists use open questioning to allow the participant to construct the meaning of an experience or interaction (Crotty, 1998). Social constructivism explores the participants' social, historical and cultural norms, drawing upon experience and interaction with others; particular attention is paid to the setting within which the participant lives and works (Creswell, 2013). Researchers acknowledge that their prior experiences influence their interpretation of the data. It is the researcher's role to interpret the meaning of the data in order to 'inductively develop a pattern of meaning' or develop a theory, rather than testing one (Creswell, 2014). Social constructivists therefore, identify their position in the research, intertwining their prior experiences and background into the interpretation of the data (Creswell, 2013).

This position complements the current research question as it was perceived that HCPs would have differing experiences of PR. It was anticipated that some would have very little experience of the programme, but it was deemed important to include these views as the research aimed to establish the perceptions of HCPs who had the ability to refer to PR, regardless of their actual experience of doing so. It was considered that a lack of familiarity or knowledge would be a reflection of the individual's experiences, and thus shape their perceptions of the programme.

### **3.2.2 Ontological Position:**

Ontology questions what is the essence of reality and the world (Creswell, 2013). The ontological position adopted by interpretivists, is relativism (Denzin & Lincoln, 2011). Constructivism is described as *non-realist* and suggests that social reality is not a separate

reality; it is formed and socially constructed, and often multiplies based upon interaction with the social world (Guba, 1990). Therefore, a relativist ontology was adopted as it is believed that no single reality exists, and there are a number of realities constructed, dependent on the individual's experiences and views (Ponterotto, 2005). The notion of multiple realities is accepted within relativism, as it is considered that the only way of ensuring a clear representation, is through openness and the re-defining of constructs (Guba, 1990). The researcher therefore does not aim to establish one 'truth', and thus endeavours to understand multiple different realities, as individuals can experience and perceive the same phenomenon in a number of different ways (Ponterotto, 2005).

### **3.2.3 Epistemological Position:**

Epistemology is described as the theory of knowledge and focuses on how we know and learn knowledge (Crotty, 2003). The epistemological orientation is that of subjectivism, which complements social constructivism/interpretivism (Denzin & Lincoln, 2011; Scotland, 2012). Subjectivism promotes that the world is shaped by our knowledge of it, and our knowledge of the world is formed by our lived experiences (Lincoln, Lynham & Guba, 2011). It re-affirms that realities are individual and only exist in individuals' thoughts, therefore in order to establish these constructs, subjective interaction needs to occur (Guba, 1990). A subjective perspective proposes that there are multiple accounts of the same phenomenon, each specific to the individual and their interpretation; this is referred to as viewing the world through a lens, as reality cannot be directly observed (Howitt, 2010). Subjectivism therefore directly relates to the current research question, as each HCP had variable levels of knowledge and experience of PR, however these experiences need to be viewed through individual *lenses* to portray a full representation of each individuals' perception.

### **3.2.4 Theoretical Perspective:**

An inductive approach was adopted, as it aims to identify any emerging patterns and meanings (Smith, 2004). It was identified from early immersion in the literature that there was a lack of knowledge surrounding HCPs' perceptions of PR. It was therefore considered that it would be useful to develop either a theory or model, to explain HCPs' views on PR and the referral process. Initially, grounded theory appeared to be an appropriate choice (Glaser & Strauss, 2017), however prior personal experiences made it difficult to fully approach the data with no preconceptions, which grounded theory advocates (Glaser, 2002). Grounded theory also requires the study to be approached with minimal knowledge

of the literature, thus exploring broad aspects of the research topic, rather than having a definitive research question; hence the resulting theory is grounded purely in the data collected (Charmaz, 2015). As the systematic review was conducted during the study design phase, and identified that very little knowledge of the topic existed, grounded theory was therefore deemed unsuitable. Additionally, it was considered more important to gather in-depth individual accounts in order to gain greater insight into the phenomenon, rather than gaining a collective insight through various means of data collection such as interviews, diaries, observations, which grounded theory promotes (Corbin, 2017). Thus, a phenomenological approach appeared most appropriate to understand the individual perceptions of HCPs.

Phenomenology is the study of human consciousness (Lopez & Willis, 2004), it seeks to understand lived experiences of the world in which we live, however acknowledges that the world is present before an individual attempts to reflect upon their experiences (Merleau-Ponty, 1962). There are two definitive strands to phenomenology, descriptive (eidetic) phenomenology and interpretive (hermeneutic) phenomenology, each having differing stances upon how the research and data should be approached (Flood, 2010). It is important when conducting phenomenological research to acknowledge which type will be used.

Edmund Husserl (1859-1938) was one of the key founders of phenomenology as a philosophical approach (Ashworth, 2008). He promoted descriptive phenomenology, which suggests that '*reality and experience are deemed to be socially constructed and represent but one of many truths rather than an absolute truth*' (Preist, 2002, pg. 53). Intentionality is pivotal within descriptive phenomenology when explaining human experiences and conscious awareness of objects (Earle, 2010), and knowledge is assembled via a conscious awareness of reality (Koch, 1995). Universal essences or *eidetic* structures are distinctive attributes to descriptive phenomenology and suggest that there are commonalities between all individuals who have experienced a particular phenomenon, and that these should be established to provide generalised descriptions of the phenomenon (Lopez & Willis, 2004). Husserl proposed that to achieve a descriptive stance one has to abide by a process of psychological reduction, eliminating any pre-conceptions of the world and reducing the phenomenon to its simplistic form (Walters, 1995). Some descriptive phenomenologists firmly believe that in order to bracket appropriately, there should be no immersion in the literature and no creation of a defined research question (Lopez & Willis, 2004). This notion of bracketing prior experiences, views and remaining objective is central to descriptive phenomenology, so as not to pervert judgement (Pringle, Hendry & McLafferty, 2011). As



a result of this, descriptive phenomenology was disregarded for this research, as although it was imperative to remain objective, it was considered that full psychological reduction may not have been possible, and familiarisation with the literature had already taken place due to conducting the CIS.

Interpretive phenomenology (hermeneutic) on the other hand, developed by Heidegger (1889-1976) focuses on making sense of the experiences of others via a process of interpretation (Shinebourne, 2011). Heidegger, a previous student of Husserl's, strongly opposed the idea of psychological reduction and viewed that one can never bracket one's self completely, as experiences can never truly be erased (Lavery, 2003). To account for this, Heidegger developed '*dasein*' which relates to involvement and being aware of your own activities, and interaction with others in the living world (Horrigan-Kelly, Millar & Dowling, 2016). Therefore, interpretive phenomenology draws upon hermeneutics which allows for the interpretation of meaning (Pringle et al., 2011). Heidegger does however acknowledge that interpretation will always be based upon one's own lived experiences and understanding of the phenomenon (Walters, 1995). This concept is referred to by Heidegger as '*life world*', and reinforces the view that realities are individual and shaped by personal experiences of the world (Heidegger, 1962). Within interpretive phenomenology it is important to explore the individuals '*dasein*' (lived experiences), and through interpretation enquire how these may have shaped their views of the world; rather than to purely describe and recount (Flood, 2010).

Understanding in interpretive phenomenology is referred to as the '*hermeneutic circle*', whereby all the separate components of a phenomenon need to be understood and pieced together to understand something in its entirety; this process can only occur by drawing upon the researcher's fore-structures or prior understanding (Koch, 1995). This concept was simplified by Willig (2013), who related the hermeneutic circle to the understanding of sentence structures. Willig (2013), proposed that it is not always possible to understand the context of a word without the sentence, and it is often difficult to comprehend a sentence without understanding specific words, therefore each part needs to be understood along with its whole. Hence, the hermeneutic circle refers to a continuous process of going back and forth between prior assumptions and interpretation to form an understanding of phenomena. This process is facilitated using the researcher's prior experiences to guide interpretation and thus increase understanding (Willig, 2013). Both Heidegger and his student Gadamer popularised interpretive phenomenology and reiterated the importance of hermeneutics in exploring human experience (Giorgi & Giorgi, 2013).

Phenomenology therefore has strong philosophical underpinnings (Willig, 2013), with hermeneutic phenomenology strongly influencing this current research, as it is a theory of interpretation (Koch, 1995). This involves the participant trying to understand their prior experiences, whilst the researcher aims to interpret these, referred to as a double hermeneutic approach (Smith & Osborn, 2008). Value is placed on the pre-existing knowledge and assumptions of the researcher, allowing the data to be guided, resulting in an illustrative representation of participants' experiences (Lopez & Willis, 2004). Embracing an interpretive phenomenological approach allows individuals' perceptions and experiences to be recognised more broadly, assessing the deeper meaning through interpretation of the data (Willig, 2013). Therefore, this study employed an interpretive phenomenological approach because it allows themes to emerge freely, with an emphasis on interpretation of participants' perceptions and consciousness of a phenomenon (Maggs-Rapport, 2000).

Interpretive phenomenology has therefore been employed as the theoretical perspective, as the research aims to establish HCPs' perceptions and experiences of PR as a management strategy for patients with COPD. It can be described as understanding lived experiences of a group of individuals, based upon a particular phenomenon (Creswell, 2013). The notion of exploring individuals' perceptions, thoughts and beliefs which represent experiences, enhances understanding, and is central to phenomenology (Willig, 2013). These individual lived experiences can contribute to a collective experience, however that of the individual should be preserved at all times (Smith, Flowers & Larkin, 2009). Although, it was perceived that some HCPs may have limited knowledge and experience of referring to the programme, others will refer frequently; these were both experiences the study aimed to identify. These experiences of PR, or lack of, will aim to enhance understanding of why some HCPs refer to the programme and others do not.

### **3.2.5 Interpretive Phenomenological Analysis (IPA):**

Although, it was acknowledged that an interpretive phenomenological methodological approach would be adopted, the nature of the research question and previous personal experiences influenced the decision to select IPA as the specific approach. IPA was developed by Jonathan Smith as a qualitative approach to explore individuals' lived experiences of a phenomenon (Smith, 1996). It builds upon the core theoretical principles of phenomenology, hermeneutics, and ideography, to create a rigorous approach in exploring experience (Smith, Flowers & Larkin, 2009; Smith, 2017). It is acknowledged that in order to achieve this, a level of interpretation is required, '*as humans are sense making organisms*' (Smith & Osborn, 2015a, pg 41). IPA is *ideographic* as it focuses on the

individual (Smith, Flowers & Larkin, 2009), as opposed to *nomothetic* research which is the study of groups of individuals (Shinebourne, 2011). IPA is particularly popular within the field of health psychology, allowing those who have experienced healthcare services, or have a particular condition, to voice their views and feel as though their opinions have been heard (Reid, Flowers & Larkin, 2005). It draws upon the perspectives of psychologists such as Carl Rogers, Gordon Allport and William James who placed importance upon exploring individual experiences within the psychology discipline (Smith, 2017).

IPA should be considered as a *stance* adopted on how to approach the research, data collection and analysis, as opposed to just another method of analysis. IPA surpasses description, and not only does the researcher take an insider's perspective during the analysis, they also create an interpretive narrative of what it means for the participant to have their experiences discussed in relation to the phenomenon in question (Larkin, Watts & Clifton, 2006). Carefully considered IPA studies should therefore be rigorous in nature and include a high degree of '*interpretive flair*' (Smith, 2011, pg. 23), allowing the researcher a degree of flexibility in the exploration of different perspectives (Larkin, Watts & Clifton, 2006). This is reinforced by Smith who emphasised that he wanted to develop an '*approach which is rigorous and systematic, but which also has an important role for exploration and creativity*' (Smith, 2017, pg 303).

IPA does not aim to achieve generalisability or representativeness, however researchers are urged to focus on theoretical transferability. Providing in-depth rich quotations and placing them within the context of the participant narrative, allows readers to assess this, enabling them to make their own judgements on the transferability of the account to other participants interviewed. (Smith, Flowers & Larkin, 2009). This is successfully achieved in IPA via the purposeful sampling of a homogenous group; these individuals should all have close alignment to the research topic, allowing similarities and divergences of opinion to be easily identified (Chapman & Smith, 2002). In addition, providing statements which situate the findings in the context of the current body of literature, provides the reader with greater depth to form their appraisal of theoretical transferability. The success of IPA research is therefore distinguished by the understanding gained within this wider context (Smith, Flowers & Larkin, 2009).

IPA was chosen for the current research, as it allows prior experiences of the researcher to be accounted for, however it is important to remain objective during the conduct of the study, in order to gain the individual perspective of the participant (Smith & Osborn, 2008). Accounting for prior researcher experiences is a particularly advantageous aspect of IPA,

and it is imperative that the researcher's role in the study is clearly documented (Brocki & Wearden, 2006). This is where such significant prior experiences of helping to care for a relative with COPD were drawn upon, and fully acknowledged throughout every stage of the study. In other methods of analysis such as thematic analysis, such notable previous experiences could be considered as potential biases, however in the case of IPA they can be recognised and used to guide the research (Lopez & Willis, 2004). This is one of the most significant differences which separates IPA from different methods, as importance is placed upon the researchers' interpretation of the data (Hale, Grogan & Willott, 2010). Hence, it was perceived important to use an approach where these experiences can be perceived as a strength.

### **3.3 METHODS:**

The methods will provide details on the research design, ethical approval, the recruitment of participants and the different approaches taken in primary and secondary care. This is followed by information on the final sample, the data collection process, and finally details of the data analysis and validation of findings.

#### **3.3.1 Research Design:**

The study design adheres to the principles of phenomenology, with a key focus on interpretive phenomenology. As previously discussed, IPA was chosen as a *stance* and method of analysis, as it allowed for the generation of a detailed narrative built from the in depth perceptions of participants. Immersion in the data from the very beginning, enabled creation of the narrative surrounding HCPs' perceptions of PR. Acknowledging previous personal experiences of helping to care for a relative with COPD was also an important consideration. It was believed that this would assist with the understanding of a phenomenon where currently very little research has been undertaken. One-to-one interviews were conducted to ensure that the individual's personal experience was captured.

#### **3.3.2 Ethical Approval and Health Research Authority Approval (HRA):**

Ethical approval was obtained from Edge Hill University Faculty of Health and Social Care Research Ethics Committee (FREC), prior to conducting the research, in May 2016 (Project Ref: FOSH143) (see appendix 8). Health Research Authority (HRA) approval (IRAS ID:

208153) (see appendix 9), was also gained on 26<sup>th</sup> August 2016. A research passport (see appendix 10) was granted by the lead site (one of the hospital trusts), and was approved individually by each of the other Research and Development departments, this allowed access on to sites if face-to-face interviews were requested.

As a result of poor uptake in secondary care an amendment to the ethics application was approved for secondary care by the HRA on 2<sup>nd</sup> May 2017 (see appendix 11), and also by FREC on 10<sup>th</sup> May 2017 (see appendix 12). This allowed the researcher to visit general medical wards with the two gatekeepers, to remind HCPs in person of the previously distributed email, and to raise awareness of the study.

### **3.3.3 Recruitment and Participants:**

Purposeful recruitment of HCPs with the ability to refer COPD patients to PR was employed. This is in keeping with IPA, whereby researchers should seek to achieve a homogenous sample, and endeavour to collect the views of those with a close connection to the research question (Chapman & Smith, 2002; Pietkiewicz and Smith, 2014; Smith, Flowers & Larkin, 2009). Ability to refer to PR was the homogenous factor, and gaining perspectives from different professional groups allowed for similarities and differences to be explored between groups. Participants were therefore recruited from four professional groups, GPs and practice nurses (PNs) in primary care, and doctors, and general nurses (GNs) working on general medical wards in secondary care. Recruitment took place in clinical commissioning groups (CCGs) in both Greater Manchester and the North West Coast, along with two hospital trusts in the North West of England. Thus, a large geographical area was covered, enabling the research to be classified as a North West study, see chapter 4, figure 7, for map representations of approximate participant recruitment locations.

It was viewed that it would be useful to gather perceptions of HCPs from general medical wards, as it is likely that they will encounter COPD patients frequently. This was considered important, as when reading the literature, it became apparent that COPD patients are often admitted to general medical wards with comorbidities of their condition (Hillas et al., 2015), yet it remained unclear whether HCPs working on the ward would be aware of PR or if they refer to it. The inclusion criteria therefore consisted of GPs and PNs in primary care, and doctors and GNs working on general medical wards in secondary care. The exclusion criteria encompassed any HCP who did not have the ability to refer COPD patients to PR, and any HCP in secondary care who did not work on a general medical ward. For the purpose of this study, a general medical ward was defined as a ward with no particular

specialism, which cares for patients with various conditions. This included, but was not exclusive to, medical assessment units (MAUs), GP assessment areas, ambulatory units, general medicine departments, elderly care wards, acute medicine and clinical decisions wards.

Purposeful sampling was perceived to be the most appropriate recruitment strategy, as it allowed for recruitment from these specific professional groups, ensuring representation of each profession (Robinson, 2014). It was this purposeful selection of participants which enabled inclusion of those who had experience and/or views of PR, thus adding insight to the phenomenon and providing a more comprehensive picture (Coyne, 1997). A different recruitment strategy was adopted for those working in primary care, in comparison to those working in secondary care, both of which will be discussed below.

#### *Primary Care Participants:*

In primary care, invitation letters (see appendix 13) and participant information sheets (see appendix 14) were sent by post, and individually addressed to the GP or PN invited to participate. Primary HCPs were contacted in batches via letter, to inform them of the study, these were sent at weekly intervals to ensure data collection was manageable. Potential participants were identified using the NHS Choices website, or by following the link to their own practice website. These two avenues were used to identify GPs and PNs working in practices for which HRA approval had been granted (North West Coast CCGs and Greater Manchester CCG). Letters were sent to different practices across the North West Coast CCG and Greater Manchester CCG, until data saturation had been reached. An Excel database was created containing details of primary HCPs working in the catchment areas, using the details obtained from the websites. All information included in the database was therefore freely available online. This facilitated the creation of a mail merge for the production of individually addressed letters, and the recording of HCPs who had been contacted, and the outcome of any replies.

HCPs expressed an interest and opted into the study either by returning the reply slip on the bottom of the invitation letter, in the prepaid envelope provided, or by responding directly to the researcher via email or telephone. The paper reply slip was pre-printed with the individual's name and practice where they worked to ensure correct notation of each response. HCPs were also provided with the option to tick a box stating they would prefer not to participate, and in this case no further contact was made. This was an effective strategy as it assisted in establishing the number who declined participation. The Excel

database was also updated for those who wished to participate; with each stage of the recruitment process noted, for example documenting when individuals had been contacted to thank them for their interest, details of when an interview had been scheduled, and the date the interview had been conducted. This ensured participants were informed of the study arrangements, without overburdening them. Only the primary researcher (ES) had access to the excel database, which was stored on a password protected computer for the purpose of detailing those already contacted. If after one week no replies had been returned from a particular practice, the researcher telephoned the surgery and requested to speak to the practice manager. This approach was adopted in an effort to improve response rates and to ensure that the letters had been received. Overall, practice managers were facilitating, with some agreeing to add the study to the agenda to discuss at the next practice meeting, which assisted with uptake. A depiction of response rates and participation in primary care, can be seen in Figure 5.

There is an absence of literature surrounding the effectiveness of recruiting HCPs via letter, however more generally personalised invitation letters have been considered to build a rapport prior to participation (Kypri & Gallagher, 2003). Others however have seen little difference in participation rates when distributing a questionnaire at the same time as an invitation letter (Treweek et al., 2010).

#### *Secondary Care Participants:*

A different recruitment strategy was adopted within secondary care, as it was not possible to identify all HCPs working on general medical wards online. As it is noted that recruiting within large organisations, particularly the NHS, can be a complex process (Cob, Srinivasan & Lambiase, 2016), with the pre-requisite of requiring organisational level permissions, a gatekeeper is often recruited who has the ability to identify participants and distribute study information (Robinson, 2014). This approach of recruiting gatekeepers to assist with the recruitment of eligible participants was perceived most appropriate for secondary care.

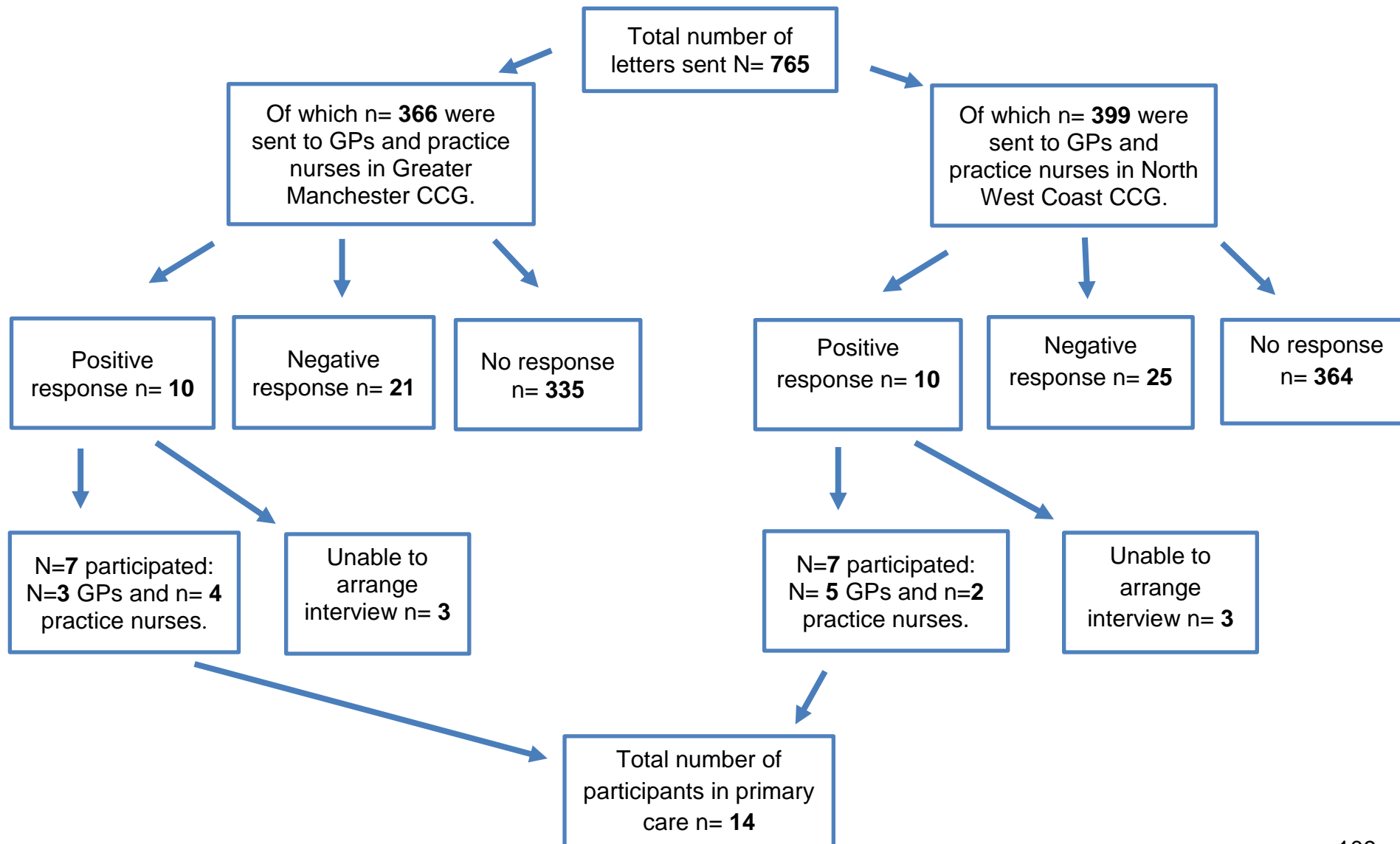
Two gatekeepers were established; each were respiratory consultants working in different hospital trusts in the North West of England, for which HRA approval had been received. The gatekeepers were initially contacted via email to inform them of the study and asked if they would be willing to undertake the role. One gatekeeper was happy to discuss their role in the research via email, the other preferred to meet face to face at the hospital. Both consultants agreed to distribute the invitation email (see appendix 15) and participant information sheet (see appendix 14) to HCPs who met the inclusion criteria, working on general medical wards within their trust. HCPs expressed an interest in the study by

contacting the researcher by email or telephone on the details provided in the email; the participant made no contact with the gatekeeper. A reminder email was sent by the gatekeeper one week after the initial email. It became apparent that recruitment via email in secondary care was going to be problematic, due to a poor response rate to both the email and reminder. From the emails distributed in secondary care only four individuals responded, of which only two participated in the study.

Discussion occurred with both gatekeepers on ways to increase participation, with one suggesting that the researcher should accompany them to general medical wards to discuss details of the study in person with the HCPs working there. An HRA amendment was received to enact this, which was approved on 2<sup>nd</sup> May 2017 (see appendix 11). As HCPs had already received the invitation email and reminder, if they wished to participate that day, a suitable time was arranged and the interview was conducted face to face on site. Both gatekeepers arranged and accompanied the visits to the general medical wards where the emails had previously been distributed. This proved an effective alternative strategy, and allowed for awareness of the study to be raised face to face. Some HCPs asked if they could take part in the interview immediately, or asked if they could participate after their ward round, and this was facilitated.



**Figure 5: Response Rate and Participation from Letters in Primary Care**



### *Final Sample:*

The overall sample was 27 participants, which when split into each professional group was: GPs (n=8), PNs (n=6), Doctors (n=6), GN (n=7). Although, this may be considered a large sample size for IPA (Brocki & Wearden, 2006), this takes into consideration the narrow focus of the research topic and the desire to explore perceptions from a variety of professional backgrounds. Further participant characteristics and demographic information is provided in chapter 4, in table 6 and 7.

Although IPA research generally promotes the use of smaller samples (Brocki & Wearden, 2006), it should be noted that there are no specific rules in relation to larger sample sizes, and attention should be paid to the depth of data and any limits surrounding data collection, along with how the researcher wishes to compare different accounts (Pietkiewicz & Smith, 2014). Similarly, IPA researchers have been urged not to focus attention on the number of participants, but rather the richness of the data in relation to the phenomenon being studied (Larkin & Thompson, 2012). This supports the views of Pope, Ziebland and Mays (2000), who suggest that sample size should be dictated by the research question, however, Yardley (2000) advises caution with particularly large samples as it may not be possible to conduct the analysis in sufficient detail. Nevertheless, participants should be purposefully selected to best represent the research population, and therefore selected for their specific attributes and due to holding knowledge or an opinion on the topic (Morse et al., 2002; Yardley, 2000). This notion has been reaffirmed more recently by Smith and Eatough (2012), who state that there is no correct answer as to how many participants should be recruited in an IPA study, and that this should purely be driven by the data. They advise that some studies require larger numbers, and the researcher should assess the richness of individual participant responses, along with how they wish to compare and contrast cases, alongside any time restrictions for analysis.

Smith (2004) recommends that saturation in IPA studies commonly occurs at between six and 10 cases. Saturation is proposed as the gold standard in establishing a purposive sample (Guest, Bunce & Johnson, 2006), however there are a number of definitions available which establish how best saturation is achieved (Francis et al., 2010). The current study adopted the definition that saturation occurs when no new ideas or concepts emerge from the data (O'Reilly & Parker, 2013) along with consideration of the point when a representative picture of the data could be drawn (Smith & Osborn, 2015b), and at which point recruitment ceased. Due to recruiting from different professional groups, saturation was sought from each group of HCPs, therefore the anticipated sample size prior to the

study was predicted at 24-40 in total (Smith, 2004). This is referred to as a '*multi-perspectival*' study (Smith, Flowers & Larkin, 2009, pp. 52), and is promoted for increasing a greater understanding of a phenomena amongst different groups of individuals (Borg Xuereb, Shaw & Lane, 2016). Others believe that it is difficult to determine saturation within a qualitative study and therefore data collection should cease when only a representative picture along with any inconsistencies in the data has been presented (Elliott, Fischer & Rennie, 1999). It is however perceived reasonable to use the term saturation in conjunction with IPA, as long as it is clearly documented as to how this process has been carried out (Hale, Treharne & Kitas, 2008). This process of defining when saturation had been reached was adopted for the research, along with consideration of the point when a representative picture of the data could be drawn. As IPA allows for data collection and analysis to occur concurrently, each participant was assessed as an individual case before assessing any parallelism or divergences (Smith & Osborn, 2015b). Immersion in the data from the beginning allowed a pronounced picture to be built throughout, which therefore assisted with the identification of saturation. Recruitment therefore ceased at different times per professional group, dependent on when no new information emerged from the data, and was in line with the prior anticipated sample size at N=27.

#### **3.3.4 Data Collection:**

One-to-one semi-structured interviews were conducted with each HCP; congruent with standard data collection methods for IPA studies (Chapman & Smith, 2002). HCPs were given at least 24 hours after receiving the invitation letter/email and the participant information sheet, to decide if they wished to take part. Prior to the interview participants were asked to read and sign the consent form (if face to face interview), or provide verbal audio recorded consent over the telephone (see appendix 16) and asked if they had any questions. The interview topic guide was created, drawing upon the literature available surrounding patients' perceptions and experiences of PR, along with personal experiences of helping to care for a family member with COPD. The literature discovered when conducting the CIS (see Chapter 2), surrounding HCPs' perceptions, aided further refinement of the topic guide (appendix 17).

Interviews were semi-structured in nature, which allowed for flexibility and deviation from the interview schedule, to follow up on interesting responses pertinent to the research question (Chapman & Smith, 2002) and incorporate points raised by participants into

subsequent interviews. The use of open-ended questions enabled participants to provide in-depth and detailed responses, discussing aspects which were of importance to themselves. Interview probes facilitated discussion and elaboration on particular questions, allowing for the richness required for IPA (Smith, Flowers & Larkin, 2009). This technique is promoted as it gathers honest open responses, helps participants to feel at ease, and their views listened to (DiCicco-Bloom & Crabtree, 2006). Each participant was encouraged to talk freely about their views, in order to gain insight into their personal and social world (Smith & Osborn, 2015b). All interviews were audio digitally recorded with the participants' consent.

Question specific probes were also used which had been pre-determined when the topic guide was created. All interviews took place at a suitable time for the participant, either face-to-face or over the telephone. Interviews conducted in primary care were all via telephone (n=14), at the request of the HCP, and often due to time constraints. Conversely, the majority of interviews in secondary care were conducted face to face at the hospital where the HCP worked. Onsite face to face interviews typically took place in offices just off the general medical ward, or in a family or day room if unoccupied. Some who participated in face-to-face interviews asked if they could do '*joint interviews*' with other colleagues; this was declined, as the study was only approved for one to one interviews. It was decided early within the research design process that one to one interviews would be most appropriate, to establish rich individual perceptions, and to build individual cases required for IPA (Smith & Osborn, 2015b). It was perceived that a group situation may have also led to bias and influence of each other's responses; a common limitation seen with focus group interviews (Sim, 1998). Possible disadvantages of telephone interviews such as not being able to build the same rapport or observe non-verbal cues (Opdenakker, 2006) have been highlighted, however this did not appear evident in this research. Conversely, it is argued that there is very little difference in the quality of data obtained when performed face to face or over the telephone (Novik, 2008). Furthermore, due to busy workloads, the flexibility of telephone interviews increases participation as often if this option was unavailable they would not have the capacity to conduct one face-to-face (Harvey, 2011). Other complications discussed in relation to telephone interviews can be the diminished quality of the recording, however it was often the case that recordings were clearer over the telephone, as the noise and equipment on general medical wards often caused disruption in face to face interviews. It was viewed that the quality of data obtained from primary and secondary care was comparative, however there were many more interruptions present on the wards.

The interviews in primary care lasted on average 22 minutes 22 seconds (range, 11 minutes 33 seconds to 37 minutes 24 seconds). Those in secondary care on average were shorter in duration lasting 9 minutes 33 seconds (range, 6 minutes 18 seconds to 18 minutes 49 seconds). The length of interview was due to the specific nature of the research question, and the level of detail in which the participant chose to discuss their views. Details of participant demographics, including role, gender, age, years in practice, speciality/ interest, ward type and interview format are provided in Chapter 4, in table 6 and 7.

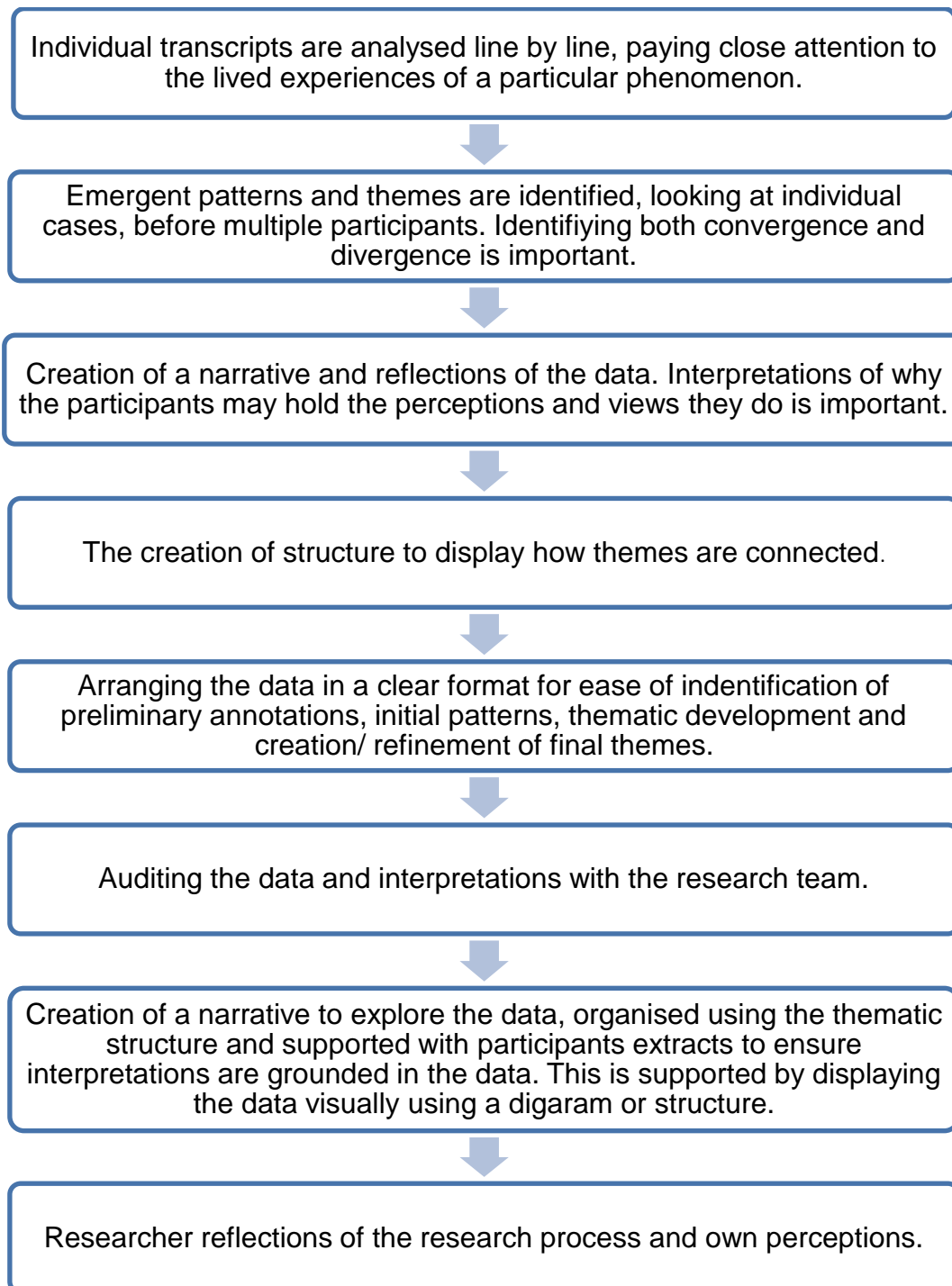
A researcher reflexive diary was completed during the recruitment process, with notes being taken after each interview, after transcription and during data analysis. This process allowed for any initial thoughts, feelings or interpretations to be accounted for and later incorporated into the analysis (Biggerstaff & Thompson, 2008). This is discussed in further detail in the researcher reflections chapter, with example excerpts also provided (Chapter 6).

### **3.3.5 Data Analysis:**

In adopting a hermeneutic (interpretive phenomenological) approach, it is accepted that accounts which the participants detail, are their construction of their reality and experiences (Koch, 1999). Due to the ideographic nature of IPA, each participant transcript was analysed as an individual case before making more generalised statements (Smith, 2004). Interpretation rather than description is the key focus, and all participant extracts should be supported with an interpretive narration (Smith, 2011). This facilitates the adoption of the double hermeneutic approach, whereby the participant tries to make sense of their prior experiences, whilst the researcher interprets them (Smith & Osborn, 2008). Although IPA follows a series of steps to collect and analyse the data, it is acknowledged that these are provided for guidance with minor modifications accepted, due to each study having differing requirements (Pringle et al., 2011; Smith, Flowers & Larkin, 2009). IPA data analysis follows a hermeneutic circle, as previously discussed, whereby interpretation requires the researcher to transfer back and forth, casting attention between 'the part' (a section of a transcript or individual case) and 'the whole', searching for common themes or divergences between the individual participant, as well as collectively assessing what other participants' views were (Smith & Osborn, 2008). A pragmatic approach has to be taken when conducting the analysis, as the hermeneutic circle is ongoing and often difficult to exit, therefore the researcher is required to decide when their interpretation and analysis displays an accurate representation of the data (Smith, 2007).

Analysis of the data occurred concurrently with data collection. The main steps of data analysis followed the guidance provided by Smith, Flowers and Larkin (2009) (see Figure 6).

**Figure 6: The Main Steps of IPA Data Analysis (Adapted from Smith, Flowers & Larkin, 2009)**



Verbatim transcription occurred after each interview. Commencing this process prior to the following interview allowed for instant immersion in the data, and for any new and interesting topics or emergent themes to be noted and incorporated into subsequent interviews (Smith & Osborn, 2015b). This also enabled the notation of any significant pauses, utterances or laughter, and was useful when used in conjunction with the researcher reflexive diary, as some of the comments made supported the behaviours and language used. This approach facilitated the detailed analysis of viewing each participant as an individual case.

Transcripts were analysed case by case and line by line, with notes made of any pertinent quotes in relation to HCPs' perceptions of PR. It was important at this stage to read and re-read the transcript, as each familiarisation had the potential to add new insight (Smith & Osborn, 2015b). This initial analysis was conducted by hand using key words, phrases, sentences or paragraphs to describe, summarise and provide interpretations of the data (see appendix 18). As greater familiarity with the transcript was achieved, similarities, disparities and contradictions in participant perceptions throughout the transcript were noted (Smith, Flowers & Larkin, 2009). After completion of this process, the transcript was revisited, in order to categorise notations into initial emergent themes, using more specific phrases to represent the data. The development of themes creates '*a slightly higher level of abstraction and may invoke more psychological terminology*', however this remained grounded in the data (Smith & Osborn, 2015b, pg 41).

Those conducting IPA are urged to be confident in their analysis, going beyond first order themes which are merely used to describe the data, and instead provide interpretation enhancing analysis to a conceptual level (Larkin, Watts & Clifton, 2006). This was achieved by creating and drawing upon a narrative and reflections of the data, and detailing interpretations of why the participants may hold the perceptions and views they do. Initial themes were documented in the order that they appeared in the transcript, however in the second phase a thematic account was created by establishing connections and similarities amongst themes, which were then clustered (Chapman & Smith, 2002). It is recommended that analysis should be conducted using hard copies of transcripts, however it is acknowledged that researchers are now thematising data on a computer (Smith, Flowers & Larkin, 2009). Thus, Smith (2009), suggests it is useful to create files of emergent themes and paste direct supporting participant quotations on to each document, to determine the coherence, disparity of different participants' perceptions, along with the frequency of supporting statements. Identifying and incorporating both differences and similarities into the analysis supports the ideographic nature of IPA, allowing each participant to be represented as an individual, rather than being grouped and lost within the analysis (Smith,

2017). It was therefore decided at this point of the analysis that NVivo 11 ® (QSR International, 2015), a software package which assists with the organisation of qualitative data, would be the most appropriate to support this process. Once all the transcripts had been uploaded to NVivo 11® (QSR International, 2015), the software facilitated easy manoeuvrability of quotations, as emergent patterns arose, allowing for in depth analysis to occur.

These clusters were then assessed to ensure that they represented the verbatim quotations held within them, an iterative process which enabled the initial decision making to be questioned, ensuring that it was representative of the participant perceptions (Smith & Osborn, 2015b). The clusters of themes were then transferred into a table and given a label to encompass and represent all of the themes within them, this is referred to as a super-ordinate theme (Willig, 2013). An additional check was carried out to identify that all themes within the super-ordinate theme best represented participant perceptions of the phenomenon. If any themes at this stage appeared no longer suitable, nor provided rich participant perceptions, they were removed or moved to another more appropriate super-ordinate theme (Smith, Flowers & Larkin, 2009).

The same process was followed for each case, viewing it as a separate entity (Pringle et al., 2011). Each started by becoming familiar with each participant's data before noting initial ideas, with an individual table of themes and super-ordinate themes created for each participant. This allowed each transcript to be analysed in its own right, focusing on particular individuals' perceptions, rather than trying to ensure fit into pre-established themes (Willig, 2013). This allowed new themes to emerge from each case, and complements the inductive, cyclical approach to data analysis (Smith, Flowers & Larkin, 2009).

After carrying out this process for each case, a master table of themes was created, by condensing and refining the data, where certain sub-themes are merged, split or modified, as a result of further immersion (Smith, Flowers & Larkin, 2009). At this point super-ordinate themes, and sub-ordinate themes were not solely selected due to their occurrence, consideration was also given to the richness of the data, and determining the most suitable fit with the research question, constantly referring back to the aims of the study (Smith & Osborn, 2008). It is important to note that the data from primary care HCPs was analysed separately from those working in secondary care. Two separate master tables of themes were therefore created, one for primary care, and another for secondary care, thus allowing comparisons to be drawn in the findings and discussion chapter.



The data was audited by the supervisory team, to ensure that super-ordinate and sub-ordinate themes were grounded in the data; 100 percent agreement was achieved. Subsequent to this, themes were pulled together in a '*structure*', a jigsaw figure to display a visual summary and representation of the analysis and how each theme was connected (Larkin & Thompson, 2012). A narrative was then formed to explain the structure in more detail, using direct quotations to support interpretations (Pietkiewicz & Smith, 2014); this formed a large proportion of the data analysis. It was the intention to take the reader on a journey through the participants' experiences and views, providing verbatim quotes, discussing interpretation and acknowledging instances of disparity (Smith, 2011). Analysis was rigorous and all interpretations were grounded in the data, and supported with excerpts of the interview (Brocki & Wearden, 2006). This ensured that there was clear representation of the participants' views, to allow the reader to differentiate this from the researcher's interpretation (Smith, Flowers & Larkin, 2009). Convergences as well as divergences of individual's accounts were explored, and an interpretive coherent representation of different experiences and perceptions of the same phenomenon was provided (Smith, 2011).

As previously discussed, Smith (2011) supports larger sample sizes, and has provided detailed guidance on how best to analyse the data with a larger number of participants (Smith, Flowers & Larkin, 2009). The guidance suggests that detail should be provided of the recurrence of the number of individual cases that compose a superordinate theme. It is recommended that a criterion should be set that a notion should be present in a third or half of cases in larger samples, to classify it as a super-ordinate theme (Smith, Flowers & Larkin, 2009). This suggestion was followed and was supported with detailed documentation of the number of individual cases that each theme occurred in (this is depicted in table format for easy identification, see Chapter 4) (Smith, Flowers & Larkin, 2009; Smith, 2011). Participant quotations were provided to reinforce interpretations, and it is advised that a minimum of three to four should be displayed per theme (Smith, 2011); this approach was also adopted.

Koch (1999) suggests that when writing the data analysis section, it is imperative that clear documentation of how the data was interpreted and an explanation of key decisions made during the research process, is highlighted. Thus, researcher reflexivity was a valuable way to capture this information, and supported the data analysis, providing justification of key decisions made. This approach was embraced at all stages of the study, from the commencement of data collection through to the completion of data analysis.

### **3.3.6 Validation of Findings:**

Verification and validation of findings is the process of confirming the quality of qualitative research, and to confirm and maintain reliability, validity and rigour (Morse et al., 2002). Evaluating the reliability of findings allows conclusions to be drawn surrounding integrity, robustness and quality of the research, and if the chosen methods complement the research question and aims (Nobel & Smith, 2015). In a seminal piece by Lincoln and Guba (1985), a set of criteria was created to assess qualitative research, and suggested that credibility, transferability, dependability and confirmability should be maintained at all times. They recommended that exploring negative cases and carrying out member checking would increase credibility, detailed documentation of methods and analysis would assist with transferability, and keeping an audit trail would help maintain dependability and confirmability. Smith, Flowers and Larkin (2009), however recommended two different guides for establishing the quality and validation of IPA research, by Elliott et al., (1999) and Yardley (2000). Therefore, aspects from each of these papers will be explored in further detail, to examine how the findings have been verified and validated in the research. Other notable papers which also discuss these aspects, will be identified and drawn upon.

During transcription all interviews were quality checked, to increase reliability. This process involved initially transcribing the interview verbatim, and listening back to the audio recording whilst simultaneously reading the transcript, to ensure accuracy. An iterative process occurs when conducting qualitative research, whereby the researcher is continuously immersed in the literature, the recruitment of participants, data collection, and analysis. This systematic procedure ensured suitable fit with the research question, and as discussed previously, allowed for modification of the topic guide to follow up on any interesting responses with future participants (Morse et al., 2002). Negative and deviant cases were also recognised and highlighted during data analysis. This is considered an advantage to increase rigour, as it is important that all participant accounts are reported, and not just those that support the common theme (Smith, Flowers & Larkin, 2009). Identifying and discussing why some may deviate from the opinion of others provides clear details for the reader to draw their own conclusions (Meyrick, 2006). This verification throughout the research assisted with maintaining reliability, validity and rigour.

A principal way of increasing rigour within qualitative research is to provide a detailed documented account of the research process. The aim therefore was to provide enough detail to allow replication of the study (Mays & Pope, 1995). This is promoted by Yin (1989), who suggests to document decisions from the research design through to data analysis, to

enable someone else to understand the thought processes if required. This process was systematic and rigorous, when documenting key research decisions (Pope, Ziebland & Mays, 2000).

Conducting initial checks as the researcher, throughout the research process is considered as an important way to increase the validity of an IPA study (Smith, Flowers & Larkin, 2009). Therefore, an initial audit was carried out by the researcher after the super-ordinate and sub-ordinate themes emerged as '*one is forced to check the rigour of ones claims*' (Smith, Flowers & Larkin, 2009, pg 183). For greater transparency within the research, being reflexive and adopting a level of self-criticality was also important (Seale, 1999), and this was facilitated by keeping the researcher reflexive diary. This allowed deeper levels of reflexivity to be incorporated into the analysis, and for personal motivations for conducting the research to be accounted for, referred to as '*owning one's perspective*' (Elliott, Fischer & Rennie, 1999, pg 221). Reflection on society was also incorporated, for example pressures within the NHS at the time of data collection, which assisted in situating the research (Yardley, 2000). In order to quality check the data analysis peer validation was also conducted by the PhD supervisory team, this enabled an audit of the data to be carried out; reducing bias (Nobel & Smith, 2015), by assessing and discussing levels of agreement (Mays & Pope, 1995). This ensured that participant quotes had accurately been represented under each super-ordinate theme. Peer validation is often considered more effective than member checking for an IPA study, due to the interpretive nature of data analysis and synthesis of multiple accounts (Larkin & Thompson, 2012). Rather than using member checking, the credibility was checked using respondent validation with participants during the interview, confirming responses via the use of follow up questions (Elliott, Fischer & Rennie, 1999).

During data analysis, providing participant characteristics, situating the sample (Elliott, Fischer & Rennie, 1999), and including verbatim quotes along with interpretations to support the themes, enhanced credibility (Noble & Smith, 2015). This is reiterated by Smith, Flowers and Larkin (2009), who state that high quality IPA studies should include details and tell the story of individual participants, as well as establishing commonalities between participant perceptions within the themes.

### **3.4 ETHICAL CONSIDERATIONS:**

Ethical considerations are viewed as moral principles which are adhered to throughout the research process (Gray, 2009). Any potential ethical issues should be therefore be taken in to account in order to reduce harm to both the participant and the researcher (Willig, 2013). The main issues identified surrounding ethical considerations for the study were those related to ensuring that informed consent was obtained, anonymity and confidentiality of information was maintained, and what to do if poor practice was identified. These ethical issues were reviewed consistently throughout the project, to ensure that procedure was carried out in accordance with university policy, and as stated on the ethics and HRA documentation.

#### **3.4.1 Ethical Issues:**

Informed consent was gained from each participant before taking part in the research. Each participant was provided with a participant information sheet and the primary researcher's (ES) contact details if they wanted to ask any questions, and were given a minimum of 24 hours to decide if they wished to participate. HCPs were notified by both the researcher and the participant information sheet that participation was voluntary, and that they were free to withdraw up to seven days following the interview, without any given reason. Ensuring that participants are aware that they can withdraw from the study is perceived as important in order to offer reassurance if they change their mind at a later date (Elmes, Kantowitz & Roediger, 1995). Verbal consent was audio digitally recorded for each telephone interview, the audio recording was saved securely, encrypted on a password protected computer, and transcribed verbatim. HCPs working in secondary care often preferred a face-to-face interview, and in this case written consent was obtained. Written consent forms were scanned into a computer and stored securely using a password protected file. Hard copies of consent forms were stored in a locked filing cabinet in the researcher's office, which only the researcher has access to.

Anonymity and confidentiality is an important ethical consideration (Creswell, 2013), and this was maintained by storing all data on a password protected computer, and on a shared drive, with access restricted to the research team. All participants were given an identifying number as recommended by Braun and Clarke (2013), for example, GP 1, and only the primary researcher (ES) was able to match the number to their name, for withdrawal purposes. Any identifying information disclosed during interviews, such as the name of the

practice/ward where they worked, was removed during the transcription process, and replaced with [name of practice/ward]. To further maintain anonymity, the decision was taken not to identify the hospitals where participants were recruited in secondary care. Therefore, only an approximate location is provided using a hospital icon on a map (see Figure 7). In keeping with emerging practice, anonymised data will be made available for sharing with other researchers should a request be received. The data sharing policy was made clear to potential participants within the participant information sheet, and each participant was asked if they would be happy with this during the consent process. The data sharing policy was approved by FREC. A precaution was put in place that if a participant did not consent to their data being shared, they could still participate in the research, however their transcript would be withheld if a request to share anonymised data was received. All participants consented to the data sharing policy.

Due to the nature of the healthcare profession, it was expected that HCPs would feel comfortable talking about COPD. It was therefore not anticipated that the interviews would cause any distress or upset to participants. This appeared to be the case for the interviews conducted, with many being open and honest about their experiences of PR, or lack of. The only potential issue that could have arisen, was if one of the participants had a close relationship with an individual with COPD, or if concern was evoked because they did not know about the PR programme. It was not anticipated that this would be a likely situation, as participants volunteered to take part after reading an information sheet, and having the opportunity to ask any questions. However, each participant was made aware that they could stop the interview at any point, and all were debriefed after the interview had taken place. If concern was caused through a lack of knowledge about the PR programme, the participant was signposted to the BTS (2013), or the 'Health Care Professional Study Days' and workshops run by the BLF. They were also made aware that the BLF (2015) provide advice on how to access appropriate training for HCPs.

Disclosure of unsafe or poor practice was something that close attention was paid to, both during data collection and analysis. As the interviews were conducted by ES who is not a registered HCP, she was therefore not qualified to make any final decisions on unsafe or poor practice. As patient safety and wellbeing was paramount throughout the study (Wolf & Hughes, 2008), if unsure at any time, advice was sought from the supervisory team, which contained registered HCPs. As the supervisory team were also involved in the auditing of the data, and on occasions viewed the anonymised transcripts, this acted as a second verification.

### **3.5 CHAPTER SUMMARY:**

This chapter discussed the methodological and theoretical approach adopted for the research. Justification for adopting a phenomenological approach was outlined and more specifically why interpretive phenomenological analysis was chosen. Being able to acknowledge personal experiences as a researcher, and use a degree of '*interpretive flair*' to explore the individual experiences of HCPs, was perceived an advantage of IPA (Smith, 2011, pg 23). The recruitment of participants and the different approaches adopted in both primary and secondary care was detailed, as well as the data collection process. The data analysis approach was discussed in detail and follows the key steps of IPA as outlined by Smith, Flowers & Larkin, (2009), along with discussion of how the data was validated. Justification for decisions has been provided throughout, along with a description of the ethical considerations.

The successive chapter will display the findings from the 27 participants interviewed, and will follow the IPA approach discussed in this chapter. The data from those in primary care was analysed separately to HCPs working on general medical wards in secondary care. The three super-ordinate themes identified were the same amongst the two groups, however independent sub-ordinate themes were identified, and therefore comparisons will be drawn.

## **CHAPTER 4: FINDINGS**

### **4.1 INTRODUCTION:**

This chapter provides an overview of the findings from 27 HCPs interviewed. The chapter begins with demographic details for each participant and a map representation of the dispersion of participants across the North West of England who were recruited. The data has been organised and displayed under three super-ordinate themes: *COPD Illness Perceptions*, *Pulmonary Rehabilitation Beliefs*, and *Organisational and Referral Pathway Perceptions*. A table detailing individual participant characteristics and general perceptions of PR has been displayed within the chapter to preserve the ideographic nature of IPA, and allow the reader to become familiar with each participant before reading the narrative. As discussed in the methodology and methods chapter (Chapter 3) individual participant's accounts contribute to the narrative, outlining their perceptions of PR as a management strategy for patients with COPD. The narrow focus of the research question enabled a greater number of HCPs to be recruited than typical for an IPA study. Similarities and differences in participants accounts have been highlighted throughout this chapter. However maintaining individual accounts remained paramount and the central focus, therefore clear distinction is made between different individuals' perceptions.

### **4.2 PARTICIPANTS:**

A total of 27 HCPs were interviewed. The sample comprised of GPs (n=8) and practice nurses (PNs) (n=6) working in primary care in CCGs in either the North West Coast or Greater Manchester clinical research network (CRN) areas, and doctors (n=6) and general nurses (GNs) (n=7) working on general medical wards in two hospital trusts in the North West of England. Participant demographic details have been provided in table 6 for primary care and table 7 for secondary care.

**Table 6: Participant Demographics Primary Care**

<b>Participant ID and Mode of Interview:</b>	<b>Gender:</b>	<b>Age:</b>	<b>Years in Practice:</b>	<b>Interest:</b>	<b>List Size:</b>	<b>Area (CRN):</b>
<b>GP 1</b> (Telephone)	M	61 +	31-40	General practice	< 5,000	North West Coast
<b>GP 2</b> (Telephone)	F	31-40	6-10	Women's health	5,001-7,000	Greater Manchester
<b>GP 3</b> (Telephone)	F	41-50	11-20	General medicine, often works with respiratory patients with multiple chronic conditions.	13,001-16,000	North West Coast
<b>GP 4</b> (Telephone)	F	31-40	1-2	Palliative care	13,001-16,000	North West Coast
<b>GP 5</b> (Telephone)	M	41-50	21-30	Respiratory medicine, research, and epidemiology.	7,001-10,000	Greater Manchester
<b>GP 6</b> (Telephone)	F	51-60	21-30	General practice	10,001-13,000	North West Coast
<b>GP 7</b> (Telephone)	F	41-50	11-20	Children's, women's health and dermatology	7,001-10,000	North West Coast
<b>GP 8</b> (Telephone)	F	51-60	21-30	Muscular skeletal, women's health and diabetes	7,001-10,000	Greater Manchester
<b>PN 1</b> (Telephone)	F	61+	41-50	General practice	7,001-10,000	Greater Manchester
<b>PN 2</b> (Telephone)	F	41-50	31-40	General practice	16,001 +	Greater Manchester
<b>PN 3</b> (Telephone)	F	51-60	21-30	Respiratory conditions	10,001-13,000	North West Coast
<b>PN 4</b> (Telephone)	F	51-60	31-40	General medicine	10,001-13,000	Greater Manchester
<b>PN 5</b> (Telephone)	F	25-30	6-10	Diabetes	7001-10,000	Greater Manchester
<b>PN 6</b> (Telephone)	F	41-50	21-30	Respiratory conditions	10,001-13,000	Greater Manchester

**TABLE KEY:** GP: General Practitioner      PN: Practice Nurse      M: Male      F: Female



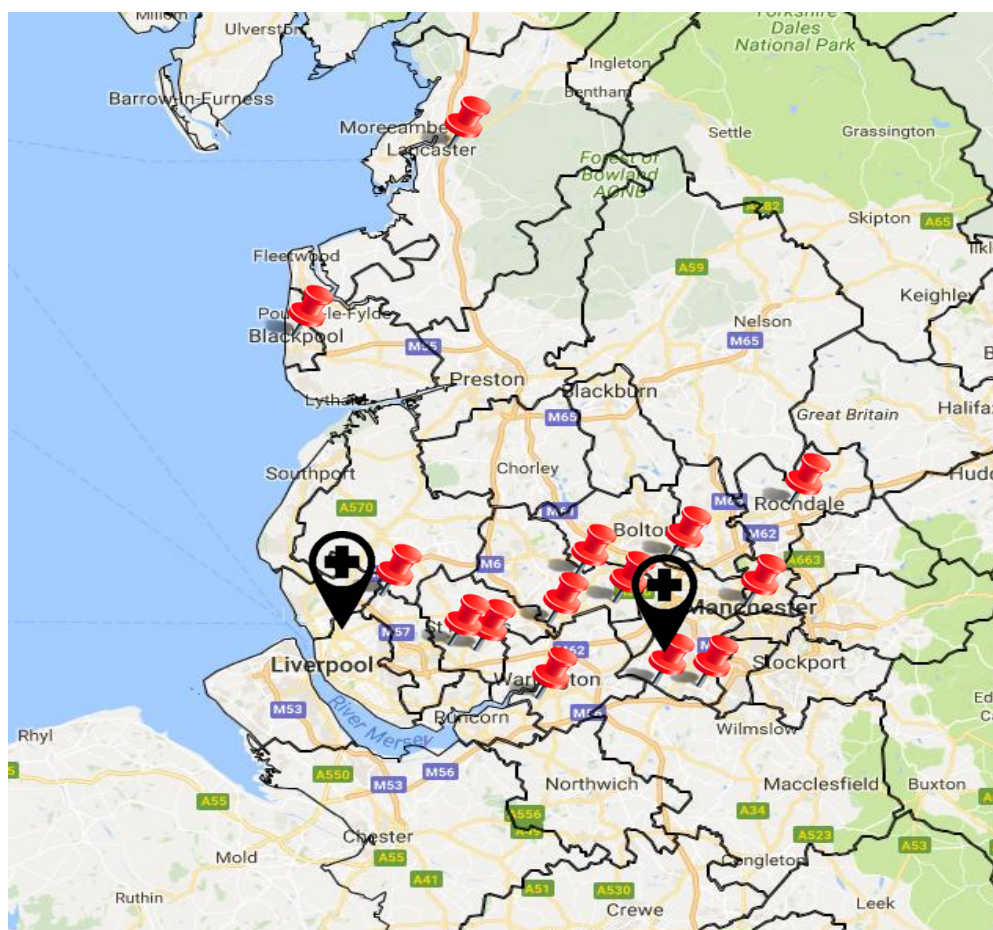
**Table 7: Participant Demographics Secondary Care**

<b>Participant ID and Mode of Interview:</b>	<b>Role:</b>	<b>Gender:</b>	<b>Age:</b>	<b>Years in Practice:</b>	<b>Interests:</b>	<b>Hospital Site:</b>	<b>Ward Type:</b>
<b>DR 1</b> (Face to face)	Junior Doctor (FY1)	F	25-30	1-2	Surgery	Hospital 1	Acute Medical Unit
<b>DR 2</b> (Face to face)	Junior Doctor (FY1)	F	25-30	< 1 year	Cardiology	Hospital 1	Acute Medical Unit / Endocrine
<b>DR 3</b> (Face to face)	Registrar	F	31-40	6-10	A & E	Hospital 1	Acute Medical Unit / A & E
<b>DR 4</b> (Face to face)	Registrar	M	25-30	3-5	General medicine	Hospital 1	Acute Medical Unit
<b>DR 5</b> ( Face to face)	Junior Doctor (FY2)	M	25-30	1-2	Anaesthetics	Hospital 2	Acute Medicine Unit
<b>DR 6</b> (Face to face)	Junior Doctor (FY1)	M	25-30	< 1 year	General practice	Hospital 2	Acute Medicine Unit / Ambulatory Emergency Care Unit
<b>GN 1</b> (Telephone)	Nurse	F	51-60	21-30	Intensive care and acute medicine	Hospital 2	Acute Medicine Unit
<b>GN 2</b> (Face to face)	Nurse	F	41-50	11-20	Acute medicine	Hospital 1	Acute Medical Unit
<b>GN 3</b> (Face to face)	Nurse	F	20-25	1 -2	Acute medicine	Hospital 1	Acute Medical Unit
<b>GN 4</b> (Face to face)	Nurse	F	41-50	6-10	Acute medicine	Hospital 2	Assessment Unit
<b>GN 5</b> (Face to face)	Nurse	M	51-60	3-5	Elderly Care	Hospital 2	Acute frailty unit/ Assessment and Rehabilitation Day Unit
<b>GN 6</b> (Face to face)	Nurse	F	41-50	11-20	General medical	Hospital 2	Acute frailty unit/ Assessment and Rehabilitation Day Unit
<b>GN 7</b> (Telephone)	Nurse	F	41-50	11-20	Respiratory and acute medicine	Hospital 2	Acute Medical Unit / Ambulatory Emergency Care Unit



**TABLE KEY:** **DR:** Doctor working on a general medical ward **GN:** Nurse working on a general medical ward **M:** Male **F:** Female  
**FY1:** Foundation doctor (year one) **FY2:** Foundation doctor (year two)

A map (Figure 7) representing dispersion of participants displays the approximate location of the seven HCPs recruited from the North West Coast CCG area, and the seven recruited from the Greater Manchester CCG area, in primary care. Each HCP working in primary care is displayed using a red pin; the two hospital trusts where participants were recruited in secondary care are displayed using a hospital pin icon. It should be noted that no precise location has been identified to maintain participant anonymity; the purpose being to highlight the general dispersion of HCPs interviewed within the North West of England.

**Figure 7: Map Representation of the Dispersion of Participants**



**Map Key:**

-  Individual participants in primary care
-  Hospital trust where participants were recruited from in secondary care

### 4.3 DATA ANALYSIS:

The data from HCPs working in primary care was analysed independently to those working in secondary care, as although it was possible that they may hold similar views, fundamentally they are very different working environments. Thus, it was decided that it would be beneficial to display the individual views of GPs and PNs, separately from those of nurses and doctors working on general medical wards. Comparisons between the two groups are drawn upon in the discussion (Chapter 5).

After immersion in the data through repeated reading of transcripts, and following close line-by-line analysis of each participant, sub-ordinate themes were clustered to form super-ordinate themes (see Table 8 and Table 10 for a summary of the super-ordinate and sub-ordinate themes and how they developed from emergent themes). It became apparent that the same super-ordinate themes were present across both primary and secondary care, with different sub-ordinate themes lying within.

The super-ordinate themes were defined as: *COPD Illness Perceptions*, *Perceived Patient Characteristics*, *Pulmonary Rehabilitation Beliefs*, and *Organisational and Referral Pathway Perceptions*. These are depicted in figure 8; the concept of a jigsaw has been used to demonstrate how each super-ordinate theme relates, or connects, or has the potential to overlap the others in some way. Piecing the jigsaw together illustrates participants' perceptions of PR as a management strategy for patients with COPD, with similarities and differences in opinion highlighted. The completed jigsaw allows for a clearer picture of HCPs' perceptions of the programme.

The analysis has been displayed in the form of a narrative, with the most pertinent quotes selected to support each super-ordinate theme. As IPA is ideographic, participant quotations will be provided, along with demographic details and information drawn from the researcher's reflexive diary, to ensure that individual perceptions and identities remain at the heart of the analysis (See Box 1, for details on how participant identifiers have been constructed). Therefore, individual participant characterisations are displayed in table 12, to provide readers with a concise overview of each HCPs' overall perception of PR, and details of how regularly they refer patients to the programme; this preserves the ideographic nature of IPA. Guidance regarding working with large sample sizes in IPA discussed by Smith (2011) was adhered to, whereby he advises providing numerical values to depict the frequency that super-ordinate and sub-ordinate themes are referred to by each participant; this process has been explained in further detail in Chapter Three. Thus, the occurrence of

super-ordinate and sub-ordinate themes throughout primary care and secondary care are represented in table 9 and 11.

**Box 1: Example of how Participant Identifiers are Constructed.**

HCPs will be referred to within the analysis as either a:

**GP:** General practitioner

**PN:** Practice nurse

**DR:** Doctor working on a general medical ward

**GN:** General medical nurse working on a general medical ward

In order to identify participants throughout the analysis, they will be provided with a label. An example has been provided below:

*In Primary care:*

HCP identifier – Gender – Age range – Line numbers of quotation in transcript

Example:

(PN 4, F, 51-60, Lines 160-161)

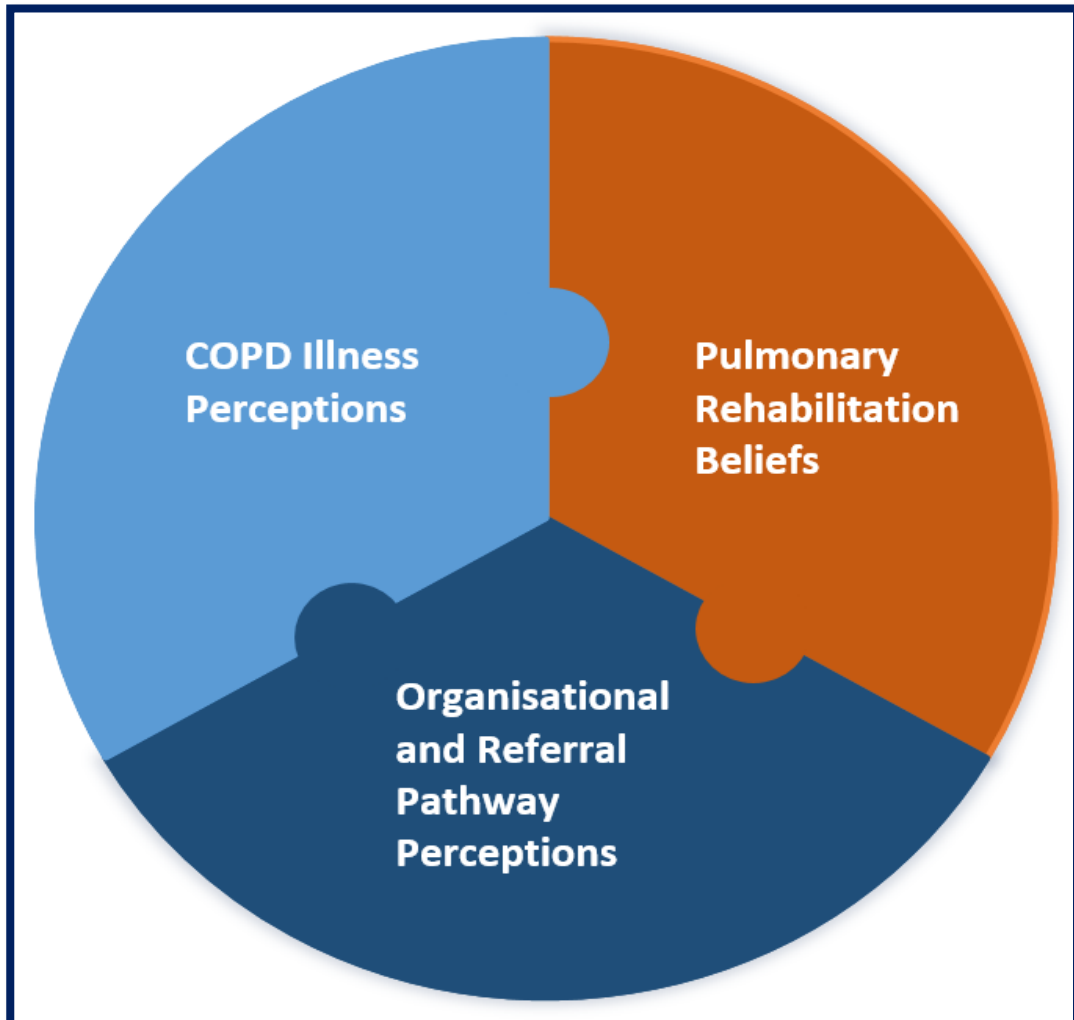
*In secondary care:*

HCP identifier – Gender – Age range – Hospital identifier - Line numbers of quotation in transcript

Example:

(DR 6, M, 25-30, Hospital 2, Lines 62-63)

**Figure 8: *Piecing Together the Jigsaw*: This Figure Represents the Superordinate Themes which Connect Together to Represent HCPs' Perceptions of PR**



**Table 8: Creation of Super-ordinate and Sub-ordinate Themes in Primary Care**

Primary Care:		
Super-ordinate themes:	Sub-ordinate themes:	Developed from emergent themes:
COPD Illness Perceptions	The psychological impact of COPD	<ul style="list-style-type: none"> <li>- Impacts emotional and mental health</li> <li>- Breathlessness vicious cycle</li> <li>- Induces fear and anxiety</li> <li>- Patients need a strong support network</li> </ul>
	Adds pressure to the NHS	<ul style="list-style-type: none"> <li>- High prevalence</li> <li>- 'Frequent attenders'</li> <li>- Seasonal increase of attendance</li> <li>- It is a difficult condition to manage</li> </ul>
	Stereotypical beliefs surrounding COPD	<ul style="list-style-type: none"> <li>- Patients lack motivation and are resistant to change</li> <li>- Patients need reassurance</li> <li>- Patients need to take responsibility for their own health</li> <li>- Need to be willing to try a non-pharmacological approach</li> </ul>
Pulmonary Rehabilitation Beliefs	Beliefs of what PR entails and patient suitability.	<ul style="list-style-type: none"> <li>- Exercise programme</li> <li>- Improves exercise tolerance and breathlessness</li> <li>- Education</li> <li>- Multidisciplinary support</li> <li>- Characteristics of patients eligible to attend</li> </ul>
	Uncertainty	<ul style="list-style-type: none"> <li>- Lack of understanding of PR</li> <li>- Lack of local programme knowledge</li> <li>- Lack of awareness of COPD guidelines and PR evidence base</li> <li>- Unaware of the benefits of attending: 'Non-specific benefits'</li> </ul>
	It's helpful	<ul style="list-style-type: none"> <li>- Increases confidence</li> <li>- Ongoing support from HCPs</li> <li>- Improves quality of life</li> <li>- Seeing is believing</li> <li>- It 'completes the picture'</li> </ul>
	Perceived barriers to PR	<ul style="list-style-type: none"> <li>- Patients dislike the idea of PR</li> <li>- Location and accessibility</li> <li>- Deprivation</li> <li>- Inconvenience</li> <li>- Issues with group setting</li> <li>- Non-attendance</li> </ul>
Organisational and Referral Pathway Perceptions	Defers responsibility	<ul style="list-style-type: none"> <li>- Not considered their job</li> <li>- 'It's not a priority'</li> <li>- 'other people do it rather than me'</li> </ul>
	Lack of information from the service	<ul style="list-style-type: none"> <li>- Better communication required of what the service provides</li> <li>- HCPs unsupported by the service</li> <li>- Lack of communication between the service and patients prior to starting PR</li> <li>- Lack of feedback from the service</li> </ul>
	Difficult referral	<ul style="list-style-type: none"> <li>- Unaware of the 'ideal time to refer'</li> <li>- Unsure of how to access PR</li> <li>- Difficult sell</li> <li>- Time consuming</li> </ul>
	Facilitators to referral	<ul style="list-style-type: none"> <li>- Simple referral</li> <li>- Information provided by the service</li> </ul>

**Table 9: The Occurrence of Super-ordinate and Sub-ordinate Themes Throughout Primary Care**

<b>Super-ordinate and Sub-ordinate Themes:</b>	<b>GP 1</b>	<b>GP 2</b>	<b>GP 3</b>	<b>GP 4</b>	<b>GP 5</b>	<b>GP 6</b>	<b>GP 7</b>	<b>GP 8</b>	<b>PN 1</b>	<b>PN 2</b>	<b>PN 3</b>	<b>PN 4</b>	<b>PN 5</b>	<b>PN 6</b>	<b>Total:</b>
<b>COPD Illness Perceptions:</b>	X	X	X	X		X	X	X	X	X	X	X	X	X	<b>13</b>
The psychological impact of COPD			X					X	X	X	X		X		6
Adds pressure to the NHS		X	X			X	X	X	X	X	X	X	X		10
Stereotypical beliefs surrounding COPD	X	X	X	X		X	X	X		X	X	X	X	X	12
<b>Pulmonary Rehabilitation Beliefs:</b>	X	X	X	X	X	X	X	X	X	X	X	X	X	X	<b>14</b>
Beliefs of what PR entails and patient suitability	X	X	X	X	X	X	X	X	X	X	X	X	X	X	14
Uncertainty	X	X	X	X	X	X	X	X	X	X		X	X	X	13
It's helpful	X	X	X	X	X	X	X	X	X	X	X	X	X	X	14
Perceived barriers to PR		X	X		X	X	X	X	X	X	X	X	X	X	12
<b>Organisational and Referral Pathway Perceptions:</b>	X	X	X	X	X	X	X	X	X	X	X	X	X	X	<b>14</b>
Defers responsibility	X	X	X	X	X	X	X	X	X	X		X	X		12
Lack of information from the service		X		X		X	X	X	X	X	X	X	X	X	11
Difficult referral		X	X	X	X	X	X	X	X	X	X	X		X	12
Facilitators to referral		X		X	X			X		X	X	X	X	X	9

**Table 10: Creation of Super-ordinate and Sub-ordinate Themes in Secondary Care**

<b>Secondary Care:</b>		
<b>Superordinate themes:</b>	<b>Subordinate themes:</b>	<b>Developed from emergent themes:</b>
<b>COPD Illness Perceptions</b>	Perceived patient burden	<ul style="list-style-type: none"> <li>- No cure, only management</li> <li>- Worsening symptoms</li> <li>- Exertional shortness of breath, limits activity</li> <li>- Psychological impact of the condition</li> </ul>
	Adds pressure to the NHS	<ul style="list-style-type: none"> <li>- Frequent attenders</li> <li>- Difficult condition to manage due to a multitude of symptoms and other comorbidities</li> </ul>
	Stereotypical beliefs surrounding COPD	<ul style="list-style-type: none"> <li>- Caused by smoking</li> <li>- Patients lack motivation</li> <li>- Patients lack compliance and adherence</li> <li>- Patients are unable to learn</li> </ul>
<b>Pulmonary Rehabilitation Beliefs</b>	Perceived patient suitability for PR	<ul style="list-style-type: none"> <li>- Early stage COPD</li> <li>- Those who have been hospitalised for a prolonged period</li> <li>- Young or middle aged patients</li> <li>- Smokers</li> <li>- Poor levels of education or socio-economic status</li> <li>- PR as a last resort, after everything else has been tried</li> </ul>
	'So what is it?'	<ul style="list-style-type: none"> <li>- Lack of local programme knowledge</li> <li>- Lack of knowledge of COPD guidelines</li> <li>- Lack of knowledge of evidence base</li> <li>- Unsure of the benefits of PR</li> <li>- Unsure of the concept of PR and what it involves</li> <li>- Never heard of PR: 'so what is it?'</li> </ul>
	Appreciation of potential benefits	<ul style="list-style-type: none"> <li>- Allows patients to self-manage</li> <li>- Assists physically, psychologically and provides education.</li> <li>- Non-medicalised approach</li> <li>- May help patients to stay in the community</li> <li>- PR is a 'bit like a safety net'</li> </ul>
	Perceived barriers to PR	<ul style="list-style-type: none"> <li>- Transportation and location</li> <li>- Oxygen</li> <li>- Patients find it too difficult and are incapable of exercise</li> <li>- Instability or other comorbidities</li> <li>- PR causes patients to exacerbate</li> <li>- Would rather have medication</li> <li>- The inverse care law</li> </ul>
<b>Organisational and Referral Pathway Perceptions</b>	Lack of awareness and publicity	<ul style="list-style-type: none"> <li>- No significance placed upon PR during education and training</li> <li>- Lack of exposure to PR</li> <li>- Poor publicity</li> <li>- Provided suggestions to raise awareness</li> </ul>
	Defers responsibility	<ul style="list-style-type: none"> <li>- Defers responsibility</li> <li>- Disinterested in respiratory conditions</li> </ul>
	Unaware of patient suitability and how to refer	<ul style="list-style-type: none"> <li>- Unaware of referral criteria</li> <li>- Unsure how to initiate a referral</li> <li>- Lacks confidence in referring patient</li> </ul>



**Table 11: The Occurrence of Super-ordinate and Sub-ordinate Themes Throughout Secondary Care**

<b>Super-ordinate and sub-ordinate themes:</b>	<b>DR 1</b>	<b>DR 2</b>	<b>DR 3</b>	<b>DR 4</b>	<b>DR 5</b>	<b>DR 6</b>	<b>GN 1</b>	<b>GN 2</b>	<b>GN 3</b>	<b>GN 4</b>	<b>GN 5</b>	<b>GN 6</b>	<b>GN 7</b>	<b>Total:</b>
<b>COPD Illness Perceptions:</b>	X	X	X	X	X	X	X	X	X	X	X	X	X	13
Perceived patient burden		X	X	X	X	X	X	X		X		X	X	10
Adds pressure to the NHS		X	X	X	X		X	X	X	X	X	X	X	11
Stereotypical beliefs surrounding COPD	X	X	X		X	X	X			X		X	X	9
<b>Pulmonary Rehabilitation Beliefs:</b>	X	X	X	X	X	X	X	X	X	X	X	X	X	13
Perceived patient suitability for PR	X	X	X	X		X	X			X	X	X	X	10
'So what is it?'	X	X	X	X	X	X	X	X	X	X	X	X	X	13
Appreciation of potential benefits	X	X	X	X	X	X	X	X		X	X	X	X	12
Perceived barriers to PR	X	X	X	X	X		X	X	X	X	X	X	X	12
<b>Organisational and Referral Pathway Perceptions:</b>	X	X	X	X	X	X	X	X	X	X	X	X	X	13
Lack of awareness and publicity	X	X	X	X	X	X	X	X	X	X	X	X	X	13
Defers responsibility	X	X	X	X	X	X	X	X	X	X	X		X	12
Unaware of patient suitability and how to refer	X	X	X	X	X	X		X	X	X	X	X		11

**Table 12: Participant Characteristics and General Perceptions of Pulmonary Rehabilitation**

Primary Care:		
Participant:	How often they refer patients to PR:	General Perceptions of PR:
GP 1 (M)	<b>'On average every two months or so'</b> . Deferred responsibility believed that it was the practice nurses role during COPD annual reviews.	Tentative over potential benefits of PR; perceived that it would possibly give patients the <i>'confidence to undertake exercise'</i> and provide <i>'understanding of their condition'</i> . Although appeared unconvinced, stating that many benefits would be <i>'non-specific'</i> if patients had the motivation to exercise and <i>'get out every day'</i> . Held limited local programme knowledge, and ultimately, lacked knowledge surrounding eligibility criteria, believing that PR was most suitable for patients at the <i>'worse end of the spectrum'</i> , <i>'very inactive'</i> and <i>'almost housebound'</i> .
GP 2 (F)	<b>Infrequently:</b> Believed this was mainly the practice nurse's role.	Believed PR was a service for patients who lack <i>'knowledge'</i> of COPD, have a <i>'decreased exercise capacity'</i> , are <i>'not responding to treatment'</i> , or <i>'motivated to want to try something other than medication'</i> . Local programme knowledge was <i>'limited'</i> , however appreciated that PR would help educate patients, as those delivering the programme have <i>'more time'</i> . Appeared uninterested in PR and unsure of patient's perceptions of the programme, as it is not something she <i>'followed up'</i> . Overall, did not <i>'prioritise'</i> PR due to time restraints or because <i>'you just don't think about it at the time'</i> .
GP 3 (F)	<b>Does not refer:</b> <i>'other people tend to be doing that other than me'</i>	Admitted that she knew <i>'very little'</i> about PR. Perceived it was a programme to help patients <i>'live with their condition'</i> , however she was not confident when discussing the details of the programme and often related it to pain management, which she appeared more familiar with. She appeared to lack passion and understanding of the programme, and was unconvinced of its benefits as patients <i>'often tell me they haven't found it useful'</i> . She frequently deferred the role of referral and did not perceive it to be her job as she did not want to be <i>'responsible'</i> for it and felt <i>'overloaded'</i> .
GP 4 (F)	<b>Never referred:</b> Defers responsibility to the respiratory department in secondary care.	Believed that PR was an <i>'exercise programme'</i> to improve <i>'breathing'</i> of COPD patients. She was aware that she could refer patients but <i>'did not get too involved'</i> as she believed that the nurse specialists did <i>'a lot of the COPD management'</i> and deferred the role of referral to the <i>'respiratory team'</i> in secondary care. Lacked local programme knowledge and was unaware the practice nurses could refer. At the end of the interview stated she was <i>'in favour'</i> of PR but wanted more information; she later admitted she wanted to take part to raise awareness that there are HCPs with very little knowledge of PR.

GP 5 (M)	<p><b>Infrequently:</b> Only <i>'new patients'</i> who are <i>'MRC 3 and below'</i>. Possibly four or five in the practice per year.</p>	<p>Believed that PR was <i>'individually set'</i> for patients and extremely useful for breathlessness. He perceived that it had <i>'more beneficial effects than most of the inhaled medications'</i>; along with assisting patients physically it also aids psychologically, reducing <i>'social isolation'</i>. Although he had local programme knowledge he was unaware of how often patients attended PR, and avoided questions surrounding how often he referred. Referral did not appear prioritised as he added that he hoped he <i>'remembered'</i> to refer. He viewed that many patients <i>'can't see the point'</i> of attending and disliked the thought of a group setting.</p>
GP 6 (F)	<p><b>Does not refer:</b> Places referral responsibility on the practice nurse, to complete during annual COPD review.</p>	<p>Aware of the definition of PR and associated benefits. Knowledgeable that it is part of the management strategy for COPD, and perceives it can offer as much <i>'relief as even the inhaler based therapies'</i>. Understands the referral criteria, however has <i>'limited'</i> local programme knowledge. Considers it difficult to convince patients that the programme will be <i>'beneficial'</i>. Defers referral responsibility to the practice nurse, yet patients had discussed with her that PR is <i>'one of the best things they've done'</i>. Perceives there is a lack of contact and information from the service.</p>
GP 7 (F)	<p><b>Never referred:</b> Uncertainty that GPs can actually refer patients to PR</p>	<p>Aware of patients referred to PR, although they have <i>'been under the respiratory clinic in the hospital'</i>. Unsure of local programme specifics, however understands the programme involves education, <i>'exercises'</i> and believes there are <i>'some games'</i>. Lacks knowledge surrounding eligibility criteria and the benefits of attending. Considers that there may be a long waiting list, and would like more information. Assumes that the service would <i>'accept any patient with a respiratory issue'</i>, as <i>'they call it pulmonary rehab'</i>.</p>
GP 8 (F)	<p><b>Previously referred:</b> Now considers it the nurse practitioners role in the COPD annual review</p>	<p>Knowledgeable about the local programme and defined PR as helping patients to <i>'develop exercise tolerance'</i>, <i>'educate'</i> and assist with <i>'breathing exercises'</i>. Appreciated the benefits of PR, however viewed that it is <i>'frustrating'</i> for herself and the nurse practitioner who makes the referral, that many patients do not attend. She appeared annoyed that patients have <i>'often got an answer'</i> for not wanting to exercise. There was little information available and felt the information provided by the local service online was tailored to the elderly.</p>

PN 1 (F)	<b>Frequently refers:</b> <i>'it happens every week'</i>	Passionate about PR, assists with all aspects of the disease, rather than just medication. Perceived that it helps psychologically, increasing <i>'confidence'</i> and socialisation; viewed that the <i>'light exercise'</i> and education increases <i>'quality of life'</i> . She was pro-active and visited the local programme to increase her knowledge, to allow her to give the patients an <i>'idea of what to expect'</i> . Positively promotes PR to all patients, however annoyed and felt de-valued by the service over the <i>'one way road of information'</i> . She stated that better communication was required providing feedback on patient outcomes and details of local programme specifics.
PN 2 (F)	<b>Refers:</b> <i>'maybe once every three months'</i>	Knowledgeable and passionate about how PR can change patients' lives. Perceives that the programme involves <i>'exercise'</i> and <i>'education'</i> and is delivered by a <i>'respiratory nurse'</i> or <i>'physio therapist'</i> . Believes that it is particularly beneficial for the psychological aspects and <i>'anxiety'</i> associated with COPD. Perceived a lack of consistency with the local service and issues with funding have led to deterioration, which has caused a difficult and changeable referral process. Due to the referral process being difficult she perceived that she was too busy to refer some patients, and was also uncomfortable with the lack of local programme knowledge, therefore she felt unable to fully inform patients.
PN 3 (F)	<b>Frequently tries to refer:</b> <i>'I consider everyone that hasn't been on it'</i>	Knowledgeable and extremely passionate about local programme and <i>'discusses it with everyone'</i> ; believes <i>'it is more important than half the inhalers'</i> . Perceives patients complete <i>'physical work under supervision of the physio, they then have a coffee and a chat'</i> before <i>'education'</i> . Believed it was challenging to refer patients in the area she currently works, and feels responsible when <i>'99 percent'</i> of COPD patients attended at her previous surgery. She attributes this to her patients being younger, and that it is a <i>'high cannabis use area'</i> , and perceives it difficult for them to understand <i>'something that isn't medicine is going to help'</i> .
PN 4 (F)	<b>Refers:</b> <i>'one or two a month'</i>	Aware PR is recommended for COPD patients and believed the programme educates patients about their condition; to <i>'manage the impact it has on their life'</i> . Lacks local programme knowledge, believes that the service is changeable, with differing locations. Views the support and contact for ongoing needs that patients receive when attending PR is beneficial, along with meeting those <i>'suffering the same condition'</i> . Perceived it difficult to get patients to attend, and may increase anxiety seeing those in a worse position than themselves.

PN 5 (F)	<b>Now refers frequently:</b> Just been made responsible for the COPD patients at the surgery 'due to staff changes'	Believes that PR is 'cost effective' and that 'patients who go have great outcomes'. Perceived it involves exercise and education, and that it is beneficial for 'patients to meet other people with the condition'. Was uncertain about the location of the programme and exactly which HCPs delivered it. Believed that patients either 'loved' or 'absolutely hated' it. Was positive with regards to PR increasing patient knowledge, and viewed that some particularly benefitted from attendance. Considered that transport and language barriers were issues, along with it being a difficult sell for those who considered themselves an 'expert patient'.
PN 6 (F)	<b>Refers based on patient suitability:</b> May refer a number of patients in a short space of time and then none for a while, as the nurse practitioner and community matron also refer.	Very knowledgeable about PR and the referral criteria, and tried to sell it in a 'very positive manner'. Her enthusiasm stemmed from seeing the benefits of the programme first-hand. Described how when patients return to the surgery after PR, they are aware of suitable exercises, have greater 'confidence' and 'seem to have more energy'. Perceived that there was no disadvantages to the actual programme, as there was even transport provided. However, believed a patient barrier after referral was the wait to commence as it was 'months and months'. Disappointed over the lack of 'feedback' from the service, and believed that it would be helpful to receive a 'brief letter' detailing patient improvement.
<b>Secondary Care:</b>		
DR 1 (F)	<b>'Never referred':</b> Unaware of the referral process	Text-book understanding of PR, believed that it was a non-pharmacological management strategy which incorporated 'exercise', to 'improve breathing' and quality of life. Previously completed a placement on the respiratory wards, where patients 'seemed quite engaged' with PR. Perceived that patients do need to take ownership of their health and want to attend PR for themselves. Viewed there would be 'logistical issues' associated with transportation, and difficulties for patients who require 'oxygen'. Lacked knowledge of referral criteria and the local programme; would 'consider' referral if the service provided more information. However, did also defer responsibility to primary care as she considered it a 'holistic approach'.
DR 2 (F)	<b>Never referred:</b> 'I didn't really know it was a service'	No knowledge of PR, suggests that it may be a similar concept to cardiac rehabilitation, which she was knowledgeable about. Due to inadequate knowledge she was unaware and unconvinced of the benefits, however 'assumed' that PR would have an evidence base, otherwise the NHS would not support it. Acknowledged a lack of confidence with respiratory conditions and deferred responsibility to the respiratory team. Was 'not averse' to PR and 'would refer' if supplied with more information from the service.

DR 3 (F)	<b>Never referred:</b> <i>'brand new to me'</i>	Inadequate knowledge, presumed that PR may be <i>'something like a chest physio'</i> . Was provided with a brief definition of the programme, and some questions were answered based upon her perceptions of the definition given. Perceived that it may help to reduce hospital admissions, educate patients on the correct time to present at hospital, and allow them to carry out self-management. Unaware of how to refer, however would only initiate a referral on recommendation of a consultant. Deferred responsibility to the respiratory team as she does not <i>'diagnose COPD'</i> . Sees COPD patients frequently, although they had not mentioned attendance at PR.
DR 4 (M)	<b>Never referred:</b> Did not consider it his role.	A good general understanding of PR. Believed the programme was usually <i>'led by respiratory physiotherapists'</i> and focused on <i>'reconditioning'</i> , via exercise and education. Perceived it would be beneficial in allowing patients to gain independence; assisting psychologically and aiding <i>'mobility'</i> , thus promoting <i>'survival'</i> . Also knowledgeable about the evidence base. Viewed that the disadvantages of PR would be that some patients may <i>'find it too difficult'</i> and discussed the <i>'inverse care law'</i> , suggesting the patients who need PR most, probably cannot access the programme. Previously, had completed a four month respiratory placement, and currently sees COPD patients frequently. Perceived it was not his role to refer and deferred responsibility to other HCPs. Unaware of the referral process, and considered programme knowledge needs to be raised.
DR 5 (M)	<b>Never referred:</b> <i>'I don't know about pulmonary rehabilitation'</i>	Lack of awareness of PR. Admitted that it was his second day working in the Acute Medical Unit (AMU), however <i>'had lots of exposure'</i> to COPD, as it is something that he sees every day. Misinterpreted the purpose of PR and stated they had a hospital discharge team, and asked if they had the same role. Was provided with a definition of PR, due to a dearth of knowledge. After the definition, he perceived PR would be useful to educate patients, however viewed that an issue may be encountered due to COPD patients lacking <i>'compliance'</i> . Believed there was a lack of focus on the programme during his medical degree, however learned about other services such as stroke rehabilitation; suggested the service needs to be advertised better.

DR 6 (M)	<b>Never referred:</b> <i>'I'd probably have to speak to a respiratory doctor to find out how to refer'</i>	Believed PR is for patents with <i>'quite severe COPD'</i> . Had good knowledge of the key components of PR, and aware that it encompassed physical and psychological support <i>'to improve their exercise tolerance and independence'</i> . Gained his knowledge sitting in COPD clinics, whilst on a specially selected placement during his medical training; he was newly qualified working on AMU as his <i>'first job as a doctor'</i> . Perceived he had enough knowledge to discuss PR with patients, but would be unable to make the referral without assistance. A barrier to making a referral, would be a patient not willing to <i>'comply'</i> . Reluctant about the overall benefits <i>'it can be quite useful'</i> , and perceived that awareness needs to be increased amongst <i>'general medical doctors'</i> .
GN 1 (F)	<b>Never referred:</b> Not considered her role and held negative perceptions.	Very limited knowledge of PR, emailed prior to the interview to ask if there was anything she needed to revise; appeared uncomfortable over her lack of awareness. Presumed the programme should encompass: psychological support, coping mechanisms, and enable patients to remain in the community. Believed there is no cure, and therefore <i>'not a medical problem that you can actually deal with'</i> . Deferred responsibility of referral throughout the interview, and did not perceive it her role to assist with the management of COPD; viewed it was her job to provide support for the <i>'acute issue'</i> . She had spoken to another nurse on the ward prior to the interview, who had previously worked in the community. This nurse described <i>'how every time people went into pulmonary rehab, they would exacerbate and end up coming into hospital'</i> . She now held the same negative perceptions.
GN 2 (F)	<b>Never referred:</b> <i>'It's not something that I've heard of at all'</i>	Total lack of programme knowledge; aware of cardiac rehabilitation but not PR. Deferred responsibility of referral to the discharge team, <i>'who are called in at the last minute'</i> to assist, however was unsure of their role. Unaware of referral criteria, and overall appeared to have a lack of interest in the programme and COPD management. Interview raised her knowledge of the programme.

GN 3 (F)	<b>Never referred:</b> Not heard of PR prior to the interview.	Complete lack of awareness of PR, and lacked knowledge of what the programme involves. Highlighted that during her nursing degree she <i>'might have been taught about it but I can't remember anything'</i> . Unaware of the referral criteria, however perceived that PR may be something that the discharge team at the hospital deliver, believing <i>'maybe they do pulmonary rehab'</i> . Deferred responsibility, highlighting that patients on AMU <i>'are really poorly'</i> , therefore referral may be something other wards would consider, if patients are transferred. Highlighted, if she was to consider referral she would require a simplified system, with support and reassurance to decrease responsibility. Overall, would like to receive more information from the service.
GN 4 (F)	<b>Never referred:</b> <i>'I've never had to refer anyone to it, I've never been asked to either'</i>	Uncertainty surrounding PR, asked <i>'is it about when they are going home'</i> . Participant was provided with a definition to clarify, and responses to questions were based upon this. Discussed how her mum had been diagnosed with COPD and assumed she would have attended PR, however <i>'could not manage'</i> it. Frequently saw COPD patients on the ward, and viewed PR could assist with anxiety and breathing techniques, however perceived patients would need to be motivated. Did not view referral to the programme as her role, although towards the end of the interview started to consider the benefits, describing the programme as a <i>'safety net'</i> . Highlighted, she would lack confidence in making the referral, however if this could be sent electronically with an expert making the final decision on patient suitability, <i>'more people would probably do it'</i> .
GN 5 (M)	<b>Never referred:</b> Unfamiliar with PR, misinterpretation of the word <i>'rehab'</i> .	Complete lack of knowledge of PR, and seemed to become anxious when asked questions surrounding COPD and the programme. A definition of PR was provided, however he lacked enthusiasm and appeared uninterested in who referred patients to the programme. The term PR appeared to cause confusion, as he discussed how he previously worked on the <i>'rehab ward that was for hips'</i> . Frequently interrupted and talked over questions about topics he had not been asked; this was perceived as a result of having no knowledge. Throughout the interview defended his belief that it was not his role to refer patients. At the end apologised for knowing very little, but stated that this was because <i>'it's not our area'</i> . Did however believe that anything which would reduce COPD admissions, would be beneficial.



GN 6 (F)	<b>Never referred:</b> <i>'I wasn't aware I could'</i>	Belief that PR incorporates exercises, breathing techniques and <i>'monitoring'</i> . Lacked clarity around programme delivery. Perceived PR would be beneficial to increase exercise tolerance, and promoted the psychological benefits. Also considered it may help to reduce loneliness and seclusion, and provide a sense of togetherness, especially for those on oxygen. Prior experience <i>'years ago'</i> of working on a respiratory ward, however was unaware the programme was something available, which she could refer to. Very enthusiastic about the programme <i>'it sounds fab'</i> . Blamed a lack of publicity from the service for her lack of awareness. Keen to increase knowledge and asked many questions following the interview. Said she would contact the respiratory team for further details on how to refer.
GN 7 (F)	<b>Previously referred patients 'all of the time' when working in primary care:</b> Not referred anyone since working in secondary care	When working in primary care championed PR and <i>'used to advocate it for everyone'</i> . Was extremely knowledgeable, and aware of the programme benefits, evidence base and COPD guidelines. Believed that it helps to: <i>'educate'</i> , giving patients a realistic overview of their condition, <i>'pre-empt and reduce exacerbations'</i> , provide peer support, and enables self-management; improving quality of life. However, perceived some patients do not want to attend because <i>'they get stuck in their ways'</i> . Considered her current job is to get patients <i>'over the acute phase'</i> and not to refer to PR, as she believed someone else would do this. Did state she would like more local programme knowledge, as she believed things will have changed since working in primary care. Realised that as she sees COPD patients <i>'every day'</i> , she has an influential position, and should possibly refer.

### 4.3.1 COPD Illness Perceptions – Primary Care:

This super-ordinate theme was formed after the identification of three sub-ordinate themes: *The psychological impact of COPD, Adds pressure to the NHS, and Stereotypical beliefs surrounding COPD*. The multifaceted nature of the disease was highlighted, with sub-ordinate themes encompassing HCPs' illness perceptions in relation to COPD, and their perceptions of how the disease affects the individual. It was viewed important to include HCPs COPD Illness perceptions as they may provide explanation or add context to HCPs PR beliefs, discussed later in this chapter. See table 13 for the number of participant representations and references within each sub-ordinate theme.

**Table 13: COPD Illness Perceptions – Primary Care Sub-ordinate Themes**

COPD Illness Perceptions – Primary Care		
Sub-ordinate Theme:	Number of participants:	Number of references:
The psychological impact of COPD	6	12
Adds pressure to the NHS	10	35
Stereotypical beliefs surrounding COPD	12	32

#### The Psychological impact of COPD:

There was the belief that COPD had the ability to impact a patient's emotional and mental health, and this perception was held by six HCPs in primary care. It was consistently viewed that the life limiting nature of the condition adds further demands to the patient, as it not only causes physical symptoms but psychological ones as well:

*'what we have to remember is living with a life-long illness requires a lot of sort of emotion, and mental resources'* (PN 3, F, 51-60, Lines 259-260)

This was further reiterated by a GP who stated that attention needs to be paid to the psychological health of a patient, as this can have a negative impact, causing a worsening of physical symptoms:

*'recognition of, of how much the kind of anxiety and broader kind of mental and emotional health issues impact on their experience of their physical condition'* (GP 3, F, 41-50, Lines 142-143)

Anxiety was associated with impinging patients' lives, with this worry and apprehension altering belief in their own abilities:

*'I think it's that fear factor, you know you, you end up, if you feel you can't do something you won't do it'* (GP 8, F, 51-60, Lines 203-204)

The same views surrounded dyspnea, as anxiety was perceived as a contributor to breathlessness and perceived capability. A PN believed that the cognitive processes associated with breathlessness and exercise-related apprehension, led to a refrainment from activity in some. This caused patients to enter, what she referred to as, a 'breathlessness vicious cycle' (PN 5, F, 25-30, Line 308), whereby they become trapped in a continuum of inactivity, due to trepidation surrounding perceived shortness of breath. Ultimately this leads to a deterioration in their condition:

*'that cycle gets taught to them, and saying well look actually, if you don't make these activity changes you'll become stuck in this breathless cycle, and you're going to become very weak and you'll get very sick'* (Lines 308-312).

A GP related this vicious cycle to a lack of patient knowledge, that being breathless is not always negative:

*'they're scared to walk because they feel breathless, so hence they do less. When actually what they need to learn is, yes walk as far as you can to get breathless, but keep doing it and things will improve, and it will help things and stop worsening in the long run'* (GP 8, F, 51-60, Lines, 177-179)

This fear and concern transpired in different ways, having the potential to impact upon patients receiving the medical assistance they require. This worry again related to the potential of holding oneself back, and ultimately causes patient reluctance to seek help:

*'they're frightened of going to hospital for things that they'll pick up and catch'* (PN 2, F, 41-50, Lines 242-243).

Others highlighted that they associated COPD with loneliness; negatively affecting quality of life. As a result, a PN believed that as the condition progresses patients would sometimes rely heavily on family support, which may inhibit their independence:

*'If you've got somebody in sort of severe COPD, then they'll tend to be quite isolated, because it's difficult to get out and they have to use the mobility scooter, and the relatives are perhaps sometimes over supportive'* (PN 1, F, 61+, Lines 139-141)

Another PN emphasised the importance of family support due to the emotional needs of the patient. She perceived patients do not always reveal the full extent of the psychological

impact of COPD to their family. A conversation with an elderly, fearful lady, anxious about attending appointments, was recalled. It was perceived that the combination of COPD alongside other comorbidities could cause patients to enter a period of difficulty:

*'She's going to stay with her daughter for a few days, as a support mechanism.... I've said to her you know we need to follow this up, she's been struggling for quite a while this lady, and doesn't like coming to appointments because she's also got rheumatoid arthritis. So you know it makes it difficult, but I think she's been covering things up from her daughter as well, and I think now her daughter's showing you know more support, because she's aware of what she's been struggling with. I'm hoping that I will keep seeing her until you know we've got other services involved to help her.'* (PN 2, F, 41-50, Lines 260-268).

It was evident that HCPs held differing views regarding the impact of COPD upon a patients' emotional and mental health. Nevertheless, those who discussed this as a COPD illness belief, believed it was a prominent aspect associated with the condition, with the ability to cause a worsening of symptoms and a reduced quality of life. Therefore, many perceived that a diagnosis of COPD not only causes physical symptoms, it can also have a broad psychological impact, resulting in anxiety, fear, isolation and loneliness.

#### Adds Pressure to the NHS:

Given the name chronic obstructive pulmonary disease, it was not surprising that many considered it as a chronic and progressive condition, with 10 HCPs discussing how it *adds pressure to the NHS*. A perceived contributory factor was the high prevalence of COPD, and therefore it was not uncommon for GPs to see COPD patients on a daily basis, which resulted in them being classified as *'frequent attenders'* (GP 2, F, 31-40, Line 190). One GP viewed that the COPD population are in constant need of medical attention, with the need for hospital treatment also high:

*'obviously the COPD group are a group who are often bouncing in and out of hospital'* (GP 3, F, 41-50, Lines 203-204).

The connotations associated with the term *'bouncing'*, imply that patients are rebounding back and forth, in and out of hospital, highlighting the regularity of attendance and admittance. Others discussed how COPD patients accounted for a large proportion of their workload:

*'I mean we obviously do have a lot of patients with COPD and other respiratory conditions, so they're at least forty percent of our workload, at least.'* (GP 6, F, 51-60, Lines 58-60)

Another agreed and although did not specialise in respiratory medicine, she still saw large numbers of patients with exacerbations of their COPD:

*'I mean we have a lot of people coming in with asthma and problems with asthma, and we have quite a lot of patients with COPD who come in with acute exacerbations. That's probably most of what I deal with, really.'* (GP 7, F, 41-50, Lines 70-73)

Others viewed COPD patient attendance as variable, dependent on the season. Overall, a GP perceived the numbers as manageable, apart from during the winter. It was considered that the added presence of flu and infections causes the numbers presenting at the surgery to increase significantly. This seasonal variability appeared quite overwhelming:

*'it depends on the time of the year, winter time a lot more, you're going to get a few in each clinic. I mean yesterday I saw two, so it varies at the time of the year because obviously flu's around and some bugs, we tend to get inundated with them, but the rest, you know this time of year it's relatively quiet.'* (GP 8, F, 51-60, Lines 90-93).

Possible explanations were provided by some as to why they perceived a large number of COPD patients to be presenting, this was often associated with the incidence of COPD relative to the area the GP surgery was based:

*'Oh, I get quite a lot of exposure, seen quite a lot, I mean I don't know if you're aware demographically [area where the practice is] has got a high population of patients with COPD, so yeah we, we see them most days.'* (PN 4, F, 51-60, Lines 82-84)

A PN also identified a high prevalence of COPD in her locality, however was passionate that this should be the reason patients need to be recognised and helped. She perceived pressure had eased due to a large number of HCPs now working together in the management of chronic conditions. The view that there is no cure was dismissed, and instead she strived for pro-active management, to improve symptoms and maintain independence:

*'I think we've got to be real, that these patients are a growing number and you know in our area we now have matrons, we have case managers and we even have attached nurses, practice nurses that are going out to do chronic disease. So yeah, I think this is a growing group and we can't just pretend they don't exist, or because you know they have these problems we shouldn't be trying to improve their general strength'* (PN 4, F, 51-60, Lines, 287-292)

GPs and PNs highlighted that COPD was a difficult condition to manage, as it causes patients to become restricted due to a decline in health and capabilities. Variation of symptoms and the perception that *'COPD's a very broad spectrum'* (GP 3, F, 41-50, Line 246), with some patients being able to do much more than others, added to the pressure

HCPs experience in the management of the condition. There was the view that patients deteriorate, and often it takes them a long time to feel well after an exacerbation. Those who saw COPD patients frequently were aware of the need to be realistic over the period required to recover from an exacerbation. This was evidenced by a GP, whose primary interest was not respiratory, yet saw *'a lot of patients with COPD, who come in with acute exacerbations'* (GP 7, F, 41-50, Line 72). She highlighted the severity of the condition and the patience and time required in its management:

*'we know that COPD can take longer to recover from an episode than we previously perhaps allowed for'* (Lines 220-221).

This decline in health status, both physically and emotionally, was reiterated by a PN. She believed that due to the deteriorating nature of the disease, and the notion that COPD is incurable, medically she was limited in what she could offer patients, however saw them frequently. This illness belief appeared to make her reticent about some of the medical options available, however she remained positive about assisting patients psychologically:

*'I see a lot more of acute exacerbation problems now, and the people that you know who are having repeat infections, struggling with breathlessness, affecting their quality of life. You know this is a progressive condition with really not an awful lot we can do to help sometimes, and I think anything that will give that patient support and you know improve their quality of life really, even though we can't cure their condition.'* (PN 2, F, 41-50, Lines 164-169).

This difficulty of only being able to aid patients in the management of their condition, without being able to restore health, was reiterated by a GP. Living with a chronic condition appeared to focus on improvement in quality of life, rather than aiming to provide a cure:

*'we're living in an era where we can't fix people's health problems, but we can work with them to help manage it.'* (GP 3, F, 41-50, Lines 230-231)

The complexities of the management of COPD and additional pressures to the NHS were often attributed to the need to account for *'other physical health issues'* (GP 6, F, 51-60, Line 268), with many patients having other comorbidities:

*'I particularly see frail elderly who've got COPD and those type of problems, but also probably have heart conditions and mental health problems as well. So, I usually am helping managing respiratory conditions in the context of lots of other things as well.'* (GP 3, F, 41-50, Lines 74-77).

A GP further reiterated the many comorbidities respiratory patients have, and suggested that symptoms of COPD, asthma and cardiac conditions often overlap. She therefore expressed the difficulty in identifying these, due to the presence of multiple similar

symptoms:

*'the only thing that's tricky is, we're talking about COPD but it's often quite difficult in practice to differentiate between COPD and asthma and other respiratory problems, and heart failure. You know they've often got kind of comorbidities and other things going on'* (GP 7, F, 41-50, Lines 421-424).

COPD was associated with a number of symptoms, which potentially cause other issues: *'some of them are underweight, that's the other problem'* (GP 8, F, 51-60, Line 196). A PN who primarily worked with patients in the acute stage of COPD suggested that it is a difficult condition to manage, due to a multiplicity of symptoms. As a result, patients often require additional resources and appointments, and commonly arrange to see the PN for reassurance. This was viewed as reaching out for extra support:

*'on the whole I see people who are struggling with their condition now, so they'll come in because their breathlessness has increased, they feel they've got an infection, they're not coping, they've got depression, they've got anorexia, you know or other issues'* (PN 2, F, 41-50, Lines 102-105).

Evidently, it was apparent HCPs believed COPD adds pressure to the NHS. There were a number of reasons attributed to this, such as the high prevalence of the condition, patients being frequent attenders, the multi-faceted nature of the condition, and complexity of disease management.

### Stereotypical beliefs surrounding COPD:

Within the super-ordinate theme, COPD illness perceptions, *stereotypical beliefs surrounding COPD* was most commonly discussed. All but two HCPs (n=12) (GP 5 and PN 1), held stereotypical beliefs regarding the condition. This related to perceptions they viewed typical for patients diagnosed with COPD.

Within some interviews there appeared to be a stigmatisation associated with smoking and the symptoms or comorbidities of COPD; insinuating that it is self-inflicted:

*'because COPD has been caused by smoking, they'll often have other conditions that are linked, so then they have heart disease and other, problems like that, adding to their respiratory symptoms'* (GP 7, F, 41-50, Lines 430-433).

This was reiterated by another GP who believed that patients were more commonly presenting and being diagnosed with the condition at a relatively young age:

*'We've got people in their forties... it's quite a deprived big council estate, most of them on benefits and they're all still smoking [laughter] and we've, we've got a high number of diabetics as well, and again we get the same issue with diabetes' (GP 8, F, 51-60, Lines 155-161)*

It was apparent this GP appeared to associate the disease with those living in a socially deprived area and being in receipt of benefits; it was evident she placed all COPD patients into the category of current smokers. This was a topic she freely chose to discuss on a number of occasions throughout the interview. Her pre-conceived perception of COPD patients appeared quite stigmatising, as she seemed to hold the view that it was a self-inflicted disease. This was evident through her responses and demeanour, yet never explicitly identified as such. It was unclear if this was an unconscious process, or as a result of first-hand experiences. The same opinion was held by this GP for those living with diabetes, associating the geographical area with a high incidence of chronic conditions. She appeared to lack empathy with patients diagnosed with chronic illnesses, and viewed the condition as something they would have to learn to live with:

*'whether it be diabetes, asthma, COPD, it's all about them accepting that this is a long term condition, it's not going to go away' (GP 8, F, 51-60, Lines 225-227).*

Many perceived the COPD population lacked motivation and enthusiasm to pro-actively do something for themselves, and this was often discussed in relation to PR. A GP reluctant and unsure of patients enthusiasm to abide to non-medicalised interventions, highlighted that they need to be motivated and made aware of the personal responsibility and commitment:

*'they need to know its them who's going to be doing the work, it isn't done to them, it isn't like they're having chest physio, or something like that, that they may feel is being done by somebody else, it's their work that's going to achieve whatever benefit comes from it.' (GP 1, M, 61+, Lines 186-190)*

Another, held similar views that patients should take personal responsibility for their condition, and perceived those with COPD often do not have this drive. She believed they have to want to make positive changes for themselves for non-pharmaceutical approaches to be effective:

*'I think sometimes it is you know, yes you can make people turn up but that doesn't make them interested or committed. They can feel that they're doing it because they have to rather than feeling that it's for them to take some control of their condition.'* (GP 8, F, 51-60, Lines 222-225)



There was a view that patients longed for a quick fix to their condition, and if this was not possible, they would be disinterested in devoting time to it. A GP discussed perceived lack of motivation at length, and referred to patients often having unrealistic expectations of programmes such as PR, viewing it as a '*miracle answer to everything*' (GP 3, F, 41-50, Line 315). This resulted in a diminished drive to persevere, due to it not turning out to be the miracle cure they thought it might be. She however, believed the problem was more deep rooted than a simple lack of motivation, it was about changing the minds and hearts of this group, to realise that a non-medicalised approach would be useful. She viewed COPD patients usually lacked the tenacity and patience to pursue something not considered to have an immediate benefit:

*'So, people sort of go along thinking this is somehow going to be some miracle answer to everything, and then two or three sessions in they're realising that actually, it's not a miracle. It could be helpful but it's going to take time and work, trial and error and things... If they'd gone in expecting it to be a, I don't mean a quick fix, but for short hand purposes, then it seems to be that two, three sessions point at which they come out again, but we see that with counselling, we see that with pain management, we see it with lots of similar services that are about how do we engage people in thinking differently about managing their health.'* (GP 3, F, 41-50, Lines 314-322).

A PN agreed and passionately discussed her views on the medicalisation of COPD, and how this was a current issue within the healthcare system. She believed patients do not realise it is only themselves who have the ability to take control of their condition, in order to make positive changes and witness improvement. She reflected on the interview and sent further thoughts in an email, and discussed how HCPs need to help patients to take responsibility:

*'Why do we continue to medicalise COPD and take responsibility for the patient's outcomes! When essentially stopping smoking, understanding the importance of activity and managing acute events require the patient to actively take responsibility in order to improve quality of life.'* (PN 3, F, 51-60, Lines 391-394)

A GP added that motivation was not attributed to disease severity; it was a reflection of the characteristics and personality of the patient themselves. She discussed how if patients are resistant and are not motivated to embrace the information and education, this could impact upon effectiveness of non-medicalised management strategies and, thus, she viewed that motivation was the key to potential success:

*'I think it depends probably a little bit on the patient in terms of their willingness to engage with it [PR], more than the actual severity of their illness ... I suspect that however severe that they are, or mild, actually going on something like that's probably helpful if they're willing to engage'* (GP 7, F, 41-50, Lines 148-151)

This lack of motivation was closely related to the view that COPD patients needed frequent reassurance, a perceived common trait for those with the condition. This was viewed as particularly prominent when suggesting exercise to patients with COPD. One GP suggested that for those with mild anxieties or reservations she would offer reassurance and promote attendance. She was however reluctant to persuade patients any further than this:

*'Maybe if they were just a bit cautious about it I'd try and encourage them to go along' (GP 7, F, 41-50, Lines 321-322).*

A PN felt the need to reassure patients by providing them with different scenarios which may occur, and believed that it was her job to make the patient feel at ease. Her in-depth knowledge of COPD and close contact with this group of patients allowed her to provide much needed reassurance and confidence, to what she considered as an anxious group:

*'Basically we warn the patients obviously if their blood gasses drop on the six minute walk they might get supplementary oxygen, and not to panic' (PN 3, F, 51-60, Lines 102-103)*

A GP further described another aspect to her role of providing reassurance and how she perceived that this was a characteristic of those with COPD. She recalled a particular patient in her fifties, and described how when patients research treatment or management options online this can cause further apprehension and reluctance to try a different approach, especially one that is not medicine. The view that if patients leave the doctors surgery with unanswered questions or eager to know more, they may research this themselves, which can sometimes become problematic. She recalled a particular patient in her fifties, who returned to the surgery for reassurance after conducting her own research into PR online. The information displayed on the website made the patient feel unsuitable and reluctant to attend. This GP discussed the effort and persuasive nature that was required with some COPD patients to reassure and restore confidence:

*P: 'I've got a patient, she had an exacerbation last week and she's been referred for it [PR], and she was saying she went online to see what it was all about .... That's, maybe there's a problem there, it's not been explained well enough to her, but she said she went online and she just saw pictures of sort of very old looking people ... oh she said, I look a bit too young for it. So, I was telling her no, no, it's not about that, it's about whether you've got a condition of the lungs or not, because that was obviously putting her off, which was a worry'*

*I: 'So has she decided to go then now?'*

*P: 'Yes, she has decided to go because I said well you know you'd be the star, if you're the youngest, you'd be zipping round [laughter] and everybody else would be slow... You'll do really well, you'll look good, and I was just trying to get her there'*

*really, basically, yes, I was encouraging her to go and she said she would, and I do believe she will go, and she's actually on smoking cessation patches at the moment. Obviously, she's in her fifties, obviously it's been a bit of a wake up for her, so I think she's really keen to do something.'* (GP 8, F, 51-60, Lines 372-389)

This patient was reassured using flattery, highlighting that she would be better than the other patients; it appeared that the GP tried anything possible to convince the patient to attend. It was apparent that the patient required a much needed confidence boost after researching the programme online, and positively selling the programme and the patient's abilities dispelled some of the apprehension. Another GP also stereotyped COPD patients as a group requiring reassurance, however held different views on how COPD patients receive this. He assumed that this would be achieved via attendance at a group exercise setting, which provides valuable social support and camaraderie. He viewed that patients may become self-assured and comforted in seeing an individual with symptoms worse than their own:

*'a fair number of people like some kind of group activity... in all sorts of ways in health service, they like the we're in it together kind of feeling, sometimes that is there's somebody worse off than me. Sometimes it's somebody else showing a good attitude in terms of getting stuck in and so on, and they feel pushed to follow them, maybe through guilt or something or whatever, but if it gets them exercising that's the vital thing really.'* (GP 1, 61+, M, Lines 226-232).

Many also believed that COPD patients are resistant to change, and this was often in relation to exercise. They perceived that patients believe physical activity delves into the realms of the unknown, and is considered an atypical approach to managing their condition. It was therefore viewed that you *'need a patient that's willing to try something different'* (PN 2, F, 41-50, Line 201-202). The term *willing* reinforces the reluctance and disinclination that some HCPs discussed in relation to certain patients undertaking a programme of exercise.

GPs discussed how COPD patients were often unreceptive to alternative ways of managing their condition. Some viewed that patients were negative about exercise, and believed that only medication could help. There was a perceived lack of knowledge and disbelief amongst patients, that exercise could ameliorate symptoms. Due to holding this illness belief, a GP believed that patients only wanted medical intervention via prescription:

*'there seems to be a belief that simply exercise ... they've got a disease, it's you know exercise, it can't possibly make them significantly better and it has to be something on prescription, you know be it a tablet or an inhaler, and why could anything else work, but that might be my assumption.'* (GP 6, F, 51-60, Lines 100-103)

It was viewed that patients need to realise that medication is not the only answer, with restrictions surrounding a purely medicalised approach:

*'that whole notion of where somebody is on a pathway of sort of believing, that actually their condition is fixable, you know the medicines will sort it, through to an acceptance ... of the limitations of medicine to be able to fix this. Actually ... yes the medicines will help but also, people need to and are able to do things differently' (GP 3, F, 41-50, Lines 136-141)*

The view that patients need to enter a stage of *acceptance*, highlighted an emotive and psychological phase that patients need to endure in order to change opinion. This GP rarely doubted patients' abilities, and believed it was their reluctance to enter this phase, or way of thinking, which held them back. This unwillingness was discussed by another GP who drew attention to the stubbornness of some patients. It appeared to be a continuous battle to convince patients that exercise was appropriate; with them often creating excuses rather than being open-minded:

*'I think we're always telling people you need to do something but they've often got an answer for it. If you tell them to go swimming, oh I don't like swimming, I can't swim, it's too cold the water. They'll come out with everything, rather than realising that you know walking, swimming, whatever, is going to improve their health in the long run.'* (GP 8, F, 51-60, Lines 211-215)

One PN held strong opinions in respect of COPD patients' resistance to change, and entered into a long dialogue to highlight her perceptions. At no point did she blame patients for their unwillingness or hesitancy surrounding a non-medicalised approach, and was very understanding and sympathetic. She considered it difficult to educate patients and change opinion, as they have almost become stuck in their ways. This was a multi-faceted issue which impacted upon the psychological barriers associated with COPD and PR:

*'you find that they're not as well managed because their education is not as good ... when they've been unwell for say you know a couple of years, they don't, this sounds awful, but they're kind of quite resistant to education because once you've been, once you've had an illness for a while you become your own expert patient, which is understandable. You know if you've got a disease, you become an expert in your own disease, and therefore trying to re-educate someone that actually being breathless is actually quite a useful thing, it's a healthy thing, it's normal and you need to learn how to manage that ... that's a huge mental change'* (PN 5, F, 25-30, Lines 277-286)

She believed it is much more difficult to alter ingrained views and beliefs of patients with well-established COPD:

*'they're much more resistant to education courses and exercise, but that's not their fault ... even though pulmonary rehab's been around for a long time ... it's a cultural*

*change you know, it's not just a cultural change in terms of patients but as in you know, something like that to be referred to.'* (Lines 287-291)

She added that even patients who she convinced to attend with mild to severe COPD, would complain, as they were averse to exercise:

*'they say well oh God it's too hard, I get muscle aches afterwards, I don't like it ... that's why for those people it's always a difficult one to know if it's appropriate because, although it is appropriate medically, it's more their resistance to change'* (Lines 528-523)

Overall, it was evident that there were a number of stereotypical beliefs held by HCPs working in primary care in relation to COPD. These were defined as patients being smokers, attributing the disease to self-infliction, the association between COPD and social-deprivation, lacking motivation, being resistant to change, and needing frequent reassurance.

#### **4.3.2 COPD Illness Perceptions – Secondary Care:**

The super-ordinate theme *COPD Illness Perceptions* was constructed for secondary care from the sub-ordinate themes: *Perceived patient burden*, *Adds pressure to the NHS*, and *Stereotypical beliefs surrounding COPD*. Although containing a lesser number of references than some of the other themes, it was apparent that HCPs working on general medical wards held strong illness perceptions with regards to COPD. Further details have been presented in table 14.

**Table 14: COPD Illness Perceptions – Secondary Care Sub-ordinate Themes**

<b>COPD Illness Perceptions – Secondary Care</b>		
<b>Sub-ordinate Theme:</b>	<b>Number of participants:</b>	<b>Number of references:</b>
<b>Perceived patient burden</b>	10	25
<b>Adds pressure to the NHS</b>	11	26
<b>Stereotypical beliefs surrounding COPD</b>	9	28

#### Perceived patient burden:

Within secondary care 10 of the 13 HCPs perceived that COPD was a burden for patients. They often held this illness belief as they viewed that COPD is a '*deteriorating condition*' (GN 2, F, 41-50, Hospital 2, Line 84), and that the patient's general health and symptoms worsen as the disease progresses. The condition was considered troublesome for patients,

as they are unable to restore health to its previous state:

*'it just tends to basically get worse, you can't sort of ... you can't cure it as such'* (GN 1, F, 51-60, Hospital 2, Lines 130-131)

Despite agreeing that COPD cannot be cured, some HCPs were quite matter of fact that patients were not going to return to full health, and therefore would never be free of their COPD. The long term, onerous nature of the disease was highlighted by a GN, however she believed that symptoms and quality of life could be improved via attendance at PR, or with a combination of lifestyle changes and medication:

*'it's an obstructive airways disease, so it means that it is a potentially progressive disorder, patients aren't going to be able to get better, but they are going to enhance and optimise their symptoms and their quality of life by different measures, all be it by pulmonary rehab, or whether or not medications and lifestyle.'* (GN 7, F, 41-50, Hospital 2, Lines 110-113)

A doctor described how he viewed shortness of breath as the most demanding and restricting aspect of the disease, as it was considered something which was never going to disappear:

*'it's irreversible damage to the airways and lungs that prevents people from ventilating and respiring adequately'* (DR 6, M, 25-30, Hospital 2, Lines 62-63)

COPD was therefore viewed as having long term consequences on an individual's health. Another doctor referred to the difficulties of breathlessness and also used the term 'ventilating' (DR 4, M, 25-30, Hospital 1, Line 50). It appeared that these doctors associated breathlessness with their medical knowledge of the mechanics of ventilation. Although knowledgeable about the symptoms of COPD, his definition significantly focused on the multi-faceted, unpredictable, nature of the disease, its impact upon breathing and limits on exercise:

*'Well it's a chronic condition, associated with sort of fixed airway obstruction and difficulty with ventilating, patients tend to have sort of exertional shortness of breath, chronic cough, often they produce a lot of sputum'* (DR 4, M, 25-30, Hospital 1, Lines 49-51)

The condition was therefore perceived as demanding for patients, due to increased breathlessness upon activity, and associated comorbidities which cause patients to alter their daily living:

*'breathlessness, short of breath on exertion, you get some weight loss, what else can we have, changes to your life style, it's all of those sort of things'* (GN 6, F, 41-50, Hospital 2, Lines 51-52)

Others empathised with patients, placing themselves in the patient's shoes. The psychological impact and strain which breathlessness causes was considered:

*'it depends on the mind-set of the patient really, trying to push through if you are feeling breathless, it must be a difficult feeling.'* (GN 7, F, 41-50, Hospital 2, Lines 245-247)

Although, HCPs in secondary care tended not to focus specifically on the psychological impact of the condition, when they did, it was commonly associated with anxiety. It was interesting to note that only one doctor in secondary care perceived that anxiety was associated with the encumbrance of COPD:

*'So, breathlessness, reduced exercise tolerance, they might have a bit of anxiety around the symptoms.'* (DR 6, M, 25-30, Hospital 2, Lines 161-162)

Although this doctor believed the symptoms of COPD caused patients to become worried, GNs appeared to specifically associate this fear with breathlessness. It was apparent that they considered anxiety to be induced by breathlessness, and believed that patients become alarmed when they feel as though they cannot breathe. This additional concern acts as a trigger to hospital presentation:

*'there's a lot of patients that come in because of anxiety, because they're unable to breathe'* (GN 1, F, 51-60, Hospital 2, Lines 131-132)

Another GN believed that patients who are anxious and short of breath need to *'know how to calm themselves down'* (GN 4, F, 41-50, Hospital 2, Line 238). A strong association was present between breathlessness and anxiety, with each intensifying the other. It was perceived that anxiety had the ability to consume patients' lives, and therefore an element of self-control and understanding of regulated breathing is required, to be able to self-manage their condition.

Given the chronic nature of the disease it was evident that HCPs in secondary care perceived COPD as both demanding and an inconvenience for patients. Both physical and psychological symptoms were perceived to impact upon daily living and quality of life, thus HCPs perceived that as they could not *cure* the condition this resulted in patients feeling burdened.

### Adds pressure to the NHS:

Due to the abundance and diversity of symptoms previously discussed, HCPs (n= 11) perceived that *COPD adds pressure to the NHS*. A large contributory factor was the belief that patients are frequent attenders at hospital, and that they often present with comorbidities of their COPD. There was a predominant view that COPD is '*probably one of the most [common] things we tend to see*' (GN 1, F, 51-60, Hospital 2, Lines 87-88). Although the HCPs interviewed did not work on respiratory wards, this emphasises that COPD patients contribute to a large proportion of their workload.

Doctors discussed the regularity with which COPD patients arrive at the acute medical unit (AMU), and often they recalled seeing a patient with COPD every day. Although, this was sometimes a *primary presentation* they were aware that patients regularly had COPD in '*the background*' (DR 4, M, 25-30, Hospital 1, Line 63). Despite not having worked in a respiratory speciality, some doctors had gained extensive exposure to COPD, due to regular patient admissions:

*'it's something that comes up every day usually, so I've had a lot of experience with it.'* (DR 5, M, 25-30, Hospital 2, Lines 45-46)

Similarly, GNs discussed how they have a lot of patients with COPD on the ward, and they therefore see them '*pretty much every day*' (GN 7, F, 41-50, Hospital 2, Line 88). COPD patients had a notable presence on general medical wards:

*'Oh, probably every shift. There's going to be at least one in your bay yeah, it's very rare that you'd have no COPD patients in.'* (GN 4, F, 41-50, Hospital 2, Lines 35-36)

Another GN tried to highlight the frequency, to display that those with COPD account for approximately a quarter of patients on the ward:

*'we take respiratory patients on here, so, yeah.... I'd say, we've got a team [a bay] of eight and normally two or three of them are chest patients.'* (GN 2, F, 41-50, Hospital 1, Lines 27-32)

This was not dissimilar to the views of those working on a frailty ward. A GN described how they '*have a lot of people in here with COPD*' (GN 5, M, 51-60, Hospital 2, Line 48). He perceived the condition triggered a cyclical process, whereby they become better whilst in hospital, they are sent home, and it is only a short period until they are next unwell, when they return:

*'we see a lot of exacerbations of COPD and they're multiple admittances ... you know what I mean, they are in every, like, so many months'* (Lines, 236-238)



Some appeared disgruntled and irked at the frequency those with COPD were admitted to hospital, and believed that nothing could be done to help in secondary care:

*'trying to keep people in the community and not keep re-attending hospital for things that you can't actually fix.'* (GN 1, F, 51-60, Hospital 2, Lines 132-133)

A doctor, who alongside working on AMU worked in A&E, also discussed the high presentation of COPD patients. She considered the treatment of exacerbations as a large part of her role:

*'we see quite a lot of infective exacerbation of COPDs and asthma, as first presentation, in A&E basically'* (DR 3, F, 31-40, Hospital 1, Lines 33-34)

For some, presentation with an exacerbation of COPD was minimal, however patients are often admitted with related comorbidities, due to the coexistence of other conditions being high within the COPD population:

*'it tends to be more like they've got comorbidities of like COPD, rather than like they come in with an exacerbation of their COPD.'* (DR 2, F, 25-30, Hospital 1, Lines 30-31)

Others perceived admittance due to an exacerbation of their COPD as high. This resulted in some patients needing additional support and being placed in an intensive therapy unit (ITU), due to the need for non-invasive ventilation. This perception was of a GN, and may be as a result of working on ITU for the majority of her career and only moving to general medicine recently. She perceived that specialist support is required for a large number of patients due to the severity of their symptoms:

*'in ITU you have a lot of like, respiratory conditions end up being ventilated so there's like a long list of either COPD or asthma or just respiratory failure for whatever reason on ITU'* (GN 1, F, 51-60, Hospital 2, Lines 88-90)

As a result of the factors discussed, the importance of easing current COPD related pressures on the NHS, was emphasised:

*'it's needed [PR] isn't it, to stop, just to stop admittance, because the hospitals too full, and A & E is too full, we're too full'* (GN 5, M, 51-60, Hospital 2, Lines 238-239)

The pressure of COPD on the NHS within secondary care predominantly focused upon the frequency of attendance of patients at hospital. HCPs considered this to add strain, as those with COPD contributed to a large proportion of their workload.

### Stereotypical beliefs surrounding COPD:

Stereotypical COPD illness beliefs which HCPs in secondary care associated with the condition were identified. These focused upon smoking behaviours, and the lack of engagement patients have with their health. Although COPD was often referred to under the umbrella term *chronic lung disease*, there was the belief that COPD was the specific respiratory condition '*most commonly caused by smoking*' (DR 6, M, 25-30, Hospital 2, Lines 61-62). Smoking was perceived the root cause of airway damage and, as a result, patients appeared to be defined as smokers. There was the belief that they should be actively encouraged:

*'to stop with their smoking ... which we know is the single most important thing that we can do for COPD.'* (DR 1, F, 25-30, Hospital 1, Lines 81-82)

One doctor appeared to have a particular grievance with smokers. She reinforced the issue and defined smokers as one group, characterising them by their life-style choices. She viewed that their negative health decisions, and not having the commitment to quit smoking, would result in being less likely to take ownership and make positive changes to their health:

*'that's the problem, because if they're not engaged in doing things for themselves, for example like stopping smoking, will be more unlikely to be engaged with a programme where they have to take responsibility.'* (Lines 85-88)

Although some highlighted smoking as a common contributory factor to the presence of COPD, they were also aware of, and acknowledged, other causes:

*'generally [COPD] is related to smoking or some kind of like industrial exposure to like dust and things like that'* (DR 2, F, 25-30, Hospital 1, Lines 75-76)

This doctor viewed that patients need to work with HCPs and be '*willing to engage*' (Line 118) in making positive changes, with some patients perceived as reluctant to this view. This was considered a problem with patients attending programmes such as PR, where commitment is considered a key factor. Although, there was a level of uncertainty and assumption, some perceived that an interest in one's health may be determined by the stage of the disease:

*'I don't know whether that would vary with regards to how far in the disease process the person is, if it was somebody who was just newly diagnosed, maybe they would engage more. If it was somebody who had quite severe COPD, obviously you know psychological issues and things you know can be there ... I suppose what I'm saying is it's when they are ready to engage, and if the person's ready to engage and embrace pulmonary rehabilitation.'* (GN 7, F, 41-50, Hospital 2, Lines 292-299)

However, one GN disagreed and did not consider the stage of the disease important. She appeared to stigmatise some COPD patients, suggesting they may not have the appropriate levels of education to learn self-management:

*'I think it's just someone who can understand what you're saying ... you know someone who you can speak to, understand what they're saying and be able to carry out instructions or things.'* (GN 4, F, 41-50, Hospital 2, Lines 199-201)

There was a view that *'compliance is a big issue with COPD patients in general'* (DR 5, M, 25-30, Hospital 2, Line 168), and it was perceived that this group do not conform when given instructions and would find it difficult to engage with programmes such as PR. It was considered that motivation and an interest in improving one's health was imperative to the success of the programme. This was consistent with the views of another doctor, who acknowledged that he was unsure if patients would commit to exercise:

*'how suitable they were in terms of whether they, how they'd comply with the exercise and whether they would actually attend, so I sort of, I think I'd discuss that with them.'*(DR 6, M, 25-30, Hospital 2, Lines 168-170)

This doctor seemed to have very little faith in the commitment of COPD patients, and his perceived patient characterisation appeared to have a significant bearing on whether he would refer to PR. This was closely related to the views of DR 5, who frequently mentioned throughout the interview that COPD patients lacked compliance, and he believed that, in some cases, patients thought they knew better. Regardless of this deep-rooted view which appeared to have manifested during his time on the wards, he suggested that he would give patients a chance to prove him wrong:

*'The only thing would be general compliance of the patient, if I don't think that they're going to, you know, listen to the advice or attend the programme itself then I wouldn't, but usually you give most people the benefit of the doubt and refer them anyway'* (DR 5, M, 25-30, Hospital 2, Lines 196-199)

It was evident that some based their assumptions upon their perceived characteristics of an individual with COPD. Therefore, there appeared to be a level of doubt amongst some of the doctors on the general medical wards, as to whether they believed patients would

conform and abide with medical instruction. Similarly, a GN believed that COPD patients lacked commitment in relation to non-pharmacological approaches such as PR:

*'I think the DNA [did not attend] rate is quite high for some of these programmes isn't it, which is a shame'* (GN 7, F, 41-50, Hospital 2, Lines 332-333)

This GN appeared empathetic, and although some suggested that the patients lacked adherence, they offered possible explanations for this. Some GNs although unsure of the specifics of PR, viewed that due to a perceived lack of patient adherence many would miss sessions, or drop out. In contrast to the doctors, some GNs believed that COPD patients were non-compliant due to living with COPD. They considered it a complex condition with a number of symptoms, where patients often quickly become unwell. This was summarised by a GN who discussed her understanding of the restrictive nature of the disease, whereby patients often withdraw due to a period of ill health:

*'there might be drawbacks due to the commitment, because of the fact that they've got chest problems, because that does just draw you back, because they become ill really quickly'* (GN 6, F, 41-50, Hospital 2, Lines 92-94)

It was therefore evident that although HCPs had varying views, many made assumptions about the *COPD group*. They perceived that there are certain behaviours or characteristics, such as being a smoker or lacking compliance that are typical of a COPD patient.

#### **4.3.3 Pulmonary Rehabilitation Beliefs – Primary Care:**

The super-ordinate theme *Pulmonary Rehabilitation Beliefs* was established after identification of the subordinate-themes: *Beliefs of what pulmonary rehabilitation entails and patient suitability*, *Uncertainty*, *It's helpful* and *Perceived barriers to PR*. Due to its direct relevance to the research question it was not surprising that this theme had a substantial number of associated references; further details of which are provided in table 15.

**Table 15: Pulmonary Rehabilitation Beliefs – Primary Care Sub-ordinate Themes**

<b>Pulmonary Rehabilitation Beliefs – Primary Care</b>		
<b>Sub-ordinate Theme:</b>	<b>Number of participants:</b>	<b>Number of references:</b>
<b>Beliefs of what PR entails and patient suitability</b>	14	57
<b>Uncertainty</b>	13	67
<b>It's helpful</b>	14	81
<b>Perceived barriers to PR</b>	12	61

### Beliefs of what PR entails and patient suitability:

All HCPs (n=14), in primary care discussed their personal opinion of what PR entails and patient suitability. It became apparent that several GPs preferred to discuss a general definition of PR, rather than focus on local programme specifics. GPs' perceptions tended to focus upon the exercise component of the programme:

*'trying to improve their ability to exercise and also clearing secretions and help reduce shortness of breath' (GP 2, F, 31-40, Lines 79-80)*

*'I know that it's sort of an exercise programme used to improve the breathing of people with COPD' (GP 4, F, 31-40, Lines 92-93)*

*'exercises and breathing exercises, and tries to get them to develop some exercise tolerance.' (GP 8, F, 51-60, Lines 180-181)*

Another GP who associated PR with exercise, considered the programme's primary aim as trying to improve patient capability and lung capacity. Although, when attempting to discuss his understanding of the local PR programme, appeared unsure and hazarded a *guess* at specifics:

*'I understand it's a number, perhaps half a dozen sessions carried out over two or three months, for people where they're taught exercises to improve their respiratory function' (GP 1, M, 61+, Lines 80-82)*

A GP who lacked clarity surrounding the length of time patients attend, very much believed that PR involves encouragement from HCPs delivering the programme, to enable patients to do things they previously would not have considered:

*'It usually goes over a few weeks doesn't it, and they get them to educate them about their illness, and they get them doing some exercises and practicing sort of breathing exercises, try and get them moving.' (GP 7, F, 41-50, Lines 109-112)*

Although GPs predominantly believed that PR consisted of exercises to increase mobility and exercise capacity, one viewed that the programme was individually tailored to patients' abilities. He believed it was inclusive, regardless of where patients were placed on the disease trajectory, and that those delivering PR worked in conjunction with patients to set individual goals:

*'in our area we have a pulmonary rehab team, which is run by a group of nurses and physiotherapists, and they have group sessions where the range of abilities range from people who may be wheelchair bound to people who are, have, are much higher functioning in their exercise ability. So the programmes are individually set for the*

*individuals... depending on what they are able to do.'* (GP 5, M, 41-50, Lines 118-122)

PNs on the other hand, appeared to have a greater understanding of the well-established history of PR, and perceived the programme to have a positive effect on patient well-being:

*'Pulmonary rehabilitation has been providing a source of education with supportive data demonstrating positive outcomes on quality of life for years'* (PN 3, F, 51-60, Lines 396-397)

The history of PR, the multi-disciplinary nature and perceived variability nationwide, in respect of both content and availability was also discussed:

*'It's been around now quite a while, pulmonary rehab, I would guess off the top of my head at least 10 years. It's a programme that usually involves exercise and education for people with any long term lung condition. It's often run by a combination of either respiratory nurse, physiotherapist, outreach teams or what we call tier two in the community, often with you know sort of a respiratory consultant that would maybe, you know, have overseen the development of that programme. I think it varies across the country, as to when it's available, how it's delivered, locally for me in [name of town], it's delivered usually over a six to eight week programme'* (PN 2, F, 41-50, Lines 132-139)

Another PN discussed the multi-disciplinary nature, yet appeared less confident with the key components of her local programme:

*I think they do one at [name of hospital], so it's run as part of the COPD team, and I think if I remember correctly they generally have a nurse and like a nursing assistant with them. I think sometimes the physios go and help run them as well. As far as I'm aware it's, people attend and they have a bit of an education time and then they do a bit of exercise time, and it's a good time for patients to meet other people with the condition so they can discuss things, that they've got time with the nursing assistants and physios to discuss things. I think if I remember correctly they get them doing exercises in the class together, and I think a lot of it's educational stuff.* (PN 5, F, 25-30, Lines, 194-202)

This PN, who was based in an inner city practice, highlighted that her main interest was diabetes management, however stated *'because of staff changes, I have now just taken over the respiratory section'* (Lines 235-236). It was very apparent throughout the interview that she appeared uncomfortable in her new role, and was undertaking it though necessity rather than choice. She did however appear very positive about the social aspect of PR, and the benefits of having HCPs on hand for a number of weeks.

Another, PN had specific knowledge of the programme content, which she attributed to going to see it first-hand. She believed that taking one day out of her schedule was

invaluable to truly understand the process, and observe the direct benefits:

*'It was very useful because it was just one session, and that session included some advice on where to put things in the kitchen so that you're not reaching high and things like that. There was some light exercise going on, and, and quite a bit of education, you know, like reassurances'* (PN 1, F, 61+, Lines 181-184)

The social aspects associated with PR such as a *'coffee and a chat'* (PN 3, F, 51-60, Line 105) and the educational components were also discussed:

*'it's a course that's recommended that patients with COPD attend, to teach them, a) about the condition, b) how to manage it, and to manage sort of the impact that it has on their life really.'* (PN 4, F, 51-60, Lines 118-120)

As a result, it was considered that patients were provided with *'comprehensive cover'* (PN 3, F, 51-60, Line 107), highlighting the well-rounded nature of the programme.

Perceived patient suitability was commonly discussed, with HCPs highlighting their views on the characteristics of eligible patients. They appeared to have distinctly different criteria as to who they would consider for PR. Some appeared to follow general guidance set by the local programme:

*'They have to have roughly an MRC 3 scale, but they will accept anybody who's willing to actually undertake the course, they don't, they're not specific to COPD, they'll take our [patients with] fibrosis on, they'll often take on our chronic asthmas as well.'* (PN 3, F, 51-60, Lines 95-98)

This PN delivered a PR programme in a previous role, and therefore was very knowledgeable and passionate about the programme. She did however discuss a group of patients that she would not consider for referral:

*'I think we have to be real and I mean if they are on sticks, they're in a wheelchair then what we've got to remember, this is a group activity'* (Lines 272-273)

Another PN followed the guidance provided, however tried to use her own judgement to perceive how the condition impacted upon a patient's quality of life:

*'the person has to have a known diagnosis of COPD. Ideally they do say as part of the criteria, the FEV<sub>1</sub> should be less than 50 percent, but we do have to look at that as a stepping stone because it depends obviously on how symptomatic the patient is and how much the condition is limiting them'* (PN 6, F, 41-50, Lines 111-115)

Others believed that PR may not be suitable for those who are still working, however highlighted an internal conflict, as referral to the programme should not be left too late:

*'obviously, there's patients that are still active and working, and coping with COPD, and it might not be suitable for them because they're not actually experiencing any difficulties. But then we've got to be careful that we don't wait till they are experiencing very, very vast difficulties and have got a very poor quality of life, because then it's a lot harder to try and put some input in and change things around'. (PN 2, F, 41-50, Lines 374-378)*

Some GPs however perceived there was nothing in particular that would influence their decision to refer a patient, *'it's when they hit the criteria'* (GP 5, M, 41-50, Line 216). This GP did however discuss that he believed patients with severe mental health problems would not be suitable, primarily due to the impact that they would have on other patients enrolled:

*'There are people with severe mental health problems that would not, maybe not tolerate being in a group environment, but I can't think of many, you know they'd be isolated incidents. Reasons why I wouldn't refer specific patients ... there may be patients who have a psychosis or a behaviour type that would be dangerous to other people. I can think of one of those that I wouldn't refer for pulmonary rehab, because it would be unfair on the other people.'* (Lines 230-236)

Although, he stated that these would be isolated incidents, certain patients may not be referred to the programme as a result of this. Strikingly, a large number of GPs considered the use of PR as a last resort, after all other medical treatments had been explored. One was of the opinion that PR would particularly be suitable for patients who are *'functionally disabled because of their condition'* (GP 6, F, 51-60, Lines 202-203), and therefore appeared mistaken with respect of patient eligibility:

*'part of the referral criteria anyway is that they should be on maximised treatment, you know so if you have medically maximised their treatment and they still got, you know significant, either breathlessness or functional restriction of their daily activities, then they clearly are an ideal group of patients to refer'* (GP 6, F, 51-60, Lines 204-208)

Another added:

*'I see quite a lot of people who are on maximal therapy and have multiple exacerbations of their COPD, I could refer some of those I suppose'* (GP 4, F, 31-40, Lines 175-177)

Frequent exacerbations were a prominent symptom that triggered referral for one GP, however she did not perceive it suitable for the housebound, or those with agoraphobia. She did not appear to consider patients with infrequent exacerbations who were responding well to medical treatment:

*'if somebody's had one, one exacerbation and they seem to have recovered from it, fairly well with steroids and antibiotics, then I probably wouldn't be referring them for*



*pulmonary rehab.*' (GP 7, F, 41-50, Lines 287-283)

Another GP believed that PR was for those patients at the severe end of the disease trajectory:

*'particularly people who have deteriorating respiratory function, who, who give an impression of living a very inactive life, and getting to the point where they were almost house bound really... It would be the worse end of the spectrum in terms of disease severity'* (GP 1, M, 61+, Lines 161-167)

This GP however added that he would not try to 'sell' the programme to a patient who appeared disinterested and unmotivated:

*'if they're negative about the whole idea then I wouldn't push, I wouldn't push it if they said I'm fine, I'll leave it and I'll think about it or something ... they've got to be motivated.'* (GP 1, M, 61+, Lines 179-181)

Conversely, some considered referral most appropriate for newly diagnosed patients, and perceived it was less suitable for those with severe COPD as they were more likely to reject referral:

*'I think the patients that are, don't seem overly engaged, you kind of get a bit like [sigh] well I'm not sure what, not that it's ever our choice you know you always offer people ... it sounds awful but you sometimes know the answer before it comes, but that's not to say that you'd not offer. I think in the more severe patients you'd kind of, you probably wouldn't really even offer actually. The really sick patients that, you know really chronic, struggling to walk into the surgery, you just think I'm not sure what we're going to get out of pulmonary rehab at this stage, because you're much more late stage. So, and maybe that's, that's a bit ignorant but that's always just what I've, I've been taught'* (PN 5, F, 25-30, Lines 487-496).

Others, referred patients for the psychological support that could be provided, rather than for any overt physical benefits:

*'the last one I did do was a gentleman again who'd got severe COPD, and he again was struggling with a lot of breathlessness, according to sort of review and check he was actually sort of stable so didn't need anything acute as such, but he didn't feel stable and his life, his quality of life was very poor, he wasn't eating very well because of breathlessness, he wasn't going out, he wasn't doing very much, and the anxiety was the biggest factor with him, where he was basically sort of panicking you know, if he moved from his chair, and because mobility of course was causing a lot of breathlessness'* (PN 2, F, 41-50, Lines 332 – 340)

A GP also felt strongly about the depth of psychological impact associated with COPD and this would be more likely to prompt her to make a referral:

*'I might be talking with someone about you know, when they were going out and seeing their friends or when you know or what ... the things that make us smile and bother to stay on this earth sort of thing, and if their breathing was something that was stopping them doing that, or their confidence in their breathing was something that was stopping that, then, then I might start a conversation with them. Well actually, do you think it would help to see a service that could help you, you work on that, an tackle that, and think about how we can help you feel more confident in being able to do those activities and not letting the COPD get in the way' (GP 3, F, 41-50, Lines 292-300)*

She did however worry about the psychological consequences of referring a patient at an unsuitable time, and believed that currently there was a *'blanket approach'* (Line 365) associated with referral. It was proposed that careful consideration was needed with regards to where the patient was within the cycle of change, before making a referral:

*'we're not accurately targeting the right people with the right sort of, the right sort of intervention, some people are still at pre-contemplation stage, they still need more on the actual talking about what's going on, some people actually need some very practical skills stuff and some confidence building' (GP 3, F, 41-50, Lines 366-369)*

It was apparent the level of general PR knowledge, alongside local programme knowledge had the ability to influence HCPs' perceptions of the programme. The disparity between perceived patient suitability was also evident, with some aware of, and abiding to local programme criteria, and others making their own presumptions based upon individual patient characteristics.

### Uncertainty:

Although HCPs had varying levels of awareness of PR, all but one (PN 3), discussed an aspect of uncertainty (n=13). In general, PNs held greater levels of programme knowledge than GPs. As a result, PNs tried to remain positive with patients during the referral process, however acknowledged a dearth of clarity and information:

*'the patient's got questions as in "well where would I go, who would I be seeing, how long will it take", which again I'm not answering those questions for the patients, and it just gets, I don't like that, I like to be able to tell them the benefits, when they'll go, who they'll see, what's going to happen, you know how long they'll wait for an appointment, so it was just too long winded'. (PN 2, F, 41-50, Lines 364-368)*

The belief that the process is prolonged, and not being able to provide the patients with information prior to consent, due to being unsure of the programme details, accentuates the difficulty and pressure associated with programme uncertainty. Those, such as PN 1, who were knowledgeable and passionate about PR, discussed anxiety associated with conversations surrounding attendance. As previously discussed this PN had visited her

local programme, and although enthusiastic about PR, remained unsure over certain aspects due to a lack of knowledge regarding local programme content. She discussed her views in relation to a patient who she provided with the pseudonym *Joe Bloggs*:

*'this is Joe Bloggs ... [laughter], he was overweight, and taking very little exercise because of his breathing, not because of pains in his legs or anything, because of his breathing. So we had a little discussion about his weight ... and then I offered pulmonary rehab, and he said what's that [laughter]. So I, and this is where it gets stuck you see, because I said well it's a series of meetings at [name of health centre], and they help you with breathing exercises, and moving around, and this it gets very, very difficult because it comes across that the health professional really does not know what she's is talking about... and I am the only nurse who's actually gone to pulmonary rehab, to see what happens.'* (PN 1, F, 61+, 240-250)

HCPs felt as though they could not fully inform and reassure patients about the programme, which makes the referral process arduous, protracted and stressful. Conversely, some GPs had very limited knowledge surrounding the general concept and aims:

*'I think it would be useful to know exactly what the service involves, like how would it be beneficial, and we'd probably refer more patients in then, so having an idea of what the expected like objectives are for somebody going there'* (GP 2, F, 31-40, Lines 166-168)

A lack of understanding also surrounded the organisation and structure of the programme. It became apparent that many of the GPs would make assumptions in order to respond to interview questions surrounding PR:

*'So they have a sort of cohort of people, and I don't know how many they have on the course, something like 20 to 30 I guess, and they all start together and they work through it all together and then they all graduate at the same time if you like, and they'll start the next course off, I think that's how they do it.'* (GP 7, F, 51-60, Lines 139-142)

Another stated:

*'exactly what happens week by week or, and so on, I really would have only the vaguest idea'* (GP 1, M, 61+, Lines 113-114)

One GP openly admitted early in the interview: *'I don't really know much about it [PR]'* (GP 4, F, 31-40, Lines 103-104). She appeared anxious over her limited knowledge, however after settling into the interview discussed:

*'It would be nice to be able to properly advise patients of the benefits that they can get from it, because I mean where I work now patients are all quite middle class and they are quite up for that kind of thing, but I used to work in a fairly lower class area,*

*and it was quite difficult to convince patients, and I think perhaps if I knew more about it myself then I think, other than knowing it's good, then I think I'd be able to convince them better.'* (Lines 155-160)

It was interesting that she perceived a non-pharmaceutical approach such as PR would have a better reception in a middle class area, although acknowledged she had insufficient insight into the programme. This was consistent with another GP, who admitted: *'probably I am too ignorant to know about it [PR]'* (GP 3, F, 41-50, Line 345). She added:

*What I know about it is, I suppose that it's available ... the sort of principles, or as I understand them the principles of delivering it, and what patients tell me about it.* (Lines 95-97)

Often she compared the programme to pain management, as this appeared to be something she had more experience with. She was very open when revealing her lack of awareness:

*'My understanding was it is something like a ten or twelve session thing, but I'm probably completely wrong on that ... I've not been to see the service or whatever'* (Lines 160-163)

This GP appeared to lack concern over her limited knowledge; it did not seem a priority to source this information, and was coupled with a diminished interest of PR:

*'I'll hold my hand up and say I haven't read the ... literature on it, to know what the evidence is... You know the idea in principle sounds great and I'm sure there must be some work somewhere, that suggests that it could be helpful, otherwise we wouldn't have been having a roll out of these sort of types of services'* (Lines 221-225)

Uncertainty regarding local programme information, such as location and frequency of the PR sessions was apparent. Some disclosed *'I don't know quite where they actually do it'* (GP 7, F, 41-50, Line 182). A hesitancy was apparent in many HCPs responses which was indicative of an element of uncertainty in the programme content, duration and location of PR:

*'I think that our nearest one is [name of place], so I think that's once a week at [name of place]. I don't know ... I think it's either six or twelve weeks that they go, but I don't actually know that.'* (PN 5, F, 25-30, Lines 223-225)

*'they do eight sessions, I think it's eight they do locally, and they must be at certain times'* (GP 8, F, 51-60, Lines 444-445)

Some lacked clarity surrounding whether patients could be re-referred:

*'I think because they're doing it as rehab as well as sort of education, then if they do*

*have another severe exacerbation they can, I think they will accept them back on the course. I think they are probably allowed to do one a year, I don't know where I've got that idea from but that's in the back of my mind'* (GP 7, F, 41-50, Lines 376- 380)

This was similar to being unaware of what happens if patients miss a session due to ill health or other commitments:

*'if you miss a day, you then have, you can catch up, you can miss up to two I think and then you, then they kick you off, regrettably. I can't quite remember.* (PN 5, F, 25-30, Lines 557-559)

The connotations associated with *kicking a patient off* the course appeared quite strong, and seemed to be a personal perception that the PN held rather than factual. When prompted she did not recall a patient arriving at the programme, to one day find they were no longer allowed to participate due to missing a number of sessions.

Another prominent aspect was a paucity of knowledge and awareness of the COPD guidelines; some knew very little, other than PR is recommended:

*'I know there's some COPD guidelines and I know that they recommend pulmonary rehab but that's about as much as I know.'* (GP 7, F, 41-50, Lines 252-253)

*'I mean other than following the guidance that has come from the trust, where we follow our own guidance I've not seen anything else.'* (PN 6, F, 51-60, Lines 263-264)

Some were uncertain of the benefits achieved from attending PR. It was interesting that it was predominantly GPs who held this view. There was the perception that pulmonary rehab was an *'add on'* (GP 4, F, 31-40, Line 166), an adjunct therapy that could be tried, and in some instances did not appear to be promoted. On occasions confidence in PR was lacking, and therefore not considered overly important:

*'I would probably think that many of its benefits are non-specific, in that it gives, encourages people to just take exercise. If people ... were very determined to get out every day or even twice a day, and were pushing themselves to keep, to maximise their exercise tolerance ... I'm not sure that it's got specific benefits on top of that'* (GP 1, M, 61+, Lines 212-216)

Patient feedback seemed to contribute to GP uncertainty, with some recalling that patients *'haven't found it that useful'* (GP 3, F, 41-50, Lines 112-113) or *'it didn't tell them anything they didn't know'* (Line 118). This GP in particular appeared to blame the programme for the lack of patient benefit:

*'the feedback I'm getting from the people who try the pulmonary rehabilitation approach if you like, is that they don't, that they don't get that engagement, that understanding of why this matters from that setting enough, ... and maybe that's the group thing, maybe that needs to be done on a one on one level first, to help people understand and engage with why this matters. Otherwise they just think they're being sat in a room to go and be talked to, or given the exercises to do and they don't understand why they're doing it.'* (Lines 147-154).

Overall, it was evident that GPs had lower levels of awareness of the specific benefits associated with PR, than PNs. As a result, *uncertainty* appeared to affect the way HCPs viewed the programme.

### It's helpful:

Although some primary care HCPs voiced their reservations over the specific benefits achieved from attending PR, all (n=14) viewed that it would be helpful in some way. Some were incredibly passionate about the programme and had great levels of knowledge regarding the advantages of attendance. HCPs such as those discussed in the sub-ordinate theme: *Uncertainty*, were perceived to have a lack of programme knowledge, however, often on reflection, they assumed and speculated that a particular component of PR would be helpful. The instances of those who believed PR was helpful and those who made speculation, will be identified and distinguished throughout.

'*Far ranging benefits*' (GP 5, M, 41-50, Line 149) were discussed in association with PR, these encompassed physical, psychological and emotional benefits:

*'it can improve anxiety, when they've learned different techniques for breathing, I think it can improve just other general wellbeing, feeling that somebody's trying to do something with them, giving them a plan you know to follow. I think it helps during their daily lives anyway, but then when they do get sort of maybe the middle of the night, you know breathing difficulties, I think they've got something to fall back on instead of just panic and phoning 999.'* (PN 2, F, 41-50, Lines 216-221).

There was the belief that PR could provide as much '*relief as even the inhaler-based therapies*' (GP 6, F, 31-40, Lines 90-91). The programme was perceived as educational, and assists with encouraging patients to exercise:

*'I think it's giving them that confidence of actually exercise is good for them, so feeling breathless, pushing themselves a little bit is actually what they need to be doing'* (GP 8, F, 51-60, Lines 204-206)

Observing this newfound self-assurance made some PNs passionate about the advantages

achieved from attending:

*'I am a massive believer in referring for pulmonary rehab, because I've seen the benefits of patients coming back and saying they are more confident with their breathing.'* (PN 6, F, 41-50, Lines 167-169)

The benefits of having frequent support from professionals delivering PR was considered valuable. One PN related this to the cognitive processes involved with habit change, and attributed the weekly sessions to its success. She believed the impact PR could ultimately have on an individual's life was instrumental:

*'so if they're seen in pulmonary rehab over several weeks, each week they're getting reminded how important exercise is, you know if you look at habit change it takes several weeks ... and that's why I think pulmonary rehab works better because you've got that slow and steady drip feed of information.'* (PN 5, F, 25-30, Lines 317-322)

Another, believed that this life-style change and being able to self-manage was a real positive to the programme, however worried that GPs would disagree:

*'are there disadvantages, I haven't found any, the doctors might disagree because when the patients come out we've taught them to self-manage, so they then go and ask for steroids and antibiotics and the doctors get a little bit my God why are they all asking for these'* (PN 3, F, 51-60, Lines 190-193)

Many PNs discussed the psychological benefits gained from attending PR. In particular there was the perception that *'it is one of the only proven things to improve quality of life'* (PN 3, F, 51-60, Line 137), with the view that many patients enjoy the programme *'because it's got a really nice social aspect to it'* (PN 5, F, 25-30, Line 516). Even if patients did not benefit from the exercise component, it was still perceived helpful as they were able to meet others in the same situation as themselves:

*'usually it's very positive, you know as I say if they haven't got a physical improvement they have formed a friend, I mean the number of friends, they say oh yeah me and, we still see each other you know, and so friendships are definitely formed there'* (PN 3, F, 51-60, Lines 300-303).

Three PNs strongly associated PR with an increased quality of life. These perceptions were defined as a case of seeing is believing. The first had attended a PR session and observed the benefits directly, she spoke confidently about a patient diagnosed with COPD relatively young:

*'there was one chap with, he was only in his mid-fifties, very, very advanced COPD*

*and his exercise involved standing up from a chair ... but it's something that he was more proficient at, through going through rehab he'd struggled and he could do it, and then I thought yeah and you know, if this goes on long enough maybe he'd be able to do just that little bit more. So, I think its quality of life, pulmonary rehab.'* (PN 1, F, 61+, Lines 185-189)

The second spoke quite emotively about a patient with severe COPD, who she had referred to PR. Her enthusiasm for PR was undeniable, as she openly discussed the frequent changes to the programme in her area, which resulted in her being unaware of local programme details and how to refer. She discussed how she sought help from her secretary, and appeared proud that she had been part of improving the patients' quality of life:

*'we did it, and he did get seen and he did benefit, and I think they did work on him with breathing techniques to help deal with the anxiety... So I, he found it very, very useful, didn't really obviously make him, he has actually died since, he didn't live much longer maybe, but I think the process up to, leading up to his death, he'd got a coping strategy to help him* (PN 2, F, 41-50, Lines 343-350)

She was also shocked and amazed at the potential the programme could offer:

*'I had one man who started walking a lot more afterwards, you know hill walking'* (PN 2, F, 41-50, Line 429)

The third discussed how she has a '*living with COPD poster*' (PN 6, F, 41-50, Lines 169-170), in her room, and how patients recall the advantages of the exercises undertaken. She discussed how attendance at PR appeared to revitalise patients and provide them with a new lease of life:

*'it's got [the poster], you know, exercises that you can do to help, and it's only like the armchair exercises, but people who have attended the COPD course will say, aww I remember doing those, and they're so good and I still continue to do them and ... it's like they've just been given a, more confidence and they seem to have more energy'* (Lines 172 – 176)

The perceptions some held with regards to the benefit achieved, highlighted the thrill some patients gain from being involved with the programme. It was perceived that patients achieved different skills from attending however, regardless of this patients benefitted in some way:

*'you get two polar opposites, people either love it, like love it and really engage with it, and you get some patients who love it so much they help run the bleeding class, honestly you do, and then you get some patients that go, they find it useful, they take the skills and they leave to get on with their life, because they're kind of the people that are still working'* (PN 5, F, 25-30, Lines 511-515)



There were however a number of GPs who speculated the benefits of PR, this appeared to be due to diminished levels of programme knowledge. One GP tried to be optimistic, although lacked certainty:

*'I think it's likely to be [helpful], I would expect it to be helpful in terms of ... directly improving their exercise, performance, perhaps gives them better, it hopefully gives them more understanding of the condition as well, and also confidence to undertake exercise rather than hesitating.'* (GP 1, M, 61+, Lines 92-95)

Another was initially reluctant over the advantages of attendance, however proceeded to discuss the range of benefits that could be achieved:

*' yeah I do think it's beneficial because they've got more time, more one-to-one, specifically looking at their inhaler technique, their lifestyle, encouraging them to exercise, put weight on, so giving them dietary advice, that kind of thing.'* (GP 2, F, 31-40, Lines 116-119)

A GP who had stated that she was unaware of the specific benefits, declared she knew the programme was helpful, as she perceived patients *'feel more happy with their lives as a result of getting out and actually doing rehab'* (GP 4, F, 31-40, Lines 112-113). She was unable to elaborate on particular benefits due to a lack of knowledge however was aware, from medical school training, that PR was useful. Although, this information had not persuaded her to make a referral:

*'I know from med school that it's good [laughter]. I know that it does improve lung function and things, it's just yeah, I've not really thought to refer anyone to it yet'* (Lines 230-232)

Overall it was apparent that although some of the GPs interviewed perceived the programme as *helpful*, the majority of PNs were far more passionate and enthusiastic about the benefits. This is accentuated by their exuberance for PR:

*'I think it's excellent, and I think everyone should do it.'* (PN 5, F, 25-30, Line 586)

*'someone who's not coping with the diagnosis I feel they can get as much out of it as somebody who is extremely breathless due to, you know, their, their functionality being compromised.'* (PN 3, F, 51-60, Lines 265-267)

The view that most PNs held in relation to the effectiveness of PR can be summarised in the excerpt below, with attention paid to how the programme cares for the whole person, encompassing both the body and mind. The benefits regardless of where the patient was

placed within the disease trajectory were acknowledged, alongside including the patient in their own healthcare decisions:

*'I think pulmonary rehab sort of completes the picture, this holistic approach to people who are struggling with COPD, or not even necessarily struggling because we send the mild, moderate and severe to pulmonary rehab... It's the all in patient, you know ... I mean I could sit there and look at a spirometry result and say, right you've got COPD, I'm giving you these inhalers, and take them ... that's very prescriptive, isn't it.'* (PN 1, F, 61+ Lines 355-364)

It was evident that the HCPs in primary care appreciated the value of both the physical and psychological benefit that patients can gain from the programme.

### Perceived barriers to PR:

Many primary care HCPs (n=12), discussed their perceptions of patient barriers associated with attendance at PR. The response of one GP encapsulated the essence of this subordinate theme: *'there are a lot of patients who don't like the idea of attending'* (GP 5, M, 41-50, Lines 158-159).

Location was frequently mentioned, with many HCPs perceiving it difficult for patients to access due to issues surrounding transportation and reduced mobility. Accessibility to PR was considered a postcode lottery, with locality viewed as having a large bearing on patients' perception of the programme:

*'So you'd probably find that people who are living near the hospital think it's great, but people that lived over the other side of the river in [name of town] ... probably find it a bit more difficult to attend.'* (GP 7, F, 41-50, Lines 190-192)

There was also the view that COPD patients had become habitual in attending the GP surgery for an appointment, and were therefore uncomfortable visiting a different location:

*'I think some people don't like seeing somebody away from the GP practice'* (PN 2, F, 41-50, Lines 243-245)

Or found the location disruptive to day-to-day life:

*'the inconvenience of having to go to a different place for an appointment'* (GP 2, F, 31-40, Lines 124-125)

It was perceived that many of the patients became reliant on public transport, or on others to take them to PR. The costs associated with this appeared to discourage attendance:

*'it's things like travel costs of actually getting to the clinic. So, some people might be put off because they have to get a bus or a taxi' (GP 7, F, 41-50, Lines 167-168)*

*'the two practices I've worked in, in the last sort of 13, 14 years have been in fairly deprived areas, so there's just a physical barrier of the cost and time and effort' (GP 3, F, 31-40, Lines 248-250)*

Again, the association with COPD and deprivation was evident in some areas. It could be interpreted that this GP believed patients living in these areas would not prioritise, or strive to attend PR. Another GP held similar views regarding deprivation, and perceived that a lack of transport was another way of patients justifying their non-attendance. Whether this was a conscious or un-conscious process was unclear:

*'it's a, you know, quite a deprived area the practice is in so, some haven't got, we get all excuses you know haven't got transport, couldn't get there, didn't want to get there, there is a nearer hospital [name of hospital] but they don't do the pulmonary rehab.'* (GP 8, F, 51-60, Lines 131-134)

This GP attributed the prominence of this barrier to cuts in the transportation service:

*'obviously transport was readily available here, there are volunteer drivers but it's even hard to get those, but nowadays people don't get transport you know, with all the cut backs it's very limited. So they do have to make their own way there' (Lines 433-436)*

The difficulties associated with deprivation and transport were further highlighted. A PN perceived that travel to PR required too much effort for some patients, however was sympathetic with regards to the anxiety associated with asking an individual with COPD to use public transport to access the service:

*'locality is the hard thing, so a lot of patients, you know were in central [name of city], we live in a very poor area, we also have a very diverse population, so you've got things like one, someone physically being able to get there, transport issues. You know a lot of these people suffer with breathlessness, they're freaked out about being breathless, you're then telling them to get on a bus, or a, and they don't like that, or to walk somewhere, and they don't like that either so it, that is definitely an obstruction in my opinion.'* (PN 5, F, 25-30, Lines 328-334)

It was interesting to note this PN perceived there were patient barriers to PR, which none of the other HCPs mentioned. She discussed that due to the ethnic diversity in the area, many patients had difficulty accessing the service, as their first language was not English:

*'the language barrier, I know that they can provide interpreters, but you've got the*

*whole thing of even if you send a letter in English. I mean we have a very large Romanian community in this area, a very large Pakistani, Bangladeshi community in this area, and it's not so much that they wouldn't attend, it's they're so nervous about travelling to an area they don't know, a lot of them they move to one area say like [name of area] or [name of other area], or whatever, and they only know that area ... they don't understand what the next borough over is, they find that very scary, because they can't even read the street signs, they can't read the letter that comes through the post, unless they happen to have a family member' (PN 5, F, 25-30, Lines 337-345)*

She also added that another barrier to patients accessing PR is that it is run during working hours:

*'we're diagnosing people earlier, but people work later and later now, you know, I've got patients that are in their nineties that work, just because they don't like not working... it keeps them going as they say, but you know pulmonary rehab is in work hours so it, which doesn't suit a lot of people.'* (Lines 354-357)

This may coincide with the view that patients potentially do not understand the significance of attending, and therefore view it as unimportant:

*'There are a lot of people who can't see the point, don't, haven't bought into the idea, maybe don't think they like interacting with groups of people so there are, are people that don't particularly like groups, there are people that don't like being organised, they, you know they like to do their own thing ... there are people who perceive that they don't have the time, don't see it as a priority, have what they would think better things to do with their time.'* (GP 5, M, 41-50, Lines 168-173)

*'a couple of patients you know couldn't afford the time to go, maybe they'd not got full information'* (PN 2, F, 41-50, Lines 420-421)

A PN who had previously delivered PR, discussed how if patients were better informed prior to commencement of the programme, this would help to alleviate some of the apprehension and fear, and increase attendance:

*'you think about these people who have become isolated, they are going into a group, they don't know what to expect, they don't know what's going to happen, so they're anxious and then they start shallow breathing, and then they start dyspnoea... it's quite complicated if you think about it, whereas if they know what they're going into, at least they've got, you know, they're not so anxious. They'll still be anxious, but not quite so anxious.'* (PN 1, F, 61+, Lines 217-223)

This PN explored a prominent topic amongst many HCPs, which was the belief there were issues surrounding the group setting. There was the view that the programme involves *'group activity and some people find that difficult to cope with'* (PN 1, F, 61+ Lines 134-135). It was also perceived that many COPD patients struggled with mental health and anxiety, and therefore a group situation would be unappealing:

*'we do have a lot of mental health and anxiety, so again I think sometimes the group situation puts people off.'* (PN 3, F, 51-60, Lines 317-319)

Another PN surmised that the group setting may intensify anxiety, and discussed the psychological effects of attending with patients who may be much further along the disease trajectory:

*'potentially if they see people you know that are at a more advanced stage of COPD it might make them aware ... I mean I suppose that could make them more anxious'* (PN 4, F, 51-60, Lines 158-160)

Different personalities within the group was also highlighted, and viewed as problematic. It was perceived that chance determined the characteristics and severity of symptoms in the cohort. One PN believed that if patients persevered, they would overcome initial worries:

*'if they get with a miserable group it can bring them down [laughter]. So sometimes personalities in the group, if it isn't managed well, it can cause problems, we get the occasional groups where it's sort of eight people will be on oxygen and somebody's fairly new to it, and obviously they, they can sometimes be a little bit scared but as they stick with the course you tend to find that evens itself out.'* (PN 3, F, 51-60, Lines 181-186)

Patient non-attendance was frequently discussed as a barrier to PR. There were some HCPs who viewed patients lacked commitment and *'don't complete the full course'* (GP 2, F, 30-40, Line 30), therefore the programme was associated with a high drop-out rate. Conversely, there were others who believed that patients accept referral and then decide not to attend. Interestingly, both a GP and a PN believed that patients were hasty and did not give PR a chance. They discussed how patients felt they had no obligation to finish the programme:

*'there is a reasonably high dropout rate, so I suspect that the people that don't like that sort of thing vote with their feet and just don't go back'* (GP 5, M, 41-50 Lines 242-244)

*'I have had a couple of people and they tend to vote with their feet, they just don't finish the course. So, we'll just get something back to say patient did not complete the course, and next time we see them they just say it weren't for me'* (PN 3, F, 51-60, Lines 306-309)

Although this PN was unaware of the reasons for non-attendance, the notion of *voting with their feet*, highlighted that some patients evidence their dissatisfaction or dislike of PR via their actions. One GP believed that the high drop-out rate was because patients *'weren't getting any more out of going again'* (GP 3, F, 41-50, Line 309). She perceived patients

would attend whilst they were benefitting, therefore if they viewed there were no further advantages from attending, there would be no hesitation in not returning. Other explanations were provided by a PN who had spoken with patients with regards to their withdrawal from the programme. She attributed non-attendance to the psychological aspects associated with living with COPD. She discussed her disappointment with patients who decide not to attend:

*'generally they didn't go because [sigh] ... you know you throw in kind of a bit of mental health problems or kind of low self-belief, or low caring about themselves, you know whatever the cause might be and they sit there and say well I forgot, and you kind of think that's really irritating because I can't keep, I can't force you to go.'* (PN 5, F, 25-30, Lines 377-382)

A GP discussed how her lack of knowledge with the reasons for withdrawal was associated with patients refusing to talk about their experience and withholding information in an attempt to conceal non-attendance:

*'There may be others who went a couple of times [laughter] who dropped out and won't let on [laughter], don't want to talk about it because they didn't like it'* (GP 7, F, 41-50, Lines 389-391).

In addition to communicating the difficulties associated with maintaining attendance at PR, HCPs also highlighted that some patients do not attend at all. One GP, who admitted that it was the role of the nurse practitioner at the surgery to make referrals to PR, emphasised her annoyance at patients not attending after acceptance. The GP reported the nurse practitioner now sells the programme, providing patients with the full details; the effort associated with this was apparent:

*'she'll you know put [forward] all the advantages, why it's set up, where it is, what goes on, she'll try and explain it as best as she can, and then if she refers them and she gets say a letter saying they've not attended, she'll ring them up, because she's equally as frustrated, you know she's done a referral, she's done all she can ... and try and find out why they didn't attend, to try and get them to engage basically., I think more and more practices are well organised with having either nurses or nurse practitioners that do the checks and offer the referral but, it's then getting the patient to go'* (GP 8, F, 51-60, Lines 235-243)

She believed that COPD patients deceived HCPs, providing false-hope of attendance. This was exacerbated by the time associated with convincing a patient to attend and making the referral; resulting in wasted effort:

*'I think it's frustrating when you've gone to the bother of seeing them, someone's done a referral and then they just don't bother. So, they look interested, you know they walk, [laughter] they say oh yeah, yeah, yeah I'm gonna, yeah, yeah, I'll go and [laughter], and they don't.'* (GP 8, F, 51-60, Lines 296-300)

There were many perceived patient barriers HCPs attributed to PR. The flexibility of the service appeared to be considered a significant issue, with sessions at inconvenient times, and difficult to access locations. The group setting was also considered stressful for some, and other patients were perceived to never attend after accepting referral. HCPs did however acknowledge that it would be impossible for the service to please everyone.

#### 4.3.4 Pulmonary Rehabilitation Beliefs – Secondary Care:

It should be noted in secondary care some were unaware of PR prior to the interview. Therefore, after disclosing that they had never heard of the programme some surmised what it could be, and others were provided with a brief description of what the programme entails, with their answers based upon their perceptions of the definition given. Instances of where HCPs had previously not heard of PR will be highlighted throughout. The occurrence of each sub-ordinate theme and the corresponding number of references is captured in table 16.

**Table 16: Pulmonary Rehabilitation Beliefs – Secondary Care Sub-ordinate Themes**

<b>Pulmonary Rehabilitation Beliefs – Secondary Care</b>		
<b>Sub-ordinate Theme:</b>	<b>Number of participants:</b>	<b>Number of references:</b>
<b>Perceived patient suitability for PR</b>	10	21
<b>‘So what is it?’</b>	13	87
<b>Appreciation of potential benefits</b>	12	96
<b>Perceived barriers to PR</b>	10	21

#### Perceived patient suitability for PR:

There were a range of opinions regarding patient suitability and the characteristics required to attend PR; these views were discussed by 10 HCPs in secondary care. It was evident that there was a difference in opinion between the two professions. Doctors on general medical wards perceived that PR was for patients with ‘*quite severe COPD*’ (DR 6, M, 25-30, Hospital 2, Lines 76-77), whereas GNs believed the opposite, whereby it was better if ‘*you catch them [patients] early, to start them off with these exercises*’ (GN 4, F, 41-50, Hospital 2, Lines 206-207). This GN clearly believed that the core component of PR was exercise, however understood the benefits of a timely referral.

Doctors perceived that specific characteristics would enable patients to attend the programme, and these were all associated with a worsening in disease severity:

*'Limited exercise tolerance, difficulty in producing sputum or problems with thick secretions, deconditioning, so sort of muscle wastage and stuff like that.'* (DR 4, M, 25-30, Hospital 1, Lines 175-176)

This was similar to a doctor who regarded PR as appropriate for those *'patients who have been admitted [in hospital] for long periods of time'* (DR 2, F, 25-30, Hospital 1, Lines 88-89). Although this was based upon assumption, PR was considered as a means of facilitating discharge from hospital for those with a severe exacerbation of their COPD, to enable them to get back on their feet.

Another doctor discussed patient suitability at length and perceived that PR was an add on, *'another option'* (DR 1, F, 25-30, Hospital 1, Line 96), and therefore did not consider the programme a priority, although believed it was worth a try as a last resort:

*'I guess that the people who you should consider are those who are getting ... worsening breathlessness, their inhalers aren't really working, you've kind of tried everything'* (Lines 177-180)

She openly admitted her uncertainty of patient eligibility, and viewed a significant issue with COPD patients is that they continue to smoke. She therefore suggested it may be appropriate to refer patients to PR to assist them in quitting:

*'I think also if they're still smoking, I think that is an appropriate referral because we can try and capture the smoking cessation within the pulmonary rehab as well'* (Lines 180-182)

Others discussed suitability in terms of the patient's age. There appeared to be the view that once patients had reached a particular point in their life, they would no longer benefit from attending:

*'middle age, youngish kind of patient I think would benefit from it more rather than elderly, they might not get much out of it'* (DR 3, F, 31-40, Hospital 1, Lines 175-176)

This doctor also associated COPD with low socio-economic status, and added that these patients would be suitable for PR, as they are lacking the education, knowledge and guidance that the programme can provide:

*'patients with a poor socio-economic status come in from areas that they lack this education, they'd benefit from that [PR]'* (Lines 179-180)



Overall, it was evident that the HCPs who discussed perceived patient eligibility for PR held various beliefs surrounding patient suitability for the programme. They appeared to use subjective judgement based upon their *COPD Illness Perceptions* to surmise which patients they considered would be most suitable.

'So what is it?':

In secondary care all HCPs (n=13) lacked knowledge of PR to varying degrees. It was however surprising that many '*didn't really know it was a service*' (DR 2, F, 25-30, Hospital 1, Line 172) or '*what it involves.*' (GN 3, F, 20-30, Hospital 1, Line 76). A prominent feature of several interviews was '*it's the first time I've heard about it [PR]*' (DR 3, F, 31-40, Hospital 1, Line 123); although not intentional, participation in the study raised awareness of the programme for many:

*'it's just not something that I was really aware of before, but ... I think that would be a very useful thing'* (DR 5, M, 25-30, Hospital 2, Lines 133-135)

This doctor believed that a scarcity of programme awareness was not an isolated issue, and felt that PR was not common knowledge within secondary care:

*'from my point of view I think some of my colleagues would have not heard of it either, I don't think there's much knowledge from our point of view'* (Lines 213-215)

This perception was reiterated by a GN who was enthused by the concept of PR:

*'I'm not aware of this, this is brilliant, I didn't know that we did this, or we could do it.'* (GN 6, F, 41-50, Hospital 2, Lines 99-100)

She was disappointed that at this stage in her career she was unaware that she could refer to the programme. This newfound knowledge appeared to initiate change, as she remarked she would contact the respiratory team to discuss referral of patients on the frailty ward.

Another GN who previously appeared unconcerned about her total lack of knowledge with regards to PR, asked towards the end of her interview '*so what is it?*' (GN 2, F, 41-50, Hospital 1, Line 166). After stating she did not know much about the programme, she appeared unperturbed when asked if she was aware of what patients experience when they attend PR, responding firmly with *No*. Her lack of awareness appeared to emphasise her disinterest in PR, however she was shocked when provided with a detailed explanation at the close of the interview:

*'So is it something that is readily available then, we've got the North West [name of department], haven't we, quite a big respiratory. So, is it something that is readily available here?' (Lines, 199-201)*

It was apparent HCPs in secondary care were 'not averse' (DR 2, F, 25-30, Hospital 1, Line 256) to PR, they required additional knowledge. There was a lack of clarity as to where the programme was delivered:

*'if I knew more about the programme that was run from here or from within their primary, wherever their primary, however it's done then yeah sure that is something that I'd definitely consider.'* (DR 1, F, 25-30, Hospital 1, Lines 141-143)

Likewise the GN, who had previously worked as a community matron for 10 years in primary care, discussed how within primary care she saw respiratory patients on a daily basis, and used to refer regularly to PR:

*'I'd go in and if somebody had an exacerbation, or if I had a new patient on my caseload who had COPD, if somebody had severe COPD but was mobile and didn't have any other co-morbidities that would restrict them from going out or being able to go to pulmonary rehab, for all the patients I probably would have referred them all'* (GN 7, F, 41-50, Hospital 2, Lines 204-208)

She had however never referred a patient whilst working in secondary care and attributed this to a lack of local programme knowledge:

*'I mean things obviously change and because I'm in secondary care, it's much more difficult I think, to have a knowledge of where the neighbourhood centres are, that this is taking place'* (Lines 166-168)

Towards the end of the interview she appeared to reflect on her responses and seemed embarrassed over her current lack of awareness:

*'I mean I've just said I don't know where they take place and you know time and motion, but potentially that needs to improve'* (Lines 253-254)

It also appeared that the word *rehabilitation* caused confusion amongst some, as they believed that *it* enabled patients to return to a state of health held prior to a diagnosis or accident:

*'Is that the rehab of the patients with the COPD and that? Erm, not really because we don't have, we don't really have anyone on that, the rehab ward, I have worked in rehab ward, that was for hips.'* (GN 5, M, 51-60, Hospital 2, Lines 84-86)

Others associated the word *rehabilitation* as a bridge between hospital and independent living. This uncertainty was apparent when a GN asked 'are you talking about when they're going home?' (GN 4, F, 41-50, Hospital 2, Line 62). There was also speculation as to what PR may entail; the concept of *rehabilitation* was associated with physiotherapists, and was considered as something carried out for the patient: 'is it something like a chest physio, or not related?' (DR 3, F, 31-40, Hospital 1, Line 69).

It was interesting that some chose to discuss cardiac rehab when asked about their knowledge of PR. A GN exclaimed:

*'I've worked in acute medicine for 20 years, and I've never heard pulmonary rehab, I've heard cardiac rehab but I've not heard pulmonary rehab.'* (GN 2 , F, 41-50, Hospital 1, Lines 155-157)

Similarly, a doctor attempted to transfer her understanding of cardiac rehab to PR, as she assumed they could be comparable:

*'I know a bit about the cardiac rehabilitation, so I'm assuming it's a similar situation, whereby patients that have been admitted for long periods of time, or you know, people think they would benefit from some kind of, I don't know if they do exercise tolerance type things, but help build up strength and sort of endurance maybe'* (DR 2, F, 25-30, Hospital 1, Lines 87-91)

HCPs had considerably greater levels of knowledge with regards to a cardiac rehabilitation approach than PR. The two hospital trusts where HCPs were recruited had well-established PR services, however it was interesting that one GN tried to justify her lack of knowledge by stating that the service was not used in her area, and therefore she did not need to know about it:

*'it's not something I've thought of because it's not something we use here, I suppose, but if it did come up I think it would benefit some of the patients'* (GN 4, F 41-50, Hospital 2, Lines 259-260)

Others lacked knowledge of the benefits and potential outcomes of the programme. In particular a GN emailed prior to the interview to ask if there was anything about PR she would need to revise; her lack of understanding was reinforced:

*'if I was right in thinking what it could be, then clearly there must be, there must be some benefit'* (GN 1, F, 51-60, Hospital 2, Lines 189-190)

This was reiterated by a doctor who was unaware of the evidence base, and therefore unclear on the programme outcomes:

*'I'm assuming it's worthwhile, just because I think you know there must be some evidence that shows that it works otherwise we wouldn't be investing in it'* (DR 2, F, 25-30, Hospital 1, Lines 257-259)

A lack of awareness of the COPD guidelines was exhibited:

*'it doesn't surprise me that there are guidelines, I don't know what the guidelines are.'* (DR 4, M, 25-30, Hospital 1, Lines 145-146)

*'I could probably google that [PR evidence base] as well, yeah. Because I'm not aware of the programme, I've probably never really looked into it.'* (GN 6, F, 41-50, Hospital 2, Lines 132-133)

*'Well everything has to be evidence based hasn't it, so I assume it is, yeah [laughter].'* (GN 5, M, 51-60, Hospital 2, Line 172)

Although a doctor was aware of PR due to spending time in respiratory clinics and hearing consultants discuss the programme, he remained unaware of the COPD guidelines and the evidence base: *'no I don't know about those.'* (DR 6, M, 25-30, Hospital 2, Line 151)

Overall, it was evident that HCPs in secondary care were uncertain of what PR entails, where it is delivered, and the COPD guidelines, which ultimately impacted upon their perceptions.

#### Appreciation of the potential benefits:

Although many HCPs in secondary care lacked knowledge of PR, all but one (n=12) discussed how they could appreciate the potential benefits of the programme. PR was perceived as multidisciplinary with advice provided by physios and specialist nurses. The non-medicalised approach was considered to improve lung capacity, and ultimately enhance patients *'well-being and way of life'* (DR 1, F, 25-30, Hospital 1, Line 57). This doctor adhered to the notion of seeing is believing:

*'from speaking to patients who, when I worked on respiratory here who have attended pulmonary rehab they all seemed quite engaged with it'* (Lines 82-83)

The educational aspect was also considered important in the management of symptoms, and it was believed this provided patients with a pragmatic, representational view of disease progression. This realistic overview was considered beneficial for patient's long-term understanding:

*'it can educate them, so they can try and pre-empt and reduce exacerbations, and try and find ways in which they can manage their condition a lot better, and obviously know what to expect as well. So puts it quite realistic really for them.'* (GN 7, F, 41-50, Hospital 2, Lines 127-130)

Others considered it would be *'valuable for the right patients'* (DR 4, M, 25-30, Hospital 1, Line 221), with the advantages of the exercise component discussed:

*'they do exercises with physios involving breathing exercises, and physical exercises to improve their exercise tolerance and independence'* (DR 6, M, 25-30, Hospital 2, Lines 77-78)

There was also a focus upon the perceived psychological benefit achieved from attending, equipping patients with strategies to '*cope with symptoms*' (DR 6, M, 25-30, Hospital 2, Line 96), and other far reaching benefits for one's life:

*'I mean in terms of patients' survival, but also you know from a psychological point of view, patients who used to be chair bound who can gain mobility and things like that'* (DR 4, M, 25-30, Hospital 1, Lines 87-89)

*'in my mind pulmonary rehab is probably about them, the psychological, being able to cope with the anxieties that like, or to keep them at home'* (GN 1, F, 51-60, Hospital 2, Lines 134-135)

One GN who had gained awareness that she could refer to PR via participating in the interview, discussed the psychological aspects of being diagnosed with COPD, and the value that a group social setting could provide:

*'I think camaraderie and community, because I think that they're quite isolated, especially when they're on oxygen, I think it would, I think it's brilliant'* (GN 6, F, 41-50, Hospital 2, Lines 85-87)

Others who lacked prior knowledge, also discussed what they believed could be achieved from attending:

*'I don't know what it exactly is but it certainly sounds like they might benefit, and reduce the amount of their exacerbations.'* (DR 3, F, 31-40, Hospital 1, Lines 84-86)

DR 3 discussed how she frequently sees COPD patients who lack knowledge surrounding their condition and how best to manage it, and that PR may be able to assist with that:

*'I think there might be benefits because most of them they actually, they come quite late, they don't know when they are supposed to come to hospital, how often they should use their nebuliser, they don't know the signs that they're being hypoxic, when they need oxygen or not, because most of them they are on oxygen as well at home, they don't know how to titrate their bronchodilator. I think they will benefit'* (Lines 103-108)

She believed that although the programme was not able to cure them, it would provide patients with the knowledge to oversee and monitor their condition:

*'it's not going to reverse their condition obviously, but at least we'd get them stable and well controlled. They'd know what to do, and when to seek help as well'* (Lines 213-215)

This notion of patients regaining control was discussed by other HCPs: '*it gives people the chance to take responsibility for their own illnesses*' (DR 1, F, 25-30, Hospital 1, Lines 78-

79). The importance of being able to govern their condition was reiterated by a GN. She believed the programme had the capability to empower patients, when previously they felt they had lost control:

*'it's a positive step for someone to go to pulmonary rehabilitation. I think that a lot of the patients can feel very alone, very uncertain, and for the likes of anxiety management and those sorts of things, and having a different perspective from different healthcare professionals and not just one. I think it's really good because people can see if they can manage their condition as opposed to their condition owning them really.'* (GN 7, F, 41-50, Hospital 2, Lines 281-286)

Some perceived that PR could be life changing, providing patients with a sense of security and a useful step after hospital admission. It was considered that COPD patients viewed hospital as a revolving door, and believed that admission enabled them to return to baseline. After returning home however, they have an uncertain wait as to how long it will be until they are next unwell and require hospital treatment. PR was described as something which may break this cycle, and was considered a comfort and potential refuge for patients:

*'It sounds as well, a bit like a safety net for the patient isn't it... they're not just going home, and that's the end of it until the next time they're unwell, they've got something for a few weeks to go to, for support and advice, and as I say symptom control isn't it, it's a bit of everything really.'* (GN 4, F, 41-50, Hospital 2, Lines 269-273)

Overall, it was deemed the programme would be highly beneficial if it was able to *prevent* re-admittance to hospital.

#### Perceived barriers to PR:

Accessibility issues appeared to be the dominant feature of perceived patient barriers; 'as long as it's accessible I can't see any issues' (DR 5, M, 25-30, Hospital 2, Line 169). HCPs discussed potential difficulties associated with reaching the service. Some were aware that PR was delivered in locations away from the hospital and GP surgery, therefore the primary issue was associated with the availability of transportation:

*'obviously transport's always an issue, these people tend to be older ... I don't know what the requirements are but they may or may not require oxygen which might have, you might need an ambulance to take the patient. I guess there's lots and lots of kind of logistical issues.'* (DR 1, F, 25-30, Hospital 1, Lines 109-113)

Patients therefore become reliant on the availability of family and friends being able to drive them to PR:

*'sometimes there were people that would have problems sort of accessing services and having somebody to be able to take them' (GN 7, F, 41-50, Hospital 2, Lines 214-216)*

Others stressed the need for convenience, however acknowledged it would be impossible for the service to accommodate the needs of everyone:

*'so it has to be at a suitable time ... you can't have it all day, every day for people to pick and choose the sessions, so that will be difficult for people' (DR 1, F, 25-30, Hospital 1, Lines 106-109)*

Similarly, the expert patients acted as a barrier to the service. This type of patient was considered as someone who had had their condition for some time and had adopted their own strategies in its management. This was however perceived problematic in respect of them attending PR:

*'sometimes if the patients have a little bit of knowledge sometimes they get stuck in their ways and think that they know everything about a condition, and then sometimes they're not open minded towards health professionals' suggestions and things' (GN 7, F, 41-50, Hospital 2, Lines 136-139)*

This GN discussed patient barriers at length, and commented that during her time in primary care some patients were *'too ill to be able to attend'* (Line 142). She also highlighted psychological barriers to attendance, and the reality of seeing someone worse than themselves, further along the disease trajectory, may result in the realisation of things to come:

*'if you see somebody further along the disease process than you are, then obviously I suppose that could be quite upsetting, because you think you know I could end up like that really.'* (Lines 139-141)

Some considered patients would rather have medication, due to it being perceived as an easier option than exercise:

*'Well I know that it's effective and I know that it depends on the patient, obviously you don't generalise to everybody, but people in general, in anything, would rather you gave them a pill to take than offer them an exercise class.'* (DR 4, M, 25-30, Hospital 1, Lines 257-259)

There was also the belief that on occasions patients *'just sometimes don't want to go'* (GN 7, F, 41-50, Hospital 2, Lines 217-218), and this was often due to PR being perceived as *'too difficult for them'* (GN 7, F, 41-50, Hospital 2, Line 245). HCPs' perceptions sometimes also acted as a barrier to PR. This was evidenced by a GN who held negative perceptions

of the programme, after gaining second-hand knowledge prior to the interview from another GN working on the ward. It appeared she had spoken to someone she considered knowledgeable about the programme, to enable her to answer questions with greater confidence during the interview. As a result, she believed PR increases hospital admissions as it causes patients to have an exacerbation:

*'one of our other ANP's [Advanced Nurse Practitioners] here used to be in community respiratory team ... she was talking about something the other day, made it [PR] sound like it was actually more about the physicality of you know breathing exercises and exercise to improve your lung function, it's what it sounded like. So she wasn't going into any detail, she was just talking about how every time people went into pulmonary rehab, they would exacerbate and end up coming into hospital... So that was then my perception of it.'* (GN 1, F, 51-60, Hospital 2, Lines 136-146)

Others did not specifically hold negative views of the programme content, however held unfavourable views concerning patient access to the programme. This was attributed to the inverse care law, with those needing the programme most not having the opportunity:

*'with the inverse care law, patients who are probably most in need of it may struggle to attend appointments, probably access to courses themselves, I assume in general probably a bit tight'* (DR 4, M, 25-30, Hospital 1, Lines 99-101)

Overall, there were a number of potential barriers that HCPs attributed to PR, however as none of the HCPs in secondary care referred to the programme, these were only potential aspects which they considered would be problematic.

#### **4.3.5 Organisational and Referral Pathway Perceptions – Primary Care:**

The super-ordinate theme *organisational and referral pathway perceptions* was frequently discussed by HCPs in relation to their perceptions of PR. It was formed from the sub-ordinate themes: *Defers responsibility*, *Lack of information from the service*, *Difficult Referral*, and *Facilitators to referral*. Each had a significant number of associated references, evidencing the high prevalence; please see table 17 for further information.

**Table 17: Organisational and Referral Pathway Perceptions – Primary Care Sub-ordinate Themes**

<b>Organisational and Referral Pathway Perceptions – Primary Care</b>		
<b>Sub-ordinate Theme:</b>	<b>Number of participants:</b>	<b>Number of references:</b>
<b>Defers responsibility</b>	12	45
<b>Lack of information from the service</b>	11	43
<b>Difficult referral</b>	12	43
<b>Facilitators to referral</b>	9	31



### Defers Responsibility:

Many HCPs in primary care (n=12), deferred responsibility of referral to PR. This appeared to be closely associated with not considering referral to the programme as a priority.

Interestingly all GPs (n=8) felt it was not their responsibility to refer patients to PR, and viewed referral as most likely to be initiated by a PN:

*'the practice nurses will certainly be one of the people asking [about PR], it may be then you know that a GP signs the form but it'll be the nurse who's initiating it'. (GP 3, F, 41-50, Lines 187-189)*

It was apparent this GP, who admitted knowing *'very little'* (Line 95) about PR, deferred discussion of the programme to the PN and suggested they should be the ones instigating the referral. This could be considered as hierarchical, with the GP ultimately approving the referral, however it could also be due to inexperience and viewing it as someone else's role:

*'I can't remember actually doing the referral... but it's partly because other people do it rather than me'. (Lines 170-172)*

Many of the GPs appeared happy to discuss PR with patients, however they were reluctant to refer patients to PR themselves:

*'I might mention it to the patient, but then I'd go and tell the practice nurse that if she is seeing the patient, I would have thought it was a good idea for that patient to be referred.' (GP 1, M, 61+, Lines 150-153)*

GPs often appeared to *pass the buck* to PNs:

*'[referral should be] generated by the practice nurses at the time they do their actual respiratory review' (GP 6, F, 51-60, Line 136-137)*

*'we try to get it all in the annual COPD check or ... when they've been to see the nurse practitioner' (GP 8, F, 51-60, Lines 191-192)*

GP 8 admitted she previously made referrals however now feels *'deskilled'* (Line 77) as she only sees patients who have an exacerbation. Her deferral of responsibility was justified by reaffirming:

*'She's [nurse practitioner] basically as good as a GP, she just doesn't do home visits, but she's got a lot more knowledge and confidence to manage this, so she can admit to hospital and all sorts of things. (Lines 102-104)*

Another stated:

*'if somebody was starting to sort of express interest then I'd probably go see my*

*colleagues in the practice. Either the respiratory lead or the nurses, and actually get them to help give the actual information to the patient.'* (GP 3, F, 41-50, Lines 263-266)

It was interesting that she believed she needed knowledge of where to access information, however did not want to be liable:

*'I think it's knowing where I can go to get that information but not being responsible for, for doing it myself'* (Lines 280-281)

Other GPs *'kind of assumed that they've [patients] already been referred'* (GP 4, F, 31-40, Line 178), and perceived it was the role of secondary care:

*'We don't tend to refer directly to it, I know we can, but usually the respiratory team at the hospital refer to it.'* (GP 4, F, 31-40, Lines 93-94)

Another held similar views perceiving that referral should be *'automatic'* (GP 5, M, 41-50, Line 275), after a hospital admission with an exacerbation of COPD. There was the belief that secondary care would have greater success in convincing patients to attend:

*'whilst you've got the captive audience of the person with the exacerbation who's been hospitalised, I think it would be a good time to, you know for the physios to introduce themselves and to get a relationship with the patient in there.... You know there are key points when it's easier to sell the, the service to a patient, so I think that would be a key one.'* (GP 5, M, 41-50, Lines 279-283)

Upon reflection towards the end of the interview one GP came to the realisation:

*'I bet quite a few of the secondary care think that we're doing it all'* (GP 8, F, 51-60, Line 542)

PNs tended to take greater responsibility for making referrals and discussing PR with patients. Although, one PN referred *'just everyone'* (PN 5, F, 25-30, Line 241), she too felt deskilled and lacked confidence on patient eligibility. Therefore she transferred the responsibility of which patients meet the criteria to the service:

*'I'm not a respiratory specialist nurse ... I'll happily assess them, I'll work them up, I'll do as much as I can, but in my opinion I want backup from a specialist'* (Lines 241-244)

Due to working in primary care she did not consider she was required to have an in-depth knowledge of the programme. It appeared she did not want to be accountable for incorrectly referring patients, and believed that as a PN as long as the guidance is followed, you are fulfilling your role:

*'in primary care because you're not a specialist, you tend to focus more on right what's the overall COPD guidance, what's the x, y and z and it'll say ensure pulmonary rehab referrals are done, but it doesn't then describe the back bits behind that, but to a certain extent as a primary care nurse you don't need to know that. All I need to know is that it's recommended by national guidance, that it's got a positive, and how to refer'* (Lines 432-438)

Another, was unaware of the specific details of the local programme, however believed the service should be responsible for providing this information to patients, rather than herself:

*'I'm not aware at the moment what time it's on, and what day it's on because sort of, we would just refer the patient, and then you know, we'd always tell the patient that they'll get, the COPD, pulmonary rehab team will get in touch with them, so we tend not to get involved with when it is, and you know where it is.'* (PN 4, F 51-60, lines 338-342)

These perceptions were often as a result of feeling overloaded, and as PR was often considered an optional additional management strategy, some believed they did not have *'any capacity to take on anything extra'* (GP 3, F, 41-50, Line 282). This lack of priority was consistent with the view of a GP who expressed he had an interest in respiratory disease, however stated:

*'I hopefully remember to do the referral, or have the discussion with them at least.'* (GP 5, M, 41-50, Lines 211-112)

PNs who were predominantly positive and passionate about the programme discussed how, although referral to PR is important, there is too much pressure to discuss it in an annual review:

*'when we are doing an annual review we've got thirty minutes to cover everything, so to actually go into it in depth, is pretty much an impossibility'* (PN 1, F, 61+, Lines 337-338)

This resulted in one PN making quite a significant decision:

*'due to time constraints and being busy I just thought, oh I'll wait and we'll review you next year and see how you've got on, but really I felt that the intervention would have been better early, but again because there's no set you know, you think, oh I'll bluff over that one for now.'* (PN 2, F, 41-50, Lines 351-354)

Although the majority of PNs understood the importance of attendance at PR, it appeared they ensured all standard checks were conducted first during an annual review. As a result, referral was often not at the top of their list of priorities. Many PNs found annual reviews arduous due to demands on time which sometimes resulted in PR being overlooked.

### Lack of Information from the Service:

It was undeniable that many HCPs believed there was a scarcity of information provided by the service. There were a number of ways in which they viewed information was lacking, however the general consensus was perfectly summarised by one PN: *'it may help if we just had a little bit more information'* (PN 4, F, 51-60, Line 327). It was considered that PR may not be advertised due to an inadequate number of places on the programme:

*'It's just a case of I know it's there, so I know how to refer on to it, but again it's probably not well advertised because they're absolutely saturated'* (PN 6, F, 41-50, Lines 213-214)

Many felt ill equipped when referring patients to the service. They were unaware of specific local programme details including *'how long sessions are, what they [patients] would be expected to do'* (GP 6, F, 51-60, Lines 126-127), along with *'timings and duration of sessions, and where they would be held'* (GP 6, F, 51-60, Line 130). It was perceived that as the service had not provided this information, it could therefore not be passed on to patients.

One PN as previously discussed, sought to increase her knowledge of the programme content, as other than being aware that PR existed had no further information. She felt disappointed in the service, and even after attending was still unaware of the course structure:

*'we knew that the service was set up. We didn't know what actually happened, which is why I actually went along [laughter]. So there's no real details about the course itself and how patients were brought through the course, because its 12 weeks, and we never got this is week one, week two, week three, the content ... we were referring people blind if you like.'* (PN 1, F, 61+ Lines 159-163)

It was considered that this lack of communication from the service was specific to PR, as there was an awareness of the process for other chronic conditions and cancer. There appeared to be a diminished level of information received, and this was attributed to the changeability of the service:

*'if we refer to say DESMOND [Diabetes Education and Self Management for Ongoing and Newly Diagnosed], for diabetes we'd know what that programme is. We get a lot of information, we know what that patients going to benefit, and what they're going to do for the full day and things, we don't with pulmonary rehab, because it changes. We've not even got like say a named person that runs a programme, or anything ... like acute COPD services at the hospital, I know that I can pick up the phone and speak to one of them, you know just to make sure that I am referring right, have we got the criteria correct, we've not for pulmonary rehab'* (PN 2, F, 41-50, Lines 305-312)

The lack of information received resulted in diminished confidence when referring to PR. There was the perception that the PR services were not willing to provide waiting times to those working in primary care, to detract from the possibility of not meeting their targets:

*'So if I've done a referral, I mean they don't actually commit and say how long the patients are waiting for but it is months and months'* (PN 6, F, 41-50, Lines 130-131)

HCPs felt unsupported by the PR services in their role as the referrer. Many discussed how a leaflet would assist them in the referral process, however this had not been provided:

*'we genuinely don't actually have any leaflets or information provided by the local service to give to them.'* (GP 6, F, 51-60, Lines 185-186)

*'I suppose we don't really have like a little leaflet, but I don't know if that's just our ignorance here at this surgery, but ... I'm sure the COPD team must have some kind of leaflet that they probably provide... I suppose they'd argue it's then then our responsibility to phone up for leaflets every so often. So I don't know if that's my ignorance.'* (PN 5, F, 25-30, Lines 387-393)

This was associated with the belief that information needs to be improved on the service's website. A GP wanted a positive message of PR to be communicated online, which highlights the inclusivity of the programme: *'be nice to maybe have a range of ages on the website'* (GP 8, F, 51-60, Line, 393).

There was an agreement that better communication was required between the service and those referring in primary care. Many appeared particularly frustrated and disappointed over the lack of feedback provided by the service. They believed that they put tremendous effort into making a referral, however the PR team did not take the time to inform them of patient progress:

*'it seems like a one way road of information, that we send loads of information about medication, spirometry, history, all this sort of stuff, and we either get patient attended pulmonary rehab, or patient failed to attend, and that's the feedback we get.'* (PN 1, F, 61+, Lines 290-293)

Due to a lack of feedback, HCPs could not observe the benefits and were therefore unaware of patient progress:

*'it would be nice if on the feedback form they could write you know they have attended and they can walk this distance comfortably ... whether they've improved'* (GP 8, F, 51-60, Lines 471-472).

Within primary care there was a perceived lack of information provided on PR from the service, and this left HCPs feeling unsupported in the referral process, and unaware of how effective the programme had been for their patients. Some HCPs who discussed this lack

of information appeared frustrated at this lack of communication from the service.

### Difficult Referral:

A difficult referral was a commonly recurring topic in primary care (n=12 HCPs). Uncertainty of the most appropriate time to refer was a prevalent issue:

*'It might be useful to have more of an idea of you know, if people have needed two courses of steroids say, is that a good time to send them over to pulmonary rehab. So some sort of clearer referral criteria into the clinic might be useful.'* (GP 7, F, 41-50, Lines 221-224)

*'At what stage, where would you be putting pulmonary rehab, at the diagnosis, or is it when you've tried a couple of inhalers and it's not working'* (GP 2, F, 31-40, Lines 285-287)

This lack of clarity of where the programme should be placed and the most appropriate time to refer, highlights the confusion this GP would face if she was to consider making a referral to the service. Others believed that being provided with a specific point where patients should enter the programme would make the process simpler:

*'if it was introduced more or less like as a next step of management, so once you change maybe from mild to moderate COPD, it should be an automatic right now you see a physio, you know a pulmonary rehab physio, who'd then, could look at your breathing and then get that very early input.'* (PN 2, F, 41-50, Lines 208-211)

Another issue adding to the difficulty of referring patients was the uncertainty of how to access PR. One GP, who apart from being unaware of the referral criteria, believed that PNs were unable to refer. This evidenced a complete lack of knowledge of the referral procedure:

*'I know patients who've used it but I don't know how they have accessed it'* (GP 4, F, 31-40, Lines 100-101)

This was similar to a GP who admitted:

*'they do take referrals, I think we can refer in as GPs, I'm pretty sure we can, but I've not actually myself done that'* (GP 7, F, 41-50, Lines 104-105)

The name pulmonary rehabilitation also appeared to cause some confusion surrounding patients' eligibility:

*'They call it pulmonary rehab, so I would think they'd accept anyone who had a respiratory issue, but again I'm not quite clear on the criteria and when they want to see people'* (GP 7, F, 41-50, Lines 438-440)

This view of uncertainty was coupled with the perception that PR is a complicated 'sell', with the issue of being able to '*encourage people to accept that intervention*' (GP 6, F, 51-60, Line 157). Many found it difficult to initiate conversations surrounding PR, as they perceived that '*a lot of them are not interested to start with*' (GP 5, M, 41-50, Line 205). This GP was honest and stated that he did not attempt to persuade those who had previously tried PR to try it again:

*'do I ever question them, well I suppose the next year when they come and see me for their annual check ... I say do you want to go, they will just answer no and I suppose I don't question that too much, if they have been before ... I think it would be a very difficult sell if somebody's already made up their mind that it's not for them'* (Lines 244-249)

Others believed that ease of the sell was dependent on the demographics of the group:

*'I've come from a well-informed group of older people. I've come to a much younger group, I mean the number of people in their forties and fifties that we're diagnosing, got quite a high cannabis use area as well, and basically just to get them to understand that something that isn't a medicine is going to help them, is a much more difficult concept to get across to this group ... I suppose it's my fault, and that's very sad that they have a completely different view, of what they deserve, really.'* (PN 3, F 51-60, Lines 120-125)

This PN held herself responsible and felt guilty for not being able to convince this *younger group*. Her passion for the programme was evident, however she perceived that for other HCPs to be able to sell PR, they first needed to understand and believe in the concept themselves:

*'I think you can probably hear that I advocate it whole heartedly. I think health professionals not just paying it lip service but being very positive about it. I think sometimes we can say "do you want to do this course", and it's like you know you've got to sell it, you've got to be enthusiastic, you've got to know that there are positive outcomes to it. There's no point saying "do you want to go on a course" if you can't actually think in your own head how is that going to benefit my patient. So I recommend that everybody that does respiratory as part of their COPD diploma, goes and spends a day at rehab, so they understand it. And then you understand it and can see the positivity coming from it, rather than ticking a box to move on your computer'* (Lines 348-357)

It was evident that many PNs tried to convince patients to attend, although this was not always a straightforward process; it was considered that the phrase '*light exercise*' (PN 1, F, 61+, Line 149) evoked fear. Although it was not always possible to persuade patients to attend during an appointment, a PN mentioned an empathetic yet honest strategy she adopted:

*'I always say to them we'll discuss it now, and that's absolutely fine but what I want you to consider, is that if at any time you change your mind, all you need to do is*

*phone me and I will complete a form. I said, I've got all the information in front of me, you don't need to sign anything ... I also then have to say it could be six months down the line before you actually get to see somebody from pulmonary rehab'* (PN 6, F, 41-50, Lines 332-337)

Others believed the referral process was arduous and convoluted, however this depended on location, as some were also very positive. There was a '*plea for simplification and stability*' (GP 3, F, 41-50, Lines 336-337), which was consistent with the view that the issues stem from the programme constantly changing:

*'I think the problem with that is that it changes all the time doesn't it. You know like the location where they do it, you know the times ... you could print leaflets and things, and you know six months down the line you've got a load of leaflets and the timing's changed or the venue's changed'* (PN 4, F, 51-60, Lines 328-331)

Referrals were considered time consuming, and in some cases acted as a deterrent:

*'if there'd been a form in his [patient] records I could have just printed, filled it in and faxed across, that referral would have gone that day, but I have to dictate a letter to a secretary, asking her to then find out where the patient can go. She often then rings me back and says well, what exactly what do you want'* (PN 2, F, 41-50, Lines 360-364)

Overall the following quote appears to summarise HCPs' perceptions of referrals to PR: '*if referrals are made easy then you do a lot more of them*' (PN 2, F, 41-50, Line 284), and this highlights the difficulties outlined above which some HCPs associated with the referral process.

### Facilitators to Referral:

Some discussed processes in place which facilitated a referral to PR. Having a '*simple pro-forma*' (GP 2, F, 31-40, Line 185) was believed to greatly assist with referral. One PN discussed the previous lengthy referral forms, and praised the simplicity since moving to an electronic system. This was assisted by an email address to contact the PR team, regarding any questions:

*'we have an email address for them which is readily available, you know we have e-referral forms to them now ... the written forms are sort of long gone now because they used to be quite protracted'* (PN 3, F, 51-60, Lines 208-211)

The electronic system had great benefits, especially with regards to time constraints:

*'obviously it's time saving [laughter], you know you're not transposing... they're self-populating forms, so you only have to fill in about four boxes ... so that's really quick, and because you then email it straight to the team, you know. You're not sort of putting*



*it to one side at the end of clinic, and then you've got to sit and fill in the form, and then you've got to fax it, and then you don't know whether they've got it, it's just less user failure in that kind of system.'* (PN 3, F, 51-60, Lines 221-227)

A GP discussed how he found the current process of creating a referral letter straight forward, however he welcomed electronic referrals. Ease appeared the key facilitator to referral:

*'it's an easy referral letter, with future electronic referrals. It would then share notes, it would be much easier if it was a touch of a button rather than filling a form out, but you know they're all fairly minor irritations ... I think it could be streamlined'* (GP 5, M, 41-50, Lines 284-287)

A PN believed that sometimes patients require further investigation, which may also initiate a referral, she discussed a patient example:

*'So one [patient] was being treated as an asthmatic her whole life, but then because she's got a significant smoking history, I was just like ... you know actually get current spirometry on you and things like that. So I did all of that, changed her inhaler therapy, and then just said look I'm going to refer you on to the COPD team. So the COPD team generally assess for pulmonary rehab, so that's the way we do it here, is we use a computer system called [name of system], and on that I've got a referral to the community COPD team, and on that form it's got little tick boxes that says referral for diagnosis, referral for oxygen assessment, referral for pulmonary rehab, referral for the acute service ... I generally just like tick off a couple, like confirm diagnosis, you know, knowledge of acute service and pulmonary rehab, that's for those that are newly diagnosed. So I think it's more I think I'm probably much more thorough with it, with the newly diagnosed.'* (PN 5, F, 25-30, Lines 451-464)

Her inquisitiveness assisted the patient in obtaining the correct diagnosis, however she admitted that a new diagnosis of COPD almost prompts her to refer to PR, and she may not have made a referral otherwise. It was evident that a simplistic, manageable referral was the key facilitator to referral for those working in primary care.

#### **4.3.6 Organisational and Referral Pathway Perceptions – Secondary Care:**

*Organisational and Referral Pathway Perceptions* were frequently mentioned by HCPs in secondary care. This super-ordinate theme was derived from the sub-ordinate themes: *Lack of awareness* and *publicity*, *Defers responsibility*, and *Unaware of patient's suitability and how to refer*. Similar to primary care, each had a significant number of associated references which are evidenced in table 18.

**Table 18: Organisational and Referral Pathway Perceptions – Secondary Care Sub-ordinate Themes**

<b>Organisational and Referral Pathway Perceptions – Primary Care</b>		
<b>Sub-ordinate Theme:</b>	<b>Number of participants:</b>	<b>Number of references:</b>
<b>Lack of awareness and publicity</b>	13	84
<b>Defers responsibility</b>	12	57
<b>Unaware of patient suitability and how to refer</b>	11	33

Lack of awareness and publicity:

All HCPs in secondary care (n=13), believed that there was a *lack of awareness and publicity* surrounding PR, and voiced a significant lack of exposure:

*'I haven't particularly been to pulmonary rehab myself, so I haven't seen exactly what goes on'* (GN 7, F, 41-50, Hospital 2, Lines 157-158)

*'I'm aware of it as being an effective tool, but I don't have much direct experience of it'* (DR 4, M, 25-30, Hospital 1, Lines 221-222)

Some provided their views on the cause of low PR awareness. This was often attributed to PR not being discussed in any detail, or forming a core part of the COPD curriculum during either their medical or nursing degree:

*'[PR] it's just mentioned as a part of the management plans generally in terms of medical education. There's no formal mention of it [PR] really'* DR 4, M, 25-30, Hospital 1, Lines 111-112)

*'I don't think I even had any teaching on pulmonary rehab at Uni.'* (DR 6, M, 25-30, Hospital 2, Line 111)

*'We might have been taught about it but I can't remember anything'* (GN 3, F, 20-25, Hospital 1, Line 87).

This uncertainty emphasised the unmemorable nature of the content, if indeed it was taught, and the lack of significance placed upon the programme. Others discussed they had only obtained knowledge about the programme from their *'own reading when I was a medical student'* (DR 1, F, 25-30, Hospital 1, Line 76). It therefore became apparent that if some HCPs had not carried out their own independent study with regards to PR, they remained unformed. Another noted the casual nature in which the programme was discussed, and the lack of importance placed upon it during medical school training:

*'pulmonary rehab, I think it was as an offhand comment, I don't really think we've ever had much mention of it ... we never actually got any exposure to pulmonary rehabilitation'* (DR 5, M, 25-30, Hospital 2, Lines 141-144)

He continued to describe how medical students were not provided with the opportunity to attend PR, something which other services provide for trainees. The value of attending experience days was highlighted:

*'[on experience days] you show up and shadow somebody who works there and they show you the ropes. It's usually only half a day sort of thing, it's not something that we do for any extended period of time, just to give you an idea of what services are out there. Not something we do a lot of to be honest, but we definitely do it with stroke, I'm trying to think of a few other things that we did, but yeah never any pulmonary rehab stuff.'* (DR 5, M, 25-30, Hospital 2, Lines 153-158)

One GN suggested PR may be the answer to many of the patients' problems, as they are currently passed from department to department. The demand for further information from the service was apparent:

*'I think we do need a lot more [information] because at the moment we're referring patients all the time, to like I said [name of follow home service at the hospital] and the respiratory team and COPD team, and they're coming down and saying the patient's too well for them because they don't need to go home with the nebulisers and stuff, but maybe the rehabilitation would be better'* (GN 4, 41-50, Hospital 2, Lines 231-235)

Lack of publicity was closely aligned with a lack of awareness, however in this instance HCPs often blamed the service for their dearth of knowledge suggesting that they *'haven't been told'* (GN 5, M, 51-60, Hospital 2, Line 209) about the local programme, or received any *'formal communications'* (DR 4, M, 25-30, Hospital 1, Line 121). There was an overriding view that it should be the responsibility of the service to raise awareness and the profile of PR:

*'I've known nothing about it before, so if there is services available it probably does need to be advertised a bit more.'* (DR 5, M, 25-30, Hospital 2, Lines 216-217)

Others were surprised at the lack of promotion of the service, despite having a large respiratory centre at the hospital:

*'Isn't it funny that we don't hear about it then, that it's just not filtering out on to the wards.'* (GN 2, F, 41-50, Hospital 1, Lines 205-206)

Some expressed frustration with regards to lack of contact and information provided by the service, and appeared despondent, as they believed that the service should make itself visible and accessible to HCPs in secondary care. One GN was displeased that she had

'never had no one come and say this is what is available' (GN 4, F, 41-50, Hospital 2, Lines 135-136). Others referred to the lack of advertisement for patients, and scarcity of promotional material provided: '*I don't know of any patient information leaflets that we could give them*' (DR 2, F, 25-30, Hospital 1, Lines 150-151). This was similar to the views of the GN discussed, who worked in primary care prior to secondary care. She was provided with information in primary care to assist with advocating the programme and increasing patient knowledge, however had not received any resources whilst working in secondary care:

*'We did have a little sort of, an education sheet that we used to give out to patients to say pulmonary education, pulmonary rehab was taking place, and you know a couple of key areas that they might find useful'* (GN 7, F, 41-50, Hospital 2, Lines 152-154)

Many spoke of ways to expand publicity, as this was considered imperative in increasing referrals:

*'sort of general awareness raising I suppose, if people knew that it was something that they should consider as a physician rather than just as a respiratory team, then people may do it'* (DR 4, M, 25-30, Hospital 1, Lines 197-199)

*'Like mail shots and posters and stuff like that, and you know how to access if we need to'* (GN 5, M, 51-60, Hospital 2, Lines 220-221)

It appeared that HCPs wanted concise information, where they could easily identify the important take home messages. Another GN blamed a shortage in publicity for her lack of awareness, however she assumed that posters about the service would exist, yet the service probably had not sent them to the frailty ward, where she worked:

*'maybe flyers or something, but I haven't seen any of them, I'm assuming that they exist but I just haven't seen them. Yeah, unless they just haven't maybe reached as far as us.'* (GN 6, F, 41-50, Hospital 2, Lines 158-160)

Publicising the programme electronically was considered beneficial, due to staff often completing work on computers after ward rounds:

*'mention it in one of the circular emails that goes round, just so that people are actually aware that it exists, just because as I've said I've never even considered it before'* (DR 5, M, 25-30, Hospital 2, Lines 222-224)

This was similar to the suggestion of another doctor, who discussed how prior to unlocking the computers on the ward, a key message appears. She perceived this may be a useful way to promote PR and increase awareness:

*'they call it like message of the day, but you know you could have it for a week or something like that, that might be a good way so that everybody would have, you know, be kind of forced to look at it and just aware of it.'* (DR 2, F, 25-30, Hospital 1, Lines 240-243)

The choice of the word *'forced'* suggests that HCPs may be disinterested in PR or be too busy to consider it otherwise. Others however favoured PR staff providing verbal information, and it was viewed that supplying details via different platforms would heighten awareness:

*'a time when someone [who] knows about it comes to speak to staff and gives us a little bit of information, send a flyer out and then people would be happy to attend, or even emails where there's like a leaflet for information about what to do, how to do, what the programme consists, then most of the staff will get an exposure to it [PR]'* (DR 3, F, 31-40, Hospital 1, Lines 196-200)

It was evident that HCPs in secondary care believed the service should play a greater role in ensuring that the programme is adequately advertised.

#### Defers Responsibility:

It was striking how often HCPs in secondary care deferred responsibility to justify their lack of referral. This is evidenced by the large number of references depicted in table 18, and was discussed by 12 HCPs. This sub-ordinate theme was formed after identification of two key areas: *defers responsibility*, and *disinterested in respiratory conditions*; each will be explored in further detail below.

Many considered they *'don't deal with that [PR]'* (GN 5, M, 51-60, Hospital 2, Lines 163-164) and did not feel that it was their responsibility:

*'I'm aware of it as being an effective tool but I don't have much direct experience of it, I'm not the one who performs it, I'm not really the one who refers for it either.'* (DR 4, M, 25-30, Hospital 1, Lines 221-223)

Although aware of the benefits, this doctor was quite dismissive of his role in the referral of patients. Despite holding this view many of the other HCPs softened it by defending their actions. One of the most prominent justifications was that the primary role of those working on general medical wards, was to assist patients with their acute condition. This is where many considered their responsibilities ended:

*'literally my role is now to see them, treat them, get them over the acute phase.'* (GN 7, F, 41-50, Hospital 2, Lines 227-228)

This view was mirrored by a doctor, who believed her role was to stabilise the patient and either transfer them to a ward or discharge them. She considered her job was to provide treatment and make decisions, however it was not her responsibility to deal with the management of the condition:

*'our main role is kind of to stabilise them and get them admitted or send them home, so we don't have that much of a further follow up of what happens next with them'* (DR 3, F, 31-40, Hospital 1, Lines 34-36)

Another adhered to this *ship them in ship them out* attitude. The hospital was considered a holding area, where medical intervention was administered until patients returned to a state of health of that prior to admission:

*'in hospital especially in the acute wards we're so focused on getting people into hospital, treating them for their acute conditions and then sending them home when they are back to their baseline. So I think therefore there's probably more of a place in primary care, in terms of it being a bit more of a holistic approach to, to their treatment.'* (DR 1, F, 25-30, Hospital 1, Lines 96-100)

Alongside viewing that as a doctor working on a general medical ward her role was to treat the acute condition, she also deferred responsibility of referral to those working in primary care, considering it a holistic approach. This emphasised that some in secondary care perceived it is not their role to help manage all aspects of the condition and provide long term support. She therefore believed that suggestion of referral to PR *'needs to start in primary care'* (Line 92).

Others also disregarded the responsibility of long term care of the patient, and appeared to lack interest in the management of COPD. It was however interesting that one GN blamed this attitude on the guidance she has been provided with:

*'it's more about the acute, so like you know starting on nebs, if we think they need to, and steroids and antibiotics if they need to ... and blood gasses. With us with the guidance it's all about the acute onset and not then managing the condition afterwards.'* (GN 1, F, 51-60, Hospital 2, Lines 230-234)

This absence of concern was further confirmed when she discussed a form available for completion after a COPD admission. She lacked knowledge with regards to the content and dismissed responsibility, and appeared to perceive this as the respiratory team's role, viewing it as someone else's problem if the patient was transferred to a different ward:

*'there's actually a big sheet that you're supposed to fill in, to make sure we're doing things like you know inhaler technique and stuff, and I have a feeling that, that's*

*actually one of the questions about pulmonary rehab. I think we tend to leave it to the respiratory nurses and the respiratory team once they've moved.'* (Lines 175-179)

Others also deferred responsibility to those working on the respiratory ward:

*'Mind you, usually the patients on the assessment unit, they move up to a respiratory ward from here, so I suppose they'd do it from there. A lot of the time they get moved up to the wards from here'* (GN 4, 41-50, Hospital 2, Lines 157-159)

This GN did not make reference to how patients who were discharged from AMU would access PR, and stated: *'I've never had to refer anyone to it, I've never been asked to either'* (Lines 163-164). Some of the doctors shared this view, almost passing the buck of responsibility to the respiratory team:

*'if the respiratory team would say you know refer them or whatever then we would act on that'* (DR 2, F, 25-30, Hospital 1, Lines 179-180)

Many discussed how COPD patients were often seen by a discharge team, and therefore presumed they may refer to PR:

*'No, I don't know if that's [referral to PR] what the [name of discharge team] do... So we have a team called [name of discharge team] who I know with the chest patients they get called in at the last minute to kind of oversee the transition from hospital to home, and that's kind of how I explain it to the patients, but what they actually do I don't know.'* (GN 2, F, 41-50, Hospital 1, Lines 94-103)

One GN centred almost the entire interview on how he did not believe that discussion or referral to PR was part of his role. It was perceived this may have been as a result of a total lack of programme knowledge, however due to the prominence of his views it was decided to focus upon some of his justifications. He appeared defensive throughout, and shifted liability by stating *'it's the wrong ward'* (GN 5, M, 51-60, Hospital 2, Line 205) for referral to PR. He did however, acknowledge that they had a number of COPD patients on the ward. Similar to GN 2, he discussed the follow home service who visit COPD patients on the ward, and also admitted *'I don't know what they do'* (Line 105). He appeared particularly uneasy about his deficient knowledge, and later deferred responsibility to the respiratory team who sometimes visit the frailty unit, where he worked:

*'we don't get involved, they [outreach from respiratory] come along, and we just say, yes there's the chest problems, and they take their details.'* (Lines 143-144)

Here, he classifies patients by their illness to identify them to the respiratory team, and appears uninterested in the long term management, as he refers to frailty as a *'short term ward'* (Line 43). At the end of the interview he stated:

*'I'm sorry I didn't know too much about it because it's not our area.'* (Line 247)

As he did not work on a specialist respiratory unit, he believed this was justification to shift liability of referral. He was therefore consistent in his view throughout, denying responsibility.

Although not specifically articulating a deferral of responsibility, one doctor reflected on his perception that doctors within secondary care are unaware of PR, and contemplated the situation in primary care:

*'I don't know whether the GPs have better knowledge of it, or whether it's just hospital doctors that don't'* (DR 5, M, 25-30, Hospital 2, Lines 215-216)

It was apparent therefore that HCPs working in secondary care felt obliged to defend their lack of referral, and this was often associated with deferring responsibility.

#### Unaware of patient suitability and how to refer:

The final sub-ordinate theme within organisational and referral pathway perceptions is: *Unaware of patient's suitability and how to refer*. Again, a large number (n=11) of HCPs in secondary care discussed this as a prominent issue, and this was depicted by the number of references displayed in table 18, highlighting the frequency with which this topic was raised.

HCPs agreed that both being unsure of patient suitability, and the referral process, acted as a barrier. Some stated that *'I wasn't aware I could'* (GN 6, F, 41-50, Hospital 2, Line 68) refer to PR. Many also discussed that they *'don't know what the requirements are'* (DR 1, F, 25-30, Hospital 1, Line 110). They therefore believed they would be incapable of making a referral, as they would be unable to assess patient appropriateness. This lack of knowledge surrounding patient suitability resulted in HCPs not considering referral to the programme:

*'I've never kind of come across a patient and thought, oh you would be a good candidate'* (DR 2, F, 25-30, Hospital 1, Lines 172-173)

This doctor highlighted the need for further information regarding referral, and stated that she would refer patients if aware of the criteria:

*'which patients would be ideal candidates, what the aim of the process or the programme is, and you know any patients that definitely aren't candidates for it, that would be really helpful'* (Lines, 213-216)



It was apparent that HCPs in secondary care lacked confidence, and wanted reassurance from the service of which patients were suitable. One GN discussed how they required a simple system where values could be input, and therefore the decision taken away from them. She described the effectiveness of a system which is completed as procedure, when intoxicated patients are admitted to the general medical ward:

*'a checklist, like a referral, so like when we have patients who like come in with alcohol excess like we'll put in how, what, how much alcohol they've had, etcetera, etcetera. It's just online and it'll flag up ... and say yeah you need to refer them.'* (GN 3, F, 20-25, Hospital 1, Lines 139-146)

Another GN agreed that she wanted reassurance and confidence that she was making an appropriate referral:

*'on our system for order and performance and stuff, if there was a pro- forma on there that we could complete and the referral was automatically sent, then the decision could be made by the team that are going to be looking after that patient, and if we put all the details on of who we've already spoke to, so we've discussed it with [the follow home service], like I was saying before the pro forma, like a tick sheet, if you put it all on the system it automatically goes then, I think that would be beneficial as well, and more people would probably do it that way as well.'* (GN 4, F, 41-50 Hospital 2, Lines 299-306)

It appeared some would worry about making an incorrect referral, and considered a pro-forma would be simple, as it would allow a member of the respiratory team to oversee the referral to PR. Others who lacked programme knowledge were unsure of the referral process, and how to initiate a referral:

*'I don't know if it's a telephone call or an email or, I don't know what the referral process is.'* (GN 6, F, 41-50, Hospital 2, Lines 166-167)

This was considered a significant deterrent to referral by many of the doctors:

*'I can imagine what it is, but I don't have knowledge of what the process is'* (DR 4, M, 25-30, Hospital 1, Line 169)

This doctor added the criteria he assumed would exclude patients from participating in PR, however he admitted that he was speculating and unaware of specific details:

*'If they have significant comorbidities, so if they have like significant cardiovascular disease, it will prevent them from doing the exercises. If they're on ambulatory oxygen, I would imagine that they're probably excluded, if they have significant sort of muscular skeletal issues as well, or if they don't actually have a COPD diagnosis, and they have something else, I imagine that probably also excludes them as well'* (Lines, 181-186)

Another doctor considered that he could possibly use initiative to find out the correct details, however this would be a time consuming task:

*'I wouldn't know how to do it, I mean I could probably figure it out and make some phone calls, but I think directly no, I wouldn't know who to contact.'* (DR 5, M, 25-30, Hospital 2, Lines 190-191)

Lastly, the doctor who had prior experience of completing a placement with the respiratory team, was confident in his abilities to sell the programme to patients, however he was also unaware of how to initiate a referral:

*'I could put the idea forward but I wouldn't know where to get more information for the patient, or I'd probably have to speak to a respiratory doctor to find out about how to refer them'* (DR 6, M, 25-30, Hospital 2, Lines, 144-146)

Overall, it was apparent that many on general medical wards would '*definitely consider*' (DR 1, F, 25-30, Hospital 1, Line 143) referral to PR if aware of patient suitability, and on the condition that the referral process was simple and undemanding.

#### **4.4 DIAGRAMMATIC REPRESENTATION OF THE FINDINGS**

A diagrammatic representation of the findings has been displayed in figure 9, which provides a visual summary of the similarities and differences in primary care. It is proposed, from the findings of this study that HCPs often enter a downward spiral with regards to referral to PR. The primary care PR downward spiral summarises the key findings from GPs and PNs who participated in the study, and for secondary care the views of doctors and GNs working on general medical wards in two hospital trusts in the North West of England.

Within secondary care, as seen in figure 9, HCPs progressed down the spiral, and as a result of a lack of knowledge and communication from both medical and nursing degrees, and information from the service, this resulted in a lack of awareness about the programme. Although, some were aware of the programme in secondary care, many only had a text book definition, and others had never heard of PR prior to the interview. Therefore, all HCPs in secondary care, apart from GN 7 who had previously worked in primary care, were unaware of the specific benefits, which consequently impacted upon their enthusiasm for the programme. As a result of this lack of passion, these HCPs did not therefore trouble themselves to enquire how to make a referral, and many discussed how if they were asked to refer a patient they would not want the responsibility, as they were worried they may

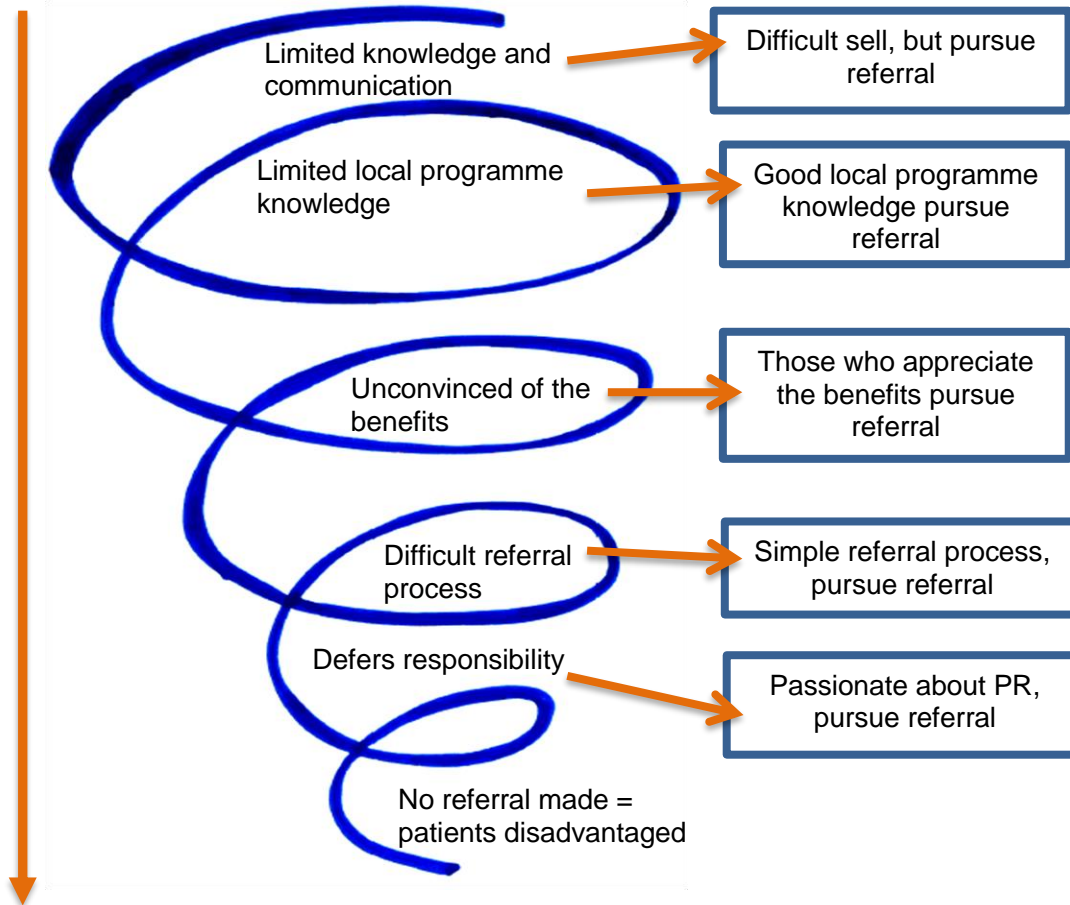
make unsuitable referrals. This culminated in all HCPs in secondary care reaching the bottom of the spiral, with no referrals made.

This downward spiral was also evident in primary care, however it should be noted that as a number of GPs and PNs did refer to the programme, they exited the downward spiral at specific points; this is depicted in figure 9. Similar to secondary care, the downward spiral begins with limited knowledge and communication, which relates to a lack of programme specific information from the service, lack of communication between HCPs as to who should be making the referral, and the difficulty associated with persuading patients to attend. At this point however, some HCPs in primary care took time to convince patients about the benefits, and although they perceived the sell as difficult, they still pursued referral. Those who did not refer at this point continued down the spiral, with some holding limited local programme knowledge, such as the location, times of PR and what patients experienced when attending. Others however, had good levels of local programme knowledge, sometimes as a result of being proactive and finding the information out for themselves, or having a service who communicated well. These individuals would also often pursue referral. Some were unconvinced of the benefits of the programme, which commonly was as a result of a lack of knowledge, however as previously discussed many were passionate about PR and had seen the benefits of patient improvement first hand. Moving towards the bottom of the spiral, some discussed how the referral process was difficult or changeable, which made the task arduous and off-putting. Conversely, those who had a simple referral process, often described as self-populating e-referral forms, referred frequently. Lastly, many of the GPs in primary care deferred responsibility for referral, which resulted in them reaching the lowest level of the spiral, with no referral made. It should be noted however, that in primary care there were a number of HCPs who were enthusiastic about PR, particularly PNs who would try to refer no matter how complex the process.

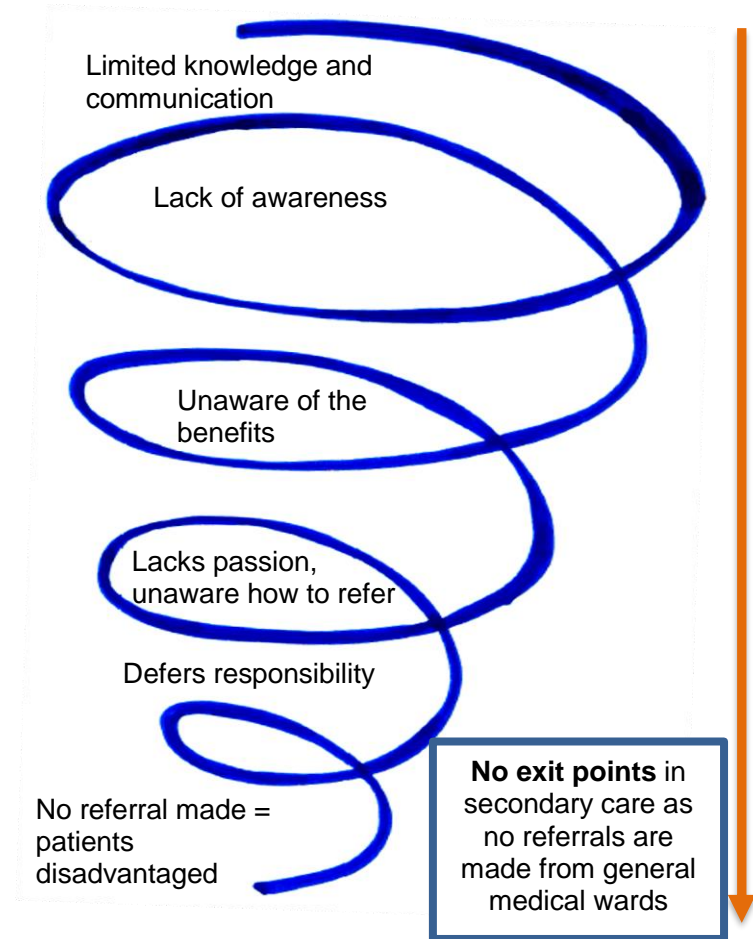
As evidenced, many of the HCPs in primary and secondary care enter a downward spiral in relation to referral to PR. There are a number of reasons which can be attributed to this as discussed. Often those in primary care exit the spiral at differing stages, however those in secondary care, working on general medical wards do not appear to have the knowledge to break this continuum. Therefore, as a result, as previously discussed, none of the HCPs interviewed in secondary care referred to PR.

**Figure 9: Healthcare Professionals Pulmonary Rehabilitation Referral Downward Spiral**

**Primary Care PR Downward Spiral:**

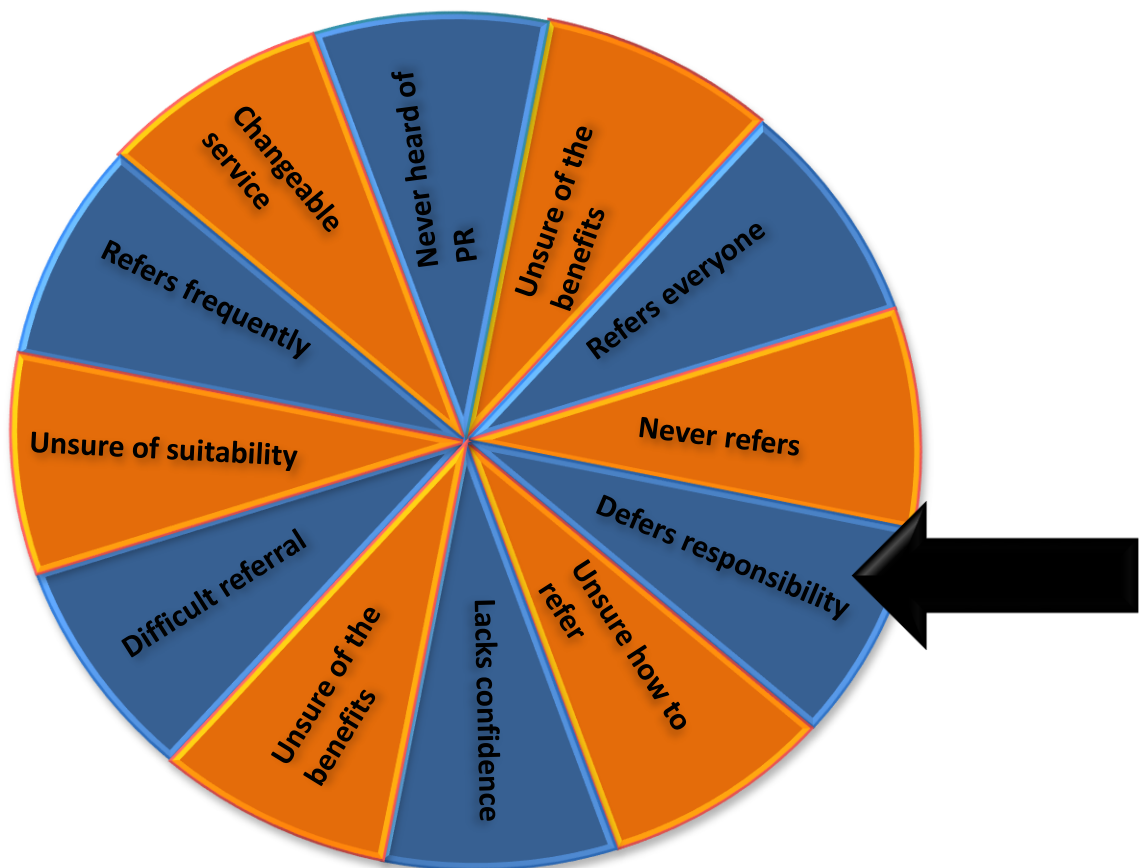


**Secondary Care PR Downward Spiral:**



Chance of referral to PR is as certain as spinning a wheel of fortune (see figure 10). This analogy has been used as the likelihood of referral depends upon which HCP the patient sees and on which day, their levels of PR knowledge, awareness of the referral process and their own internal COPD illness beliefs. It may be that a patient sees a HCP who is passionate about PR and discusses referral with all COPD patients, or one who is aware of the programme yet unsure of the referral process, and due to time restrictions decides not to refer. Lastly, there were some HCPs the patient may encounter who had never heard of the programme before, therefore no referral would have been made. Thus chance of referral is dependent on a number of aspects identified within the current study, with the key instances highlighted by HCPs displayed in figure 10. It is therefore concluded that there is an element of chance associated with which HCP a patient sees, and likelihood of referral would be based upon their beliefs of COPD, awareness of PR and prior experiences and perceptions of the programme.

**Figure 10: Wheel of Fortune to Display the Element of Chance Associated with Pulmonary Rehabilitation Referral**



## 4.5 CHAPTER SUMMARY:

The findings displayed highlight HCPs' perceptions of PR as a management strategy for patients with COPD, and were derived from 27 HCPs, in both primary and secondary care. Three super-ordinate themes were identified: *COPD illness perceptions*, *Pulmonary rehabilitation beliefs* and *Organisational and referral pathway perceptions*. A number of subordinate themes were identified within these super-ordinate themes in both primary and secondary care, and display the similarities and disparities in participant responses. Although there appeared to be some cross over between HCPs views within each theme, it is proposed that piecing together the jigsaw, creates a representative picture of the findings.

HCPs in both primary and secondary care believed that COPD, as a condition, has the ability to add pressure to the NHS due to the increased need for medical assistance and hospital care. The two groups also held stereotypical beliefs surrounding COPD, however those in primary care related this to patients needing reassurance, lacking motivation and being resistant to change, whereas in secondary care it was often considered a smoker's disease and that patients lacked adherence and compliance. HCPs' COPD illness perceptions were included within the findings as it was apparent that these views formed the basis of their assumptions, and related to their perceptions of PR.

Overwhelmingly, although HCPs could often appreciate the benefit of attendance at PR, it was evident that they did not refer as often as they should to the programme. Regardless of role, there appeared to be a lack of PR related knowledge. In secondary care many were unaware of the programme content and what it entailed; in primary care the majority were aware of the programme, yet lacked specific local programme knowledge. Diminished awareness was often attributed to inadequate publicity from the service, or a failure to sufficiently cover the topic in teaching during training.

HCPs in both primary and secondary care deferred responsibility of referral. GPs often considered it the role of PNs, and those on general medical wards passed the buck to either primary care, as it is a *holistic approach*, or the respiratory team. Many in secondary care had never made a referral, and as a consequence were uncertain of the process surrounding this. Those in primary care favoured a simplistic electronic referral, however PNs felt devalued due to the amount of information required from the service, and the lack of feedback received.

Overall, it was apparent that communication was a key issue. HCPs believed that there was poor communication from the service, regarding local programme information and referral criteria. Many in primary care found it difficult to sell and convince patients of the benefits of attendance, and there was also a lack of communication between HCPs themselves, deferring responsibility of referral to another group of HCPs. All GPs and those working on general medical wards appeared to believe that others were initiating referral to PR.

The subsequent chapter will draw conclusions and situate the findings with comparison to literature previously conducted in this and wider topic areas. After the discussion chapter researcher reflections will be provided prior to exploring the strengths and limitations of the study. Finally, conclusions will be drawn before making recommendations for future avenues of research, education and practice.

## CHAPTER 5: DISCUSSION

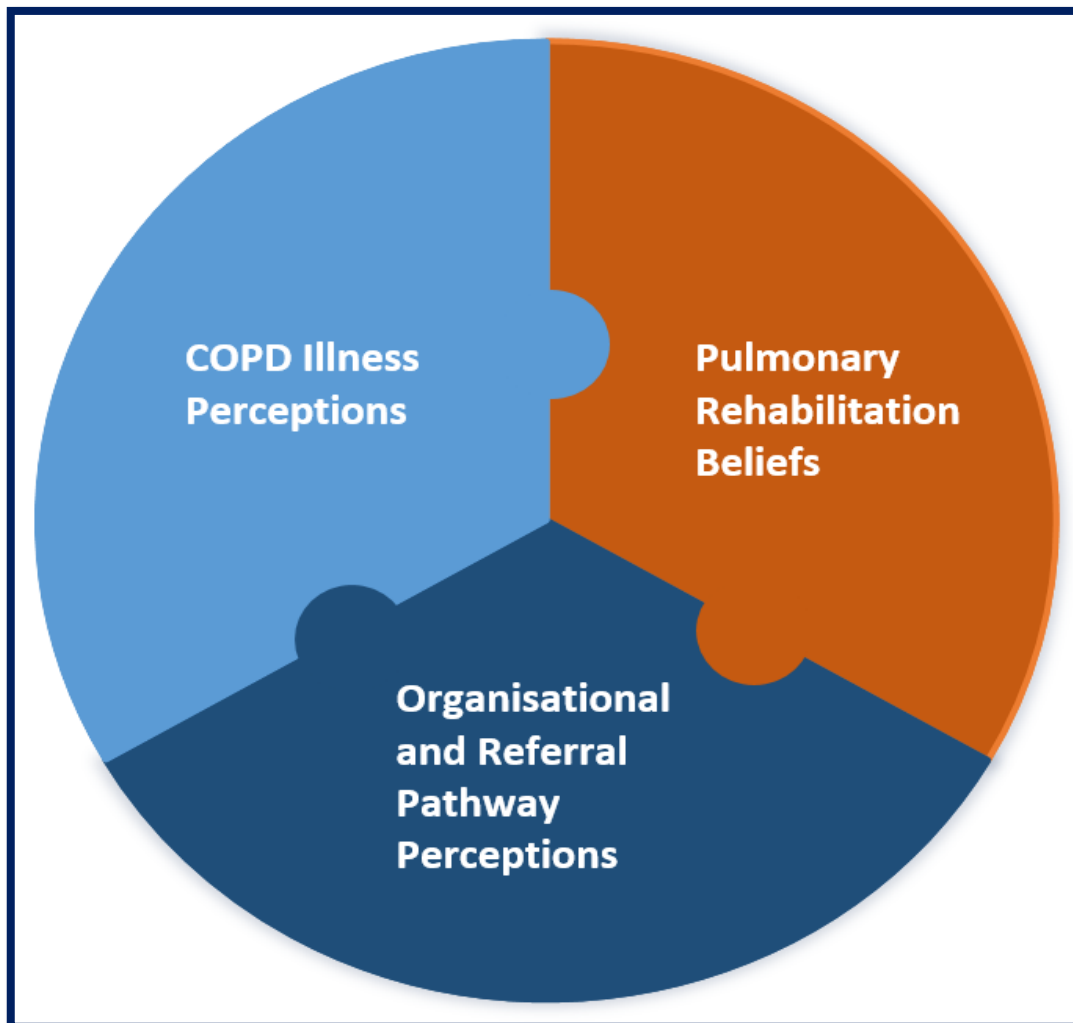
### 5.1 INTRODUCTION:

This chapter provides a discussion of the findings and situates them in the context of existing literature. The literature identified in both the background chapter (Chapter 1) and the CIS (Chapter 2) will be drawn upon along with the wider body of evidence, with any original contributions to knowledge from the current study highlighted. Within the findings chapter, three superordinate themes were established: *COPD Illness Perceptions*, *Pulmonary Rehabilitation Beliefs*, and *Organisational and Referral Pathway Perceptions*. These super-ordinate themes were common to both primary and secondary healthcare settings although, in some instances, the sub-ordinate themes within them differed. This discussion will take form under the three main super-ordinate headings, with the findings from primary and secondary care synthesised to allow for comparisons and differences to be recognised between the groups.

As highlighted in the findings chapter (Chapter 4), the super-ordinate themes are displayed using the concept of a jigsaw (see figure 11 for diagram previously depicted), and when pieced together aims to create a clearer picture of HCPs' perceptions of PR. Discussing the findings from both primary and secondary care together will facilitate this process, with inferences made regarding how certain perceptions are held, how these may influence HCPs' attitudes to PR, and their decisions about whether or not to refer to the programme. In accordance with IPA methodology, this discussion aims to situate the findings with those of other research studies, highlight the new knowledge identified, and summarise the lived experiences of PR for the HCPs who participated in the research (Smith, Flowers & Larkin, 2009).



**Figure 11: *Piecing Together the Jigsaw*:** This diagram depicts the figure previously presented in the findings chapter, and displays the super-ordinate themes which when connected represent HCPs' perceptions of PR.



## 5.2 COPD ILLNESS PERCEPTIONS:

It was apparent that HCPs held their own illness perceptions regarding COPD, with differences and commonalities present between those in primary and secondary care, and also between professional groups. Within the literature, COPD illness perceptions are most commonly discussed from a patient's view with regards to how they perceive, and then manage, their condition (Kaptein et al. 2008; Kapetein et al., 2017; Weldam et al., 2014). HCPs, in the current study, displayed that they too held COPD illness perceptions and it was considered important to include these due to the influence they may have on whether HCPs referred patients to PR. For example, it was interesting to note that those doctors in secondary care who believed COPD caused exertional shortness of breath, indicated that they would be less inclined to refer to PR due to perceiving that patients would dislike the exercise component. Literature has, however, highlighted that patients often have very different cognitive representations of their illness compared to those of HCPs (Insel, Meek & Leventhal, 2005). Individual variance in how patients perceive and discuss their symptoms is often apparent; a difference also found in the views of HCPs (Biggerstaff & Thompson, 2008). The distinction between patient and HCP perceptions is attributed to patients experiencing symptoms first hand, something HCPs often cannot envisage themselves (Insel, Meek & Leventhal, 2005).

Within primary care HCPs focused on how they perceived the condition impacts the patient psychologically; such significance, however, was not placed upon the physical symptoms of the disease. The literature highlights that in comparison to the typical population, mental health problems are between two and three times greater in those with chronic conditions (Naylor et al., 2012), with anxiety and depression being the most common psychological symptoms associated with COPD (Yohannes & Alexopoulos, 2014). Anxiety, in particular, is heightened, with COPD patients 10 times more likely to experience panic disorder than those without the condition (Livermore, Sharpe & Mckenzie, 2010). This focus upon psychological symptoms may be explained by the increase in mental health issues being managed in primary care, and GPs and PNs being better equipped to identify and manage anxiety and depression, as often they are the first HCP the patient chooses to confide in (MIND, 2016). This heightened presentation may be a result of an aging population, a greater presence of chronic conditions and the strain of living with the disease causing deterioration in a patient's mental health (Das, Naylor & Majeed, 2016). Some PNs now deliver low levels of psychological therapy to assist with depression, anxiety and the management of long term conditions (Coventry et al., 2015). It may therefore be due to the

increased exposure and awareness of mental health issues that HCPs in primary care focused upon the psychological aspects.

Although breathlessness was mentioned frequently by those in primary care it was, however, never identified as a physical symptom of the disease, and always discussed in relation to the anxiety and fear that dyspnoea evoked. Previous similar associations have been made within the literature, highlighting the worry and helplessness that breathlessness can cause (Harrison et al., 2014; Carel, Macnaughton & Dodd, 2015). HCPs in the current study related this to a vicious cycle of breathlessness, as they perceived patients become concerned about exercising for fear of becoming breathless which, due to diminished activity and increased anxiety, causes their general health to decline. This vicious cycle of inactivity and symptoms is present within the literature (Bourbeau, 2009), and reaffirms that a reduction in activity, in turn, causes deconditioning which ultimately increases ventilatory requirements that can lead to hyperinflation (air trapping causing the lungs to over inflate), inducing further breathlessness and anxiety (Cooper 2006; 2009; Polkey & Moxham, 2006; Troosters et al., 2013). The Breathing, Thinking, Functioning Clinical Model (Spathis et al., 2017) as discussed previously and displayed in Figure 1, also provides evidence of this cyclical process. It is therefore apparent that the literature highlights that COPD encompasses both physiological and psychological symptoms. Those in the current study in primary care, however, focused upon how anxiety was a contributor to breathlessness, rather than breathlessness as a physical symptom of the disease. Such emphasis upon the psychological aspects of the condition, with little reference to the physical symptoms, has not previously been reported within the literature, and therefore would require further exploration.

Anxiety was also considered by those in primary care to result in patients refraining from daily tasks. Impact upon quality of life and changes to daily living are similarly reported elsewhere (Harb, Foster & Dobler, 2017; Kessler et al., 2011; Seamark, Blake & Seamark, 2004). HCPs in the current study believed that this fear and worry transpired into patients holding themselves back. Similar losses are experienced by COPD patients, who feel controlled and restrained by their condition due to fear surrounding the onset of symptoms (Seamark, Blake & Seamark, 2004). The present study however indicates that HCPs believe patients do not understand that refraining from or minimising activity leads to a worsening of their condition. These findings support the literature whereby some patients are said to enter a COPD downward spiral (Barnes et al., 2015; Gysels & Higginson, 2009). This is often as a result of the culmination of both physical and psychological symptoms and if the cycle is not broken via an intervention, can result in a continuum of inactivity and

ill health, with one symptom intensifying another (Pepin et al., 2007). It therefore may be reasonable to consider how to better educate patients about the benefits of exercise for COPD; one proposed way is to ensure that HCPs discuss and encourage exercise, and PR at every contact (Corbridge & Nyenhuis, 2017), as increasing patients' knowledge of their condition, and attendance at PR, may help to reduce the psychological impact observed within primary care.

Although, it appears the HCPs in primary care in the current study are able to identify when patients are anxious, evidence suggests that anxiety is more often overlooked in COPD and therefore not managed or treated appropriately (Dury, 2016; Yohannes et al., 2010). Anxiety is often related to worse health outcomes in COPD (Eisner et al., 2010), and if patients were better educated about how to manage breathlessness, in programmes such as PR, it may be that the demands on hospital beds and the costs associated with high COPD admission and re-admission rates could be reduced (Steiner, 2015). The need to decrease the strain associated with hospital capacity, and the perceived additional burden attributed to COPD patients, was reiterated in the current study.

Conversely, COPD illness perceptions differed in secondary care with the complexities of the physical symptoms of the disease centred upon, perceiving them as chronic and having no cure. In particular, they perceived COPD as a burden to patients, due to them being unable to return to full health. This representation is mirrored in patient stories, as they find it difficult to remember a time without COPD and are aware that, due to the progressive nature of the condition, their symptoms will eventually worsen (Pinnock et al., 2011). In addition, common features of secondary care interviews featured the significance of chronic cough, sputum production, weight loss, and potential changes patients need to make to their lifestyle. These symptoms are frequently referred to within the literature (Bednark et al., 2008; Smith & Claverley, 2004), alongside the impact upon quality of life and the patient burden associated with living with multiple symptoms (Miravittles & Ribera, 2017). It is also proposed within the literature that the symptom burden for those with COPD is comparable to those diagnosed with cancer however, as the progression of COPD is often slower and patients live longer, the burden of the disease may be experienced for a greater length of time (Bausewein et al., 2010; Joshi, Joshi & Bartter, 2012). This was further evidenced in a seminal paper by Gore, Brophy and Greenstone (2000), who highlighted that those with COPD had worse levels of physical, social and emotional functioning than those with non-small cell lung cancer. This emphasises the extent of both the physical and psychological impact which COPD can have. The patient burden associated with COPD was clearly a

consideration for HCPs in secondary care in the current study, and one which may subsequently have influenced their willingness to refer to PR.

Doctors in secondary care discussed in detail the perceived patient impact associated with the difficulty of *ventilating*, which they believed added to the symptom burden of dyspnea, thus contributing to the strain experienced by the patient. It was apparent that they associated laboured breathing with activity-induced breathlessness, as it was believed to restrict exercise capacity and supports the medicalised model of breathlessness (Troosters et al., 2013). It could therefore be proposed that the strict use of the medical model may influence HCPs' perceptions of the disease, whereby focus is placed upon treating the disease rather than assisting patients to live with their condition and increase exercise tolerance. Again, the COPD illness perception that exercise induces breathlessness could impact upon their view of whether to refer patients to PR and is consistent with the literature, for example Mohigefer et al. (2018) found that out of 338 medical students 47.1% would not recommend exercise for those with COPD. The focus by doctors in secondary care on the difficulties experienced by breathlessness may also be as a result of patients most commonly reporting activity-induced breathlessness as the most troublesome symptom (Jolly & Moxham, 2009), and as a result they associate the condition with a difficulty breathing. The focus placed upon the physical symptoms rather than psychological symptoms in secondary care, may be due to exacerbations being the most common reason for COPD patients to present at hospital (Hartl et al., 2016; Ruparel et al., 2016).

Anxiety was briefly referred to, and similar to literature highlighting patients' perceptions (Harrison et al., 2014), it was apparent that those in secondary care perceived breathlessness as frightening for patients. The psychological symptoms described by HCPs in secondary care, which were perceived to initiate hospital presentation, are referred to in the literature as '*emotional vulnerability*' (Bailey, 2004, pg 764) or '*emotional distress*' (Dury, 2016 pg, 139).

Given the difference in focus between primary and secondary care, whereby discussion concentrated on the psychological and physical aspects of COPD respectively, it is therefore evident that HCPs' illness perceptions may be based upon familiarity, as a result of their own experiences with COPD patients. Thus, it could be proposed that those in primary care commonly see patients with the psychological impact of their COPD, whereas those in secondary care most often attend to patients admitted with physical symptoms or comorbidities of their condition. It could therefore be suggested that HCPs may not adopt a text book definition of the impact and symptoms of COPD, and rather create a

representation of the disease through drawing upon their own personal experiences. As a result these perceptions regarding COPD may impact upon their opinions and beliefs of PR, discussed further in section 5.3.

The pressure that COPD adds to the NHS was a dominant *COPD illness perception* and was attributed to an increased need for medical assistance. As a result COPD patients were labelled in both primary and secondary care as *frequent attenders*. Regardless of working in a GP surgery or on a hospital ward, many recalled how they saw COPD patients on a daily basis, even if respiratory was not their speciality. Frequent attendance in primary care was considered to be due to the high prevalence of COPD in the area where the practice was based, or the seasonal increase in patients attending the surgery during the winter months. An increase in exacerbations in the winter is thought to be associated with the heightened presence of viral respiratory infections during colder months (Donaldson & Wedzicha, 2014), with patients consequently requiring additional medical assistance.

As a result of frequent admissions, those working on general medical wards stated they would be surprised not to have a patient with COPD on the ward, either with an exacerbation or comorbidity of their condition. This relates to the notion that those with COPD often have a number of comorbidities (Vanfleteren et al., 2013), and the complexities and convoluted nature of the disease often results in the need for hospital care (Barnes & Celli, 2009). Dissimilar from primary care, those working on general medical wards appeared less empathetic towards COPD patients and some perceived that the frequency of attendance was unnecessary, as they should be managed in primary care for '*things that you can't actually fix*' (GN 1). This apathetic view that COPD patients should be cared for in the community, rather than admitted to general medical wards, is not reported within the literature. This may be as a result of the fact that no published research has specifically explored the perceptions of PR of those working on general medical wards. Alternatively, it could evidence a lack of knowledge of COPD, its management, and exacerbation of symptoms, or that this particular GN may have perceived the interview as an opportunity to assert her views of the pressures on NHS services (NHS England, 2017; British Medical Association, 2018). The suggestion of originality is however tentative given the limited sample, and would therefore benefit from further exploration.

The notion of patients '*bouncing in and out of hospital*' (GP 3) was referred to in primary care, evidencing that there was an awareness of the strains experienced across the service. The cyclical nature of the condition was therefore once again alluded to, however in this instance it was in relation to the frequency of hospital admissions. The extent of this issue

has been discussed within a recent BLF report which provides recommendations on how to reduce seasonal respiratory admissions and re-admissions (BLF, 2017c).

Frequency of presentation may however be as a result of how patients perceive their symptoms, the impact they have upon their daily life and their perceived ability to cope (Ayers & De Visser, 2018; Scharloo et al., 2007; Vaske et al., 2017). Illness perceptions and past experiences are often interpreted differently from person to person and therefore play a vital role in the development of disease related schemas (Petrie, Jago & Devcich, 2007). Potential change, unexpected or new symptoms and worry, all cause an increase in help seeking behaviours (Ayers & De Visser, 2018). The variable and multifaceted nature of the condition may be a potential reason why HCPs label those with COPD as *frequent attenders*.

Due to the complexities of the disease there was a perceived difficulty in managing COPD in both primary and secondary care, and as a result this was considered to add further pressure to the NHS. One GP discussed the pressures in identifying the difference '*between COPD and asthma and other respiratory problems and heart failure*' (GP 7). This was as a result of the presence of a number of similar symptoms and may be due to a lack of confidence in the diagnosis of COPD in primary care, as similarly evidenced in the literature (Bolton et al., 2005; Haplin et al., 2007; Miravittles et al., 2012; Poels et al., 2007). In particular, the difficulty in distinguishing between asthma and COPD symptoms has been identified elsewhere (Price, Yawn & Jones, 2010; Tinkelman et al., 2006), thus the current study has highlighted that this continues to be an issue within clinical practice. As early diagnosis is promoted to improve prognosis, due to it enabling timely treatment and management (Csikesz & Gartman, 2014; Soriano, Zielinski & Price, 2009), if HCPs were more confident in diagnosing COPD, this may reduce some of the pressures described in the current study.

The diversity and variation in symptoms and abilities amongst patients with COPD resulted in a perceived increased pressure and toll on HCPs in primary care. Many perceived that COPD adds pressure to the NHS due to there being no cure, only management; a concept which was frustrating and difficult for those working in primary care to comprehend. This frustration may be as a result of the nature of the healthcare profession, whereby training involves treating or reducing symptoms, and adhering to evidenced based practice (Glasziou, Burls & Gilbert, 2008), however they did discuss how they now realise that their role is also to help patients manage their symptoms and improve their quality of life.

Stereotypical beliefs surrounding COPD was a prominent sub-ordinate theme discussed in both primary and secondary care. Although there is vast evidence to display the correlation between the incidence of COPD and smoking (Caramori et al., 2015; Fabbri, 2016; Forey, Thronton & Lee, 2011; Mulhall & Criner, 2010), the frequency with which HCPs in the current study mentioned smoking, suggested that COPD is often defined as a smoker's disease. The literature highlights that although the tobacco industry was aware of the dangers of smoking in the 1950's, this was not common knowledge amongst the general population for some time (Procter, 2011). Around this period advertisements were seen including doctors advocating the use of cigarettes, with the dangers surrounding smoking not being publically acknowledged until the late 1970's (Gardner & Brandt, 2006). This therefore, highlights that some of the older patients HCPs see in the current study, may not have been aware of the dangers of smoking when they were younger. Both HCPs in primary and secondary care in the current study stigmatised COPD patients, categorising them as smokers, and it appeared that this was regardless of whether they were aware of the patient's smoking history or not. A number of risk factors have been identified in the literature in addition to smoking, that are associated with COPD (Gnatiuc & Caramori, 2014; Mannino & Buist, 2007; Salvi & Barnes, 2009). These risk factors include passive smoking, exposure to burning wood or coal, and heavy labour such as farming in inclement weather conditions causing repeated chest infections (Bednark et al., 2008). This highlights the potential for other risk factors to be acknowledged by HCPs, in order to reduce feelings of patient stigmatisation.

In the current study, within primary care, some HCPs appeared to associate smoking with deprivation, being in receipt of benefits, and the location of the practice. This belief was only referred to by GPs who considered the disease to be self-inflicted, and many therefore lacked sympathy. It was also associated with the belief that patients living on council estates have chronic conditions and are diagnosed with COPD at a younger age, and even after diagnosis of COPD often continue to smoke. This association between smoking and socioeconomic status is found within the literature and is recognised as a risk factor in the development of the disease (Maclay & MacNee, 2013; Pampel, Krueger & Denney, 2010; Salvi & Barnes, 2009). It appears in this current study that some HCPs stigmatised whole communities, or groups, based upon the cognitive representation they had built regarding the area where their practice was based.

Although HCPs in secondary care often categorised patients as smokers, this was perceived as more of a lifestyle choice, and not defined by living conditions. As a result of holding this illness perception, similar to primary care, they believed patients had therefore



brought the condition on themselves, which resulted in them perceiving that patients would be less likely to take responsibility for their own health; a view which could potentially have a negative impact when considering referral to PR. Those with chronic diseases who have experienced stigma, or expect to be stigmatised by HCPs, are less likely to access healthcare services, which results in diminished levels of health-related quality of life (Earnshaw & Quinn, 2011). The consequences of stigmatisation therefore have the potential to influence HCPs decisions regarding disease management, and have the potential of having a damaging effect on both a patient's physical and psychological health.

This attitude is well documented elsewhere, whereby hospital doctors view COPD as a self-inflicted disease due to a history of smoking, and hold patients more accountable than those who have smoked and have angina (Winstanley, Daunt & Macfarlane, 2008). In addition, this belief of smoking being the primary reason for development of COPD which is thus '*self-inflicted*' was also shared by physicians surveyed in the USA (Barr et al., 2005, pg. 1415.e13), previously discussed in the CIS (Chapter 2). The view is mirrored by many COPD patients, who feel a sense of guilt due to a prior smoking history, or not being able to quit (Wilson, Elborn & Fitzimons, 2010) and, as a result of the stigmatisation, have low levels of self-worth and feel undeserving of programmes such as PR (Halding, Heggdal & Wahl, 2011; Harrison et al., 2014). This highlights that if HCPs in the current study discussed smoking so openly with patients during consultations as they did during the interview, this may deter patients from accessing services such as PR, due to feeling undeserving. A study highlighted that the main cause of concern for COPD patients was the guilt associated with prior smoking history and feelings of self-infliction, and as a result some patients are described as *surrendering to fate*, by not seeking medical assistance (Lindqvist & Hallberg, 2010, pg 461). Although HCPs within this study may not have consciously been aware that they stigmatised patients due to their smoking history, they should however be cautious and sensitive during medical consultations not to cause upset, guilt or shame (Harrison et al., 2015), which leads to the development of causal beliefs, whereby patients blame themselves for the development of a condition (Petrie & Weinman, 2006).

Self-blame and feelings of helplessness in being unable to control or predict symptoms can impact upon a patient's ability to control their condition (Sheridan et al., 2011). Although doctors in the study by Winstanley, Daunt and Macfarlen (2008), saw patients who smoked, few offered smoking cessation due to considering COPD as self-inflicted. In the current study HCPs also held these nihilistic beliefs held in relation to smoking and COPD, and this may provide some explanation to the lack of referrals to PR. It was interesting that PNs in primary care were the only group where the majority did not hold stigmatising views in

relation to smoking, and were the group most likely to refer to PR. This may be due to PNs often being the ones who provide smoking cessation services (Rice, Hartman-Boyce & Stead, 2013), and as a result may be better informed on theories of behaviour change. It could be proposed that the belief that COPD is self-inflicted is a predictor of non-referral to PR, as none of the HCPs who discussed smoking, currently refer COPD patients to the programme. There is a lack of literature to support this notion, and therefore this finding is unique, however it should be viewed with caution given the small number of HCPs interviewed, and would require further substantiation.

An additional aspect in relation to stereotypical beliefs in secondary care was the perception that those with COPD have low levels of education, again associated with low socioeconomic status (Kanervisto et al., 2011). A lack of education may impact upon a patient's health literacy and their understanding of their condition (Roberts, Ghiassi & Partridge, 2008); this can have negative consequences with the potential to impact upon disease related severity and health related quality of life (Omachi et al., 2013). As opposed to low levels of education and understanding being used to define those living with COPD, it is proposed that HCPs should work with patients to actively and sensitively assess their health literacy, to reduce stigma and achieve the best possible health related outcomes (Sadeghi et al., 2013). This, however, was something which HCPs working in both primary and secondary care did not appear to invest time in.

A lack of patient motivation, enthusiasm and commitment to do things for themselves was also a stereotypical view discussed in the primary care narratives. This is a similar finding to that of Molin et al., (2016) whereby GPs highlighted that they viewed COPD patients as extrinsically motivated, which can result in themselves, as the GP, often being the main source of motivation. This differs from those who are intrinsically motivated and wish to undertake an activity due to the personal reward gained (Ryan & Deci, 2000). It could be argued, therefore, that HCPs need to do more to initiate a change in COPD patients' illness perceptions, from being extrinsically motivated to intrinsically motivated (Effing et al., 2016). This behaviour change can often be achieved via motivational interviewing (Benzo, 2013; Kruis & Chavannes, 2010), empowering patients to make their own informed choices, and establishing a strong relationship, so that patients feel valued (Langer et al., 2014). Although this may be a time-consuming process, changing patients' illness perceptions may be an effective way to reduce the costs associated with frequent hospital admissions. The *need for motivation and encouragement* was a sub-ordinate theme identified within the CIS (Chapter 2), highlighting its prominence within the pre-existing literature. It was, however, identified within the CIS that this view is not exclusive to HCPs with the ability to refer to

PR, as it is also present in those who deliver the programme, with acknowledgement that a large part of their role involves offering reassurance, motivating and empowering patients (Summers et al., 2017; Witcher et al., 2015). Holding these stereotypical illness perceptions appeared to result in some HCPs in the current study believing that PR may be worthless, as they perceived that patients would not take responsibility for their own health and were unaccepting of non-pharmacological approaches. This has not previously been reported as a barrier to referral elsewhere.

COPD patients were also stereotyped in primary care as being unable to take control of their own health and being resistant to change. This may be as a result of reluctance from the patient regarding acceptance of a different approach to management, or HCPs perceiving that the patient would not be interested. One GP reflected upon this and questioned '*how do we engage people in thinking differently about managing their health*' (GP 3). HCPs suggested that communicating and advocating non-pharmacological approaches to patients was an aspect missing from their medical or nursing degrees. This task therefore appeared to be a battle for HCPs with some in primary care discussing how even after persuasion to attend PR, patients complain and say how they dislike it. This is not exclusive to COPD, as it is also difficult to persuade those who do not usually exercise with conditions such as chronic heart failure (Brodie & Inoue, 2005; Conraads et al., 2014) and diabetes (Jansink et al., 2010) to comply with physical activity. This, therefore, is a pertinent finding and raises the question of how to better equip HCPs to think differently about engaging patients in the management of their own health, it is also associated with empowering patients and improving HCP communication skills. Empowerment requires HCPs to acknowledge that the patient is in control of their health, and HCPs should therefore motivate patients to self-manage and have the confidence to make autonomous decisions (Anderson & Funnell, 2010). Although communication skills are taught as a core component of a medical degree, there is a need for better integration across the medical curriculum (Silverman, 2009; Van Weel- Baumgarten et al., 2013). It is also acknowledged that once students complete their degree, they rarely obtain feedback on their communication with patients, which results in a lack of on-going development (Levinson, Lesser & Epstein, 2010). This lack of continued formal development of communication skills amongst some HCPs may explain why HCPs reported difficulty in engaging patients to think differently about the management of their health.

Being unable to take control of their health and being resistant to change were related to the notion, in secondary care, that patients often lacked compliance and engagement with their healthcare. Compliance, concordance and adherence to self-management has been

discussed extensively within the literature (Aronson, 2007; Bailey, Ormasionwu & Wolf, 2013; Bourbeau, Nault & Dang-Tan, 2004; Bourbeau & Bartlett, 2008; Bryrant et al., 2013; Horne, 2006), with adherence considered to be either intentional (decides not to follow recommended guidance) (Gorge et al., 2005), or unintentional due to aspects such as forgetting, poor understanding of the HCP's instructions, or a physical barrier to carrying out the specified task (Clifford, Barber & Horne, 2008). A number of aspects which contribute to effective self-management were proposed by Horne (2006), these include patient illness perceptions which underpin prior experiences and interpretation of symptoms, and consequently impacts upon the patient's perceptions of the necessity of the treatment or intervention. Contextual issues are also considered and include cultural influences, self-efficacy, satisfaction, views of others and perceived practical difficulties. Lastly, background beliefs can impact upon adherence, as negative beliefs held in relation to medicine or the intervention, may evoke concerns with regards to negative side effects. These suggestions have been reiterated in a systematic review and meta-analysis, with greater patient adherence associated with stronger beliefs of the need for treatment, or having little concern with regards to treatment (Horne et al., 2013).

The literature supports the claims made by those in secondary care that COPD patient adherence to disease management is often low, and acknowledges that HCPs need to understand the importance they play in assisting patients with long term management (Bourbeau & Bartlett, 2008). Doctors can sometimes appear authoritative to patients, instructing them on what they should do rather than empowering patients to take control of their condition and have a central part in the decision-making process (Kvarnström, Aoraksinen & Liira, 2018). This behaviour was displayed within the findings of the current study, with some of the HCPs choosing not to discuss PR with patients, thus not providing the choice of attendance and removing the decision from the patient's control. Improved HCP communication could counteract this issue, whereby if patients are provided with a coherent and comprehensive justification of how exercise would improve their condition, this could increase understanding and improve adherence (Bourbeau & Bartlett, 2008).

In order to assist HCPs in achieving this, the Information - Motivation - Adherence Model was created by Martin, Haskard-Zolnieriek & DiMatteo (2010), which expands and draws upon the concepts of both the health belief model (Rosenstock, 1974) and the theory of planned behaviour (Ajzen, 1991). The model provides a three step approach to assist HCPs to improve adherence which consists of: 1. *Information*: Provide patients with the information necessary to facilitate adherence. This may include providing reassurance and encouragement, being understanding and approachable, including them in the decision

making process and facilitating comprehension. 2. *Motivation*: Encourage a belief in the suggested treatment option by changing perceptions which may impact upon social, cultural and health perceptions. 3. *Strategy*: Provide support to surpass practical barriers such as written guidance or reminders and supply details of who to contact if they require assistance (DiMatteo, Haskard-Zolnierrek & Martin, 2012; Martin, Haskard-Zolnierrek & DiMatteo, 2010). The type of support evidenced within the Information - Motivation - Adherence Model was something which many of the HCPs in the current study struggled to execute. This was due to a resistance from patients regarding exercise, conversations regarding PR evoking fear due to HCPs lack of knowledge, and discussion of exercise often not being prioritised due to time constraints.

It is viewed that an empathetic and non-judgemental approach to medical consultations facilitates patient adherence to treatment options (Butow & Sharpe, 2013), with empathy also associated with better health outcomes (Mercer et al., 2016). It is a caring, polite and person-centred approach evidenced within the literature which nurtures patient compliance and empowerment, and allows the development of solid foundations between the HCP and patient to be formed (Bendapudi et al., 2006; Funnell, 2016; Lipp et al., 2016). This therefore, may offer a valuable insight into why those who hold stereotypical and negative beliefs towards those with COPD appear to lack confidence and struggle to convince patients of the benefits of a non-pharmacological approach.

A finding only apparent from primary care participants was the belief that those with COPD often required frequent reassurance. This may be as a result of the perceived patient stigmatisation of the disease, and the patient's general lack of confidence in their own abilities (Harrison et al., 2015). It may also however be due to the frequency with which those with COPD visit the GP surgery; HCPs may perceive this as a lack of patient confidence in managing their symptoms. HCPs have however highlighted elsewhere that reassurance and confidence is often only gained after attendance at PR, where patients realise they experience similar symptoms to others with COPD (Meis et al., 2014). The perceived need for patient reassurance may be more apparent in primary care due the enhanced role that HCPs play in both the diagnosis and management of the condition (Baxter & Cooper, 2012), or HCPs being more attuned to patients' psychological needs, as previously discussed. It may also be related to the continuity of care which is not as easy to facilitate in secondary care due to shift work and differing rotas (St Noble, Davies & Bell, 2008).

Within primary and secondary care COPD illness perceptions were held by all HCPs interviewed. The prominent focus of how HCPs consider the condition impacts on the patient, whether physical, psychological or both was apparent. The pressure and strain due to frequent attendance and the complexities with disease management was highlighted, with stereotypical beliefs in relation to patients with COPD also contributing to HCPs' illness perceptions. Although within the literature HCPs have previously focused upon how they perceive COPD to affect patients, such focus of the psychological impact of the disease in isolation to physical symptoms has not been discussed; highlighting a unique finding. Furthermore, an original finding was evidenced in the secondary care data, with some working on general medical wards perceiving that COPD patients should be treated in the community, as it was often unnecessary for them to be admitted to hospital. This nihilistic view with regards to hospital treatment has not previously been evidenced elsewhere. The findings within this theme complement the current health psychology literature and theory surrounding illness perceptions displayed in this discussion. There is however much more literature available surrounding illness perceptions of the patient, than those of the HCP. This current study therefore offers new insight, and it was considered important to detail these views and representations of how HCPs perceived COPD, as this may provide explanation of their beliefs in relation to PR. For example, it may provide context to their views of the programme's effectiveness, and whether they would refer patients, which are explored in further detail in the discussion of *pulmonary rehabilitation beliefs* below.

### **5.3 PULMONARY REHABILITATION BELIEFS:**

Fundamentally, HCPs in primary care had a good understanding of what PR entails. GPs focused upon the exercise and breathing techniques, and increased mobility, whereas PNs were enthusiastic about the multi-disciplinary nature, the history and aims of the programme. There was an apparent difference in primary care regarding how HCPs determined patient suitability for PR. PNs predominantly adhered to the guidance from the local service, however they admitted to also using judgement. Some questioned the ideal time to refer and whether this should be pre or post significant impact upon lifestyle. The BTS (2013) PR guideline advises that HCPs should consider referring any patient with mild to moderate COPD, and that all patients should be referred subsequent to a hospital admission due to an exacerbation. The NICE (2010) guidance adds that patients with an MRC score of three or above, or those whose activity is limited by breathlessness should be referred to the programme. GPs appeared less aware of this and many believed that PR would only be suitable for those at the severe end of the disease trajectory. This unfamiliarity

with the eligibility criteria has previously been evidenced in two papers discussed within the CIS (Chapter 2) (Foster et al., 2016; Johnston et al., 2011).

In secondary care HCPs focused discussion upon perceived patient suitability for PR rather than their understanding of the programme content, or what they believed PR entails. Two conflicting opinions were evidenced, hospital doctors mostly believed, similar to many of the GPs, that PR was for those at the worse end of the spectrum, whereas GPs perceived that attendance would be more appropriate during the early stages of the disease. Many HCPs in secondary care based their responses on assumption, due a lack of familiarity with the referral criteria, and this may be explained, as previously discussed, by some having never heard of the programme before. Likewise, the need for improving understanding of patient eligibility for PR amongst HCPs has been reported in the literature explored within the CIS (Foster et al., 2016; Johnston (K) et al., 2012). This demonstrates an uncertainty amongst HCPs with regards to referral criteria and perhaps could be as a result of a lack of clear guidance on suitability provided by the PR service.

There was an attitude amongst a large number of the GPs that PR should be used only as a last resort, after frequent exacerbations, functional disability, or when all other medical treatment had been tried or maximised. This finding is reinforced in a study included in the CIS (Johnston (K) et al., 2012), and emphasises that GPs are not aware of the evidence which states that although conducting PR early in the disease course may not prevent exacerbations, it does indeed lead to a faster recovery and an increased quality of life (Puhan et al., 2012). This highlights the benefit of a timely referral which many of the HCPs in the current study did not appear to initiate. It also leads to questions regarding GPs' understanding of PR and the most suitable time to refer. It was apparent in this study that some HCPs adhered to their own perceived referral criteria, and therefore did not mention PR as an option for management of their condition. It is therefore imperative to include patients in the decision making process from the outset (Fowler, Levin & Sepucha, 2011), as this would facilitate them in taking control of their health. Perceptions of patients being unable to manage their own health was an aspect previously highlighted by HCPs within the sub-ordinate theme *stereotypical beliefs surrounding COPD*, however HCPs delaying referral to PR until everything else has been tried, could contribute to this issue.

Others in primary care discussed how they '*wouldn't push*' (GP 1) referral to PR with those they perceived were disinterested in the idea or unmotivated. This is associated with the COPD illness perception discussed earlier, whereby many perceived that those with the condition lack motivation. It is therefore evident that holding this belief had negative

consequences upon referral practice, and it appears that some HCPs used subjective judgement whether or not to refer, with patient resistance or a perceived lack of motivation making the individual unsuitable; a similar finding to that of Johnston et al., (2011), again evidenced in the CIS (Chapter 2). A perceived lack of interest however may be a result of the programme benefits not being explained to the patient adequately, with UK physiotherapists highlighting that those who accept referral often arrive at the programme knowing very little about PR (Summers et al., 2017). Another explanation could be that HCPs had not established a rapport with the patient, as referral to PR is most often accepted from someone who the patient trusts and who is familiar with their personal circumstances (Arnold et al., 2006); this may be associated with the perceived need for reassurance previously discussed.

In secondary care PR was perceived very much as an add on, something which may be useful, however it was believed to be beneficial for smokers, in order to aid them quitting. Another reason to refer a patient to PR was as a result of having a low socio-economic status, as it was believed that PR could educate patients and increase their health literacy. Education is a known benefit of PR (De Sousa Pinto et al., 2013), and increasing health literacy is important as it enables illness perceptions to be positively changed, and enhances adherence to self-management (Kale et al., 2015; Omachi et al., 2013; Sadeghi et al., 2013). Others in the current study perceived that eligibility would be dependent upon the age of the patient, believing that younger patients would achieve more from the programme. This however appears to be a misconception and a lack of belief in older patients' abilities, as a programme of PR has been evidenced to improve functional fitness (Alexander et al., 2012), breathlessness and general health in the elderly (Bentsen et al., 2010).

A common feature within both primary and secondary care was the uncertainty with regards to PR and its associated benefits. The degree of uncertainty was much less in HCPs working in primary care, with the majority having a good understanding of the programme, however they did discuss some aspects in which they lacked clarity. Some GPs in primary care were unsure of the specific benefits which could be achieved from attending PR and presumed that if a patient was motivated to be physically active, then PR attendance may not be required. This evidences the lack of awareness regarding the programme components and the benefits that patients may gain from attending. The BTS (2013) suggest that the dearth of value that HCPs place on PR may be a reason for lack of referrals to the programme, however no research to date has confirmed this view. Previous research has highlighted the significant role which HCPs play in the referral process, with the majority



of patients attending PR because the HCP advocated it, and suggested it would be useful (Arnold, Burton & Ellis-Hill, 2006). The current study highlights that those who were unsure of the benefits of PR often had lower levels of programme knowledge, less appreciation for non-pharmacological approaches, and were therefore less likely to refer patients. It could be proposed that these factors all contribute to a lack of referral to the programme, therefore it is important to increase HCPs' knowledge of PR, in order to influence opinions and change referral practice.

There were some in primary care who were also unsure of specific information regarding the local programme, for example what patients are asked to do during each session and how frequently they attend. This was a prominent finding, as even those who were enthusiastic about PR and had visited the local programme personally, were still unsure of specific details, which reportedly made them feel uncomfortable when discussing PR, as they felt unable to fully inform the patient. This uncertainty has been previously evidenced in primary care and was highlighted within the CIS (Chapter 2). Similar to the findings of the current study, HCPs have stated previously that if they had a better awareness of what happens during PR they could convince more patients to attend (Harrison, Hayter & Allender, 2008). This is further reiterated by Foster et al., (2016), who affirmed in primary care that PN's had a greater understanding of PR than GPs, again supporting the findings of the current study.

A striking difference between primary and secondary care was that many working on general medical wards in secondary care, both doctors and GNs, had not heard of PR, with one GN asking at the end of the interview 'so *what is it?*' (GN 2). The effectiveness of PR in reducing COPD related hospital admissions is proven (Moore et al., 2016; Puhan et al., 2016; Revitt et al., 2013), and given the concern from HCPs on general medical wards surrounding pressures on hospital capacity, the lack of awareness surrounding PR was unexpected. The finding of HCPs never having heard of PR has been highlighted previously in two studies presented in the CIS (Chapter 2) (Alsubaiei et al., 2016; Johnston et al., 2013). A further lack of knowledge and understanding regarding PR was a key theme displayed within the CIS, and evidenced in a number of papers from different countries (Alsubaiei et al., 2016; Foster et al., 2016; Harris, Hayter & Allender 2008; Johnston et al., 2011; Johnston (C) et al., 2012; Johnston (K) et al., 2012; Johnston et al., 2013; Johnston, Maxwell & Alison, 2016). This highlights that a lack of awareness and understanding of PR is not confined to the UK. Many HCPs in secondary care were not opposed to the concept of PR, however they emphasised they would need additional information to consider referral to the programme, thus a lack of knowledge of PR could be a predictor of non-referral.

Those in secondary care also appeared confused with regards to the word *rehabilitation* and seemed to associate it with returning a patient back to full health. As COPD is a chronic and progressive condition for which there is no cure, the programme does not have these capabilities, however many in secondary care found this difficult to comprehend as other programmes of rehabilitation have this potential. The issue surrounding the word '*rehabilitation*' is an original finding and therefore not previously highlighted elsewhere, it may however provide some explanation surrounding the fear patients encounter when it is described to them as an exercise programme (Thorpe, Kumar & Johnston, 2014). Poor communication from HCPs when explaining the programme to patients, may result in them declining referral or not attending, as if '*rehabilitation*' surrounding chronic lung disease is a difficult concept for HCPs to understand, then patients may also experience a similar confusion.

A prominent finding from secondary care highlighted that HCPs on general medical wards were knowledgeable about other forms of rehabilitation, in particular cardiac rehabilitation, yet were unaware of the existence of PR. This is a unique finding which has not previously been explored within the literature, and may be as a result of a greater focus upon cardiac rehabilitation during medical or nursing training, however there is no literature evidencing this. Consequently, it appears that a lack of clarity regarding PR resulted in some HCPs being unaware of the programme outcomes, with a lack of awareness of the COPD guidelines also highlighted. A number admitted they were not surprised that there were guidelines available however, they revealed they had never looked over them. This was similar to some of the HCPs working in primary care who were also unfamiliar with the guidelines, other than being aware that PR is recommended. The COPD guidelines are a key component to the overall care and management of patients with the condition (NICE, 2010), however due to HCPs in secondary care perceiving it is their role to treat the acute issue before sending the patient home, this may explain why they are unaware of them. This lack of awareness of COPD guidelines has been demonstrated in the USA, with many working in primary care never having heard of the GOLD guidelines (Perez et al., 2012), with another American study reiterating that only those who frequently care for patients with COPD are familiar with the guidelines (Salinas et al., 2011). A scoping review highlighted that there is a lack of adherence to clinical guidelines regardless of the disease, with a lack of awareness, not agreeing with suggestions, or a scarcity of time, listed as the main reasons for not implementing recommendations (Fischer et al., 2016).

As referral to PR is recommended in the COPD guidelines (NICE, 2015), the displayed lack of knowledge and awareness of the guidelines may offer a potential explanation regarding why large numbers of patients who are eligible to attend PR, are not referred (National PR Audit, 2015). COPD is known to often present with a number of comorbidities (Fabbri et al., 2008; Hillas et al., 2015; Vanfleteren et al., 2013), and as a result it is suggested that adherence to NICE (2010) COPD guidelines may be lacking, due to providing guidance on COPD in isolation, when there are often many other aspects to consider in caring for a patient with the disease (Hughes, McMurdo & Guthrie, 2013). This, however, does not account for a general lack of awareness of the COPD guidelines and it is suggested that further research is required to assess how well they are currently incorporated into the medical and nursing curricula.

All HCPs (n=14) working in primary care believed that attendance at PR would be helpful to COPD patients in some way. There was difference in responses with some advocating the programme due to observing the benefits first hand, or when patients return to the surgery and discuss how their health or quality of life has improved. Others did have reservations with regards to the benefits of the programme, however reflected during the interview and discussed there may be particular components that patients could benefit from. The '*far ranging benefits*' (GP 5) were discussed by many, such as improvement in breathing, exercise tolerance, quality of life, confidence, and a reduction in anxiety. This supports the findings of the CIS (Chapter 2), as an increase in patient confidence was identified as a prominent synthetic construct, identified in six papers in a number of geographical locations exploring HCPs' perceptions of PR (Guo & Bruce, 2014; Johnston et al., 2013; Meis et al., 2014; Molin et al., 2016; Wilson et al., 2007; Witcher et al., 2015). Moreover, improvement in exercise capacity has been documented in the patient literature (Williams et al., 2010), with a systematic review by De Soisa Pinto et al., (2013) further reinforcing the *far ranging* patient benefits discussed in the current study. Some PNs in the current study believed that the programme taught patients the importance of exercise and acknowledged the benefit gained from this message being reinforced week by week. The behaviour change techniques taught during PR which facilitate patients to modify their behaviour in order to achieve the best outcomes were perceived as invaluable by some of the PNs. This view may be more prominent amongst PNs in comparison to GPs or those working within secondary care, as they are now often the ones delivering health behaviour change interventions (Taylor et al., 2011).

Although GPs in general were a little less certain over the benefits achieved, all perceived that attendance at PR would be useful to patients in some way. The benefits of educating

patients about their condition and the advantages of exercise were discussed, alongside the PR team having more time than GPs to provide one-to-one advice. A similar opinion was held by HCPs who deliver PR, who believe that a benefit of the programme is being able to educate patients and build upon this knowledge in each session, which those working in primary care may not have time to do (Guo & Bruce, 2014). An increase in patient knowledge has also previously been acknowledged as an advantageous aspect of PR by other HCPs (Meis et al., 2014; Wilson et al., 2007). HCPs perceptions of an increase in knowledge has however not previously been displayed in those working in England, as the study by Guo and Bruce (2014) was conducted in Canada, that by Meis et al., (2014) in The Netherlands, and Wilson et al., (2007) in Northern Ireland. In the current study some GPs highlighted that they were aware from medical school, that PR is advantageous for COPD patients, although this had not encouraged them to make a referral to the programme. This differs from those in secondary care who discussed how PR had never been referred to during their training. This is interesting to note, as all trainee doctors will have undertaken a standard medical degree, however as curricula may differ slightly dependant on university, it may be that PR was only mentioned briefly, therefore those in secondary care do not recollect it.

Regardless of whether patients benefitted physically from attending PR, PNs discussed the psychological benefit gained from the social interaction of the group setting, and how many patients form strong friendships with those in a similar situation. The reduction in social isolation via the formation of a bond with another individual with COPD is evidenced elsewhere as a benefit of PR (De Sousa Pinto et al., 2013; Willaims et al., 2010). This is advantageous as it is well established that a significant number of patients diagnosed with COPD become socially isolated (Seamark, Blake & Seamark, 2004), which can often impact upon quality of life (Gardiner et al., 2010) and mortality rates (Yorgancioglu et al., 2010). It was therefore evident that although PNs appreciated the improvement in exercise tolerance, they also had the ability, possibly due to a more in-depth knowledge of the programme, to see beyond this and appreciate the wider benefits gained from attendance, with PR described as completing the 'holistic picture' to COPD management. This notion of PR providing holistic care for patients with COPD, especially those with additional comorbidities has been evidenced previously, although an appropriate strategy has not been adopted globally (Hillas et al., 2015).

The multi-disciplinary nature of PR is believed to meet the requirements of an holistic approach, by improvement in health related quality of life (Janssens et al., 2011; McCarthy et al., 2015), exercise tolerance (McCarthy et al., 2015; Rochester et al., 2015), and ability

to carry out daily activities (Paz-Diaz et al., 2007). An enthusiasm for the programme was evident amongst the majority of the PNs interviewed in the current study, and this could be as a result of a greater understanding of the programme and the benefits achieved from attending a PR session. PNs perceived that referral to the programme would be beneficial regardless of where the patient was in the disease trajectory, as they could participate in as many of the programme components they were able to do so.

Conversely, in secondary care HCPs were able to appreciate the potential benefits of attendance at PR, however these were often assumptions due to a lack of knowledge with regards to the programme. In general the appreciation of the benefits in secondary care were closely related to the perception that the programme would be beneficial if it had the ability to reduce hospital admissions. This reiterates the experiences of those working on the general medical wards, as they perceived PR would be able to increase patients' knowledge of exacerbations and the appropriate time to seek medical intervention. Increased patient understanding of COPD and education surrounding exacerbations was also perceived beneficial by HCPs in the study by Wilson et al., (2007), displayed in the CIS (Chapter 2). Further support of this finding has been displayed in another paper detailed in the CIS whereby HCPs' perceived that a benefit of patients attending the programme was to assist with a recognition of a worsening of symptoms and to equip them to seek help promptly (Johnston et al., 2013).

In the current study it was suggested by those in secondary care, that PR may have the ability to break the cyclical nature of attendance at hospital by offering support subsequent to a hospital admission. The notion of PR reducing hospital admissions is discussed widely within the literature (Morgan, 2003; Puhan et al, 2016; Revitt et al., 2013). Other non-pharmacological approaches such as group based cognitive-behavioural therapy for breathlessness have also been effective in reducing A&E presentations amongst the elderly COPD population (Howard et al., 2010). Providing patients with a purpose and dispelling fears after hospital was deemed advantageous, and PR was therefore described in the current study as a safety net for those with COPD. This is further supported within the literature with patients reaffirming that PR enables them to regain control and positively changes their outlook on life, removing some of the associated anxiety (Zarisson, Theander & Carlson, 2014). This is similarly described by other HCPs within the literature, who discuss that PR ensures that patients do not feel as though they are dealing with the condition alone (Meis et al., 2014), with patients also finding comfort in the support gained from the programme (Toms & Harrison, 2002). Although, the HCPs working on general medical wards could appreciate these benefits of PR, it was surprising that none had referred a

COPD patient to the programme whilst working within secondary care. This finding did not differ across either of the two hospital trusts where HCPs were recruited. This was a pertinent finding and was attributed to a lack of knowledge surrounding the programme, uncertainties in how to refer, or not considering it was part of their role.

HCPs perceived patient barriers to PR was a sub-ordinate theme identified and discussed at length within both primary and secondary care. There were commonalities in perceptions of barriers to the programme between professional groups and healthcare settings, such as location, transportation and the suitability of the time for patients to attend. These issues are all prominent within the literature and were discussed extensively in the CIS (Chapter 2), and highlighted as barriers to the service by HCPs (Alsubauei et al., 2016; Johnston et al., 2011; Johnston et al., 2013; Johnston, Maxwell & Alison, 2016; Molin et al., 2016; Wilson et al., 2007) and patients alike (Keating, Lee & Holland, 2016). Similarly, issues with transportation and distance from where PR is delivered are reported as the most common reasons amongst patients for non-attendance (Hayton et al., 2013). HCPs in the current study stressed the difficulty for patients who continue to work attending a programme delivered during the day; consistent with the findings of Fischer et al., (2007), and Marthar et al., (2017). This issue may have arisen due to patients being diagnosed with COPD younger (Sanchez-Salcedo et al., 2014), and due to a growing aging population with people working later in life (Maltby, 2011). The complexities of patient access was discussed in detail by one doctor in secondary care, who associated the problem with the '*inverse care law*' (DR 4), stating that those who probably would benefit from the programme the most, are the ones most likely to have difficulties in accessing it. This raised a valid point, as the inverse care law is referred to widely within the literature in relation to patients in socially deprived areas often having greater trouble in accessing the care they require (Hart, 1971; Mclean, Sutton & Guthrie, 2006; Watt, 2002). Although this issue has been extensively referred to within the literature, this is a unique finding as it has not previously been identified as a barrier to PR. Although this association was only made by one HCP, and should be therefore treated with caution, it would be interesting to further establish if others consider the inverse care law to be a factor which inhibits access to PR.

A PN discussed how language barriers restricted patient attendance; this was a novel suggestion and was not discussed by any other participants. This participant worked in a city centre practice with a large diversity of nationalities and perceived many would not be able to attend due to being unable to read the information on the referral letter, or the street signs to access a location they were unfamiliar with. This is not present elsewhere within the literature, however it raises questions surrounding the frequency of this issue throughout

the UK, and the number of DNAs as a result. This could also be an issue for other services provided by the NHS, and supports the findings of Bischoff et al., (2003), who reported that language barriers are a risk factor for a lack of referrals to services involving physical or psychological care. The difficulties of HCPs communicating with non-English speaking patients is displayed elsewhere, with the additional time required to explain and ensure that the patient understands the information they have been told (Ian, Nakamura- Florez & Lee, 2016), with interpreters often facilitating this process (Bischoff & Hudelson, 2010; Ian, Nakamura- Florez & Lee, 2016). This may be problematic when discussing PR, given the limited time constraints surrounding appointments highlighted as an issue in the current study. Non-English speaking patients have highlighted the need for better communication as interpreters are often difficult to understand, which results in poor understanding and adherence (Raynor, 2015). Although, a difficulty in communication in English has not previously been stated as a barrier to PR, a paper included in the CIS (Chapter 2) (Johnston et al., 2013), recommended that there should be some PR programmes available in Australia, which are delivered in languages other than English. This evidences that if non-English speaking patients do attend the programme, they may be unable to understand information and follow instruction once there.

In primary care some HCPs discussed how patients reported disliking the group setting and associated this with feelings of anxiety. This contradicts opinion amongst those working in primary care who highlighted that the social interaction was a benefit of the programme. The dislike of the group setting has previously been highlighted as a barrier to patient attendance at PR within the literature displayed in the CIS (Chapter 2) (Alsubaiei et al., 2016). However, previous research by Arnold, Bruton and Ellis-Hill (2006) has highlighted that once in attendance at PR the group support encourages continued adherence. The issues surrounding the group setting were also discussed in secondary care, however these were in relation to HCPs perceiving it detrimental to patients to see another individual whose condition was worse than their own, as it may appear as though they are looking at their future self. This however contradicts the findings of the CIS (Chapter 2), where HCPs viewed that patients benefit from the bonds created with other patients who have been diagnosed with COPD (Guo and Bruce, 2014; Meis et al., 2014; Witcher et al., 2015).

There were certain perceived patient barriers highlighted which were exclusive to those working in secondary care. There was the perception that COPD patients find exercise too difficult, with some perceiving that they are incapable of it. This is a nihilistic view, however there are patients who have reported that, after attendance at PR, although they still do not enjoy exercise, they appreciate the importance of it, and attendance has made a significant

positive difference to their life (Cruse, 2007). This view was also related to the perception of one GN, who discussed how she perceived that PR caused COPD patients to exacerbate. She therefore believed that PR caused an increase in hospital admissions, which is the opposite of what the programme aims to achieve and the evidence that PR can reduce COPD related hospital admissions (Moore et al., 2016). This GN admitted that she had gained this perception from another GN working on the ward, however it would be unlikely that she would refer to a programme due to perceiving PR causes a deterioration in symptoms. Therefore this highlights the need for increased education surrounding PR, to ensure that HCPs are clear regarding the aims and programme outcomes, and a consistent message is achieved.

Others in secondary care perceived that there are some patients who would not want to attend. This is a similar finding to that of Johnston, Maxwell and Alison (2016), and Cochrane et al., (2016) highlighted in the CIS (Chapter 2), who also found that some HCPs perceive that there are particular patients who do not want to go to PR. In the current study this was associated with the view that patients would prefer to take medication than exercise. Again, this is pre-judgemental and possibly a belief that may be held due to COPD illness perceptions surrounding a lack of motivation and compliance. A similar barrier discussed was that some become 'expert patients', and this was attributed to the patient feeling that they know better and being resistant to suggestions on how to improve their health. Conversely, the expert patient is referred to positively within the literature in respect of chronic respiratory disease management. The expert patient is described as an individual who is knowledgeable about their condition, medication and self-management, who can communicate well with HCPs, and also act as an educator for other patients (Boulet, 2016). Previous research on HCPs perceptions of PR has not attributed 'expert patients' as a barrier to attending PR, thus this finding is unique to the current study. It however would be interesting to explore if this perceived barrier is more closely associated with certain personality types and being resistant to change, rather than the view that all those who are knowledgeable or have strong views about their condition will not attend PR.

Overall, *pulmonary rehabilitation beliefs* was a prominent super-ordinate theme. It was evident that those in primary care had greater knowledge and understanding of PR than those working in secondary care, some of whom were unaware that the programme existed until the interview. Within secondary care there was confusion surrounding the name pulmonary rehabilitation, with respect to what the programme involved and which patients would be suitable. Those in secondary care also acknowledged greater understanding of other types of rehabilitation, such as cardiac and stroke rehabilitation. All HCPs believed



that there was some benefit to patients attending PR, whether this be physical, psychological or social. HCPs in secondary care were able to appreciate the benefits however these were less certain, due to a lack of programme knowledge. Perceived patient barriers to PR were discussed at length with transportation, location, language barriers, disliking the group setting, considered problematic for some patients with COPD.

#### **5.4 ORGANISATIONAL AND REFERRAL PATHWAY PERCEPTIONS:**

*Organisational and referral pathway perceptions* was a prominent super-ordinate theme within both primary and secondary care. Discussion focused upon HCPs lack of awareness of PR and this was attributed to a lack of teaching on the programme during medical and nursing training, and a lack of publicity and information provided by the service. The referral processes associated with PR was also discussed, along with highlighting any perceived barriers or facilitators to referral.

HCPs on general medical wards appeared to blame their lack of awareness of PR on a lack of publicity. This finding was exclusive to secondary care and was often attributed to a lack of exposure to the programme. There was a consistent view that PR was missing from the medical and nursing curricula; HCPs discussed how if the programme was mentioned, little emphasis was placed upon it. This is a unique finding, as a lack of teaching of PR has not previously been attributed as a barrier to referral within the literature. Others reiterated a lack of exposure during training, adding that they were only aware of the programme as a result of their own reading. Therefore, this emphasises that knowledge of PR may be dependent on the motivation of the HCP to do additional work outside of the classroom, and may provide a possible explanation of the wide variation in referral practices. There is a recognised need that HCPs need to commit to lifelong learning, due to the possible reduction in clinical performance over a period of time and the diversity and enhancements in healthcare (Glasziou, Burls & Gilbert, 2008). Thus, it appears important that HCPs are taught the key foundations during their training, yet are also encouraged and motivated to continue to learn throughout their career.

This lack of exposure to the programme was compounded by a lack of opportunity to attend PR. One doctor highlighted that experience days were offered to trainees for other conditions such as stroke rehabilitation, however these had not been offered by the PR service. This may provide explanation as to why HCPs were familiar with other types of rehabilitation, yet have no knowledge or a diminished understanding of PR. A lack of PR exposure for medical and nursing students could disadvantage patients, as experienced

based learning is important within medical education to add depth to understanding, through adding context and consolidating thoughts and perceptions (Man, 2011). Experienced based learning theory was first proposed by Kolb (1984), and builds upon the theories of learning discussed by educational theorists and psychologists. These included yet were not exclusive to Kurt Lewin, John Dewey, Lev Vygotsky, William James, Carl Rodgers and Carl Jung. The experiential learning theory evolved through the integration of key aspects identified in the work of these theorists and psychologists and focuses upon the cycle of learning via the transformation of experiences and reflection (Kolb & Kolb, 2009). The cycle consists of a series of *concrete experiences* referred to as the process of feeling, *reflective observation* via watching, *abstract conceptualisation* taking form through thinking, and *active experimentation* which occurs through doing and trying (Kolb, 1984; Kolb, 2015). The cycle is not designed to have a start point, however it is proposed that meaningful learning occurs through the process of progression around it (Bates, 2016).

In respect of medical education, experiential learning involves creating a curriculum whereby the learner is offered opportunities to acquire knowledge and insight from those currently working in different professional roles and from the environment they work within (Yardley, Teunissen & Dornan, 2012). As a result it is perceived beneficial in medical education, as it is evident that levels of experience can impact upon individuals' perceptions of a phenomena and the understanding that is constructed as a result (Yardley, Teunissen & Dornan, 2012). This is an important aspect when considered in the respect of a lack of exposure to PR, and may provide some explanation as to why HCPs in secondary care were unfamiliar with the programme, and had never considered referral. Thus, the suggestion of observing a PR session first hand may be advantageous in increasing referrals from both primary and secondary care.

The need for further information to raise awareness of the programme was evident, and this was closely aligned to HCPs' views regarding the lack of advertisement and publicity for the programme. HCPs on general medical wards highlighted that it should be a responsibility of the service to inform staff of availability of PR, and this caused frustration. There was a belief that in order to increase referrals, the service first needed to increase HCPs' knowledge of the programme. Some therefore offered suggestions, which included PR talks for staff to attend, mail shots, posters, and displaying PR as a message of the day when unlocking their computers. This was a similar finding to the study by Foster et al., (2016), referred to in the CIS (Chapter 2), whereby GPs and PNs suggested it would be useful for someone from the PR team to come to the surgery to conduct an informative session for all staff. In the current study, it was also evident that there was a lack of information on PR

which could be handed to patient's if HCPs decided to refer, with one GN (GN 7), discussing this as a resource readily available in her previous role in primary care. These leaflets and resources are referred to within the literature as decision aids and provide patients with up to date relevant evidence based information, alongside the HCPs perceptions, to assist them in making their own informed choice (Elwyn et al., 2010). Those working in secondary care discussed how they would consider referral to PR if they had a greater awareness of the programme, and it was believed that it was the role of the local PR team to provide this information. Such responsibility has not been placed on local PR teams within the literature as a reason for a lack of referrals to the programme, thus this is an original finding. Therefore, it is apparent that PR teams need to work more closely with those in secondary care to raise awareness of the programme in order to increase referrals.

In primary care, information was lacking around specific programme details, including the programmes' structure and locations, which resulted in patients receiving unclear information at the time of referral. This is an issue, as it may impact upon the numbers of patients who actually decide to attend and may result in unrealistic views of the programme as evidenced within the literature (Harrison et al., 2015). There was the belief that this lack of information was specific to PR, with many other services such as cancer and diabetes much more forthcoming with information. This may be as a result of the often unstable nature of PR, with regards to funding and changeability of the service (Rochester & Spanevello, 2014). In an audit study of 239 PR programmes in the UK a lack of funding was acknowledged as a major barrier in the expansion of the service, and in some cases resulted in programmes being withdrawn (Yohannes et al., 2011). Issues surrounding funding were further addressed in a qualitative interview study of 17 physiotherapists in the UK, previously discussed in the CIS (Chapter 2) (Summers et al., 2017). The physiotherapists highlighted that they perceived funding to dictate the amount of support provided by the service which had further implications for the programme content and staffing. Therefore the literature evidences the disparate nature of the availability of programmes across the UK, and as a result could impact upon HCPs referral practices.

Deferral of responsibility was a prominent sub-ordinate theme discussed in both primary and secondary care, and the pertinence of this issue is reinforced by five studies identified within the CIS (Chapter 2) (Foster et al., 2016; Harris, Hayter & Allender, 2008; Johnston et al., 2011; Molin et al., 2016; Motegi et al., 2012). In the current study GPs in primary care often shifted the responsibility of referral to others, believing it was either the role of PNs or the responsibility of those in secondary care, thus not appearing to prioritise PR at all. This

may be due to the feeling of not having the '*capacity to take on anything extra*' (GP 3), or not appreciating the programme's importance, due to its non-pharmacological approach.

GPs provided excuses concerning why they felt PR referral was not part of their role, and it appeared they believed that PNs were better at referring patients to the programme than themselves. It is however recommended within the literature that referral to PR should be made by a HCP who the patient has a good relationship with and trusts (Arnold et al., 2006), and for those with COPD this often is their GP, due to patients feeling comfortable after having established a relationship with them (Sheridan et al., 2011). Similar to the findings of the current study, the literature highlights that on average more referrals are made from primary care than secondary care to PR programmes, however those referred by a GP are less likely to complete the programme (Hogg et al., 2012). This lack of PR completion from patients referred by GPs may be as a result of the lack of enthusiasm, belief, or not considering it as their role, evidenced by some GPs in the current study, or that patients do not appreciate the importance of attendance. In general, referral of patients to PR in the UK is lacking (National PR Audit, 2015), with low referral rates to PR from primary care also highlighted in a review of the literature (Johnston & Grimmer-Sommers, 2010).

It was unusual for PNs in the current study to defer referral responsibility, however they felt pressurised that the role of referral was solely left to them. Referral to PR often took place during COPD annual reviews, and PNs believed there was not enough time to complete all the other tasks in addition to the referral. The time constraints of a 30 minute review lead to one PN deciding to wait until the following year to refer a patient to PR. The restricted primary care appointment times have also been cited as a barrier to PR referral in Australia (Johnston, Maxwell & Alison, 2016), highlighting that this is not an issue exclusive to the UK. Some PNs suggested that on occasion they delayed referral, and although it was evident that a number of the PNs in the current study felt burdened, this decision could negatively impact upon the patients' health. It could also be possible that they, or whoever conducts the annual review the following year, may be experiencing similar pressures. This is similar to GPs in the study by Walters et al., (2008) who delayed the diagnosis of COPD; the authors highlighted the negative consequences that this delay can have upon the patients' health and emotions when eventually diagnosed, with patients often feeling deceived. COPD patients who highlight they do not remember being offered attendance at PR (Marthar et al., 2017), could possibly experience similar emotions as they may be disappointed to find when the programme is eventually discussed, that they could have already been benefiting from PR.

Therefore, there was dichotomy between the views of HCPs in primary care, with GPs perceiving that referral should be made during an annual COPD review, however failing to appreciate the extent of what needs to be covered, resulting in insufficient time to fully address PR. These findings were also seen within the study by Harris, Hater and Allender (2008), seen in the CIS (Chapter 2), whereby PNs felt the responsibility of referral to PR had been purely shifted to themselves, as they were responsible for chronic disease management. Furthermore, similar to the findings of the current study GPs reported feeling deskilled as a result of this. The study by Harris, Hayter and Allender (2008) was conducted within primary care in the North Midlands, thus evidencing that the issue may be apparent in a number of locations, however studies incorporating greater numbers of HCPs would be required to establish this.

It was interesting to note that one GP commented (GP 8) that many working in secondary care probably believed that GPs were referring to the programme, highlighting the cyclical nature of passing referral responsibility to someone else. The lack of taking responsibility for referral to PR evidenced here, contradicts the patient centred care approach, which endeavours to meet patient needs whilst providing a positive healthcare experience (Feo & Kitson, 2016). Patient centred consultations facilitate patient empowerment (Holström & Röing, 2010), however HCPs appear to be removing the choice of attending PR from the patient, by not discussing the programme, either due to perceiving it as someone else's role or being too busy. Therefore, this removes any shared decision making, which is imperative to patient centred care (Stiggelbout et al., 2012).

Similarly, those in secondary care deferred the role of referral to those working in primary care. The reason some provided for this was that they considered PR as a holistic approach, which had a greater place in primary care. This suggests the lack of significance those in secondary care place upon the programme and non-pharmacological interventions. The use of holistic care within COPD is strongly promoted in order to care for all of the patients' needs, due to often having a large number of comorbidities (Gruffydd-Jones & Loveridge, 2011). However, in support of the current study the literature evidences that hospital physicians may sometimes be reluctant of this form of care due to the prominence of biomedicine in their role (Malik, Hilders & Scheele, 2018). As a result, doctors in secondary care appeared to favour pharmacological management, exemplified as patients '*would rather you gave them a pill to take than offer them an exercise class*' (DR 4). This was similar to the findings of Guo and Bruce, (2014) who highlighted that patients preferred to have a '*magic pill*' (pg 5) than participate in exercise. This perceived view that patients are more receptive to medication and adherence to the medical model, as previously discussed,

may explain why doctors in secondary care did not refer to PR, despite some being aware of it.

Others in secondary care appeared disinterested in respiratory conditions, and as a result believed that their role working on a general medical ward was to treat the acute condition and return the patient back to base line. The literature however displays that if these HCPs were to consider referring patients to PR, they should not portray this lack of interest to the patient, as typically the success of the programme lies in the enthusiasm of the referring HCP, rather than the level of information provided (Bulley et al., 2009). In the current study, in secondary care, a dismissive attitude towards PR was found in HCPs working on general medical wards who did not consider PR referral as part of their job. This responsibility was then shifted to either the respiratory team, primary care, or the discharge team. Although some considered it as the discharge teams role, they admitted that they were unsure of the discharge process. It appeared in secondary care that HCPs held specific views of what their job role entailed, and possibly in order to compensate for a lack of knowledge, would transfer the responsibility of referral to someone else. One doctor in secondary care discussed how primary care probably thought that general medical wards were referring patients to PR, however they believed that primary care were the ones initiating this; a very similar story to the views of GPs in primary care. Apart from PNs, everyone appeared to defer referral responsibility in some way, with each believing it was another person's role. This could also further emphasise the lack of referrals highlighted in the National PR Audit (2015).

Referral to PR was often perceived as complex and arduous by those working in primary care; those in secondary care could not comment on this due to being unfamiliar with the referral process. Perceived HCP complexities surrounding referral are acknowledged as a prominent issue within the literature, and therefore lead to the formation of a synthetic construct surrounding this in the CIS (Chapter 2). The difficulty in knowing the most appropriate time to refer was evident in primary care, thus there was suggestion that the referral criteria needs to be clearer. Similar uncertainties are displayed within the literature with questions surrounding whether PR is most effective directly after an exacerbation or when the patient's condition has stabilised (Puhan et al., 2012). Furthermore, as previously discussed with regards to difficulties surrounding the name pulmonary rehabilitation, the word '*pulmonary*' also appeared to cause confusion over who would be eligible to attend, with some believing the programme would be suitable for any respiratory patient. This evidences a clear lack of awareness of the BTS guidelines (2013), which discuss patient suitability and eligibility for PR in detail, and how although referral criteria differs between

programmes with some accepting patients with other conditions, it is predominantly for those with COPD, as this is where the substantial evidence base exists.

Although those working in primary care in the current study were much more likely to refer patients to PR than those working in secondary care. Some had grievances with the referral forms being complicated and time consuming to complete, alongside the service constantly changing, which made it difficult to keep up to date with the most current information. The time required to complete a PR referral was highlighted as a frustration within the CIS (Chapter 2) (Cochrane et al., 2016; Johnston et al., 2011; Harris, Hayter & Allender, 2008; Molin et al., 2016). Therefore there is a clear need to streamline the referral process in order to increase referral rates. In particular, in the current study HCPs were annoyed after completing lengthy referral forms requiring copious amounts of information, that a scarcity of feedback was provided by the PR service after the patient finished the programme, often simply just stating that the patient either completed or dropped out. As a result of a lack of communication from the service HCPs were unaware of whether the patient had improved, and if so what benefits had been gained. The importance of interdisciplinary team work and effective communication is considered essential, especially when caring for those with chronic diseases, due to the multifaceted nature of the condition (Nancarrow et al., 2013). In this study, a lack of communication seemed to lead to HCPs feeling devalued by the service, and as a consequence HCPs may decide against future referrals to PR because of uncertainty regarding effectiveness.

It was perceived onerous by many of the HCPs working in primary care to convince patients that a programme which contained light exercise would be beneficial to their condition. The difficulty in persuading patients to attend acted as a deterrent to referral for some. This has been reiterated within the literature whereby HCPs sometimes overlook discussion of PR due to being worried about asking a patient to exercise (Johnston et al., 2013; Johnston, Maxwell, 2016 ). Elsewhere, PNs have also found it difficult to discuss referral to PR, as they perceive that as a nurse in good health themselves, it may appear patronising to ask someone who is struggling with breathlessness to exercise (Harris, Hayter & Allender, 2008). The literature in relation to a difficulty of convincing patients to exercise was explored in detail in the CIS (Chapter 2). This highlights the extent to which HCPs feel uncomfortable discussing exercise with those who are breathless and may be as a result of either poor knowledge of PR and being unable to persuade the patient of the programmes' benefits, or poor HCP communication with the patient not understanding the value of the programme. These issues surrounding effective HCP communication therefore need to be targeted in order to increase referrals to the programme. Those in the current study in primary care,

also believed that patients could only be encouraged to attend if the HCP believed in the programme themselves. Thus, more needs to be done to persuade HCPs of the benefits of PR in the context of COPD.

Further issues in primary care included the demographics of the group, with younger patients perceived as less likely to accept a PR referral. It was viewed that patients were being diagnosed with COPD earlier due to the increase of cannabis use in particular areas. This connection between younger individuals, cannabis use and the rise of COPD has been highlighted elsewhere (Gates, Jaffe & Copeland, 2014; Macleod et al., 2015). It therefore appears that the demographic of the 'typical' COPD patient may be changing, and as a result different approaches may need to be adopted when convincing this younger age group of the benefits of attending PR.

As those interviewed in secondary care had not previously made a referral to the programme, they were therefore unaware of patient suitability and the referral process. As previously discussed there was only one GN who had referred to PR in a previous primary care role, however had not referred whilst working in secondary care. This may have been due to considering it as the role of those in primary care, however was consistent with the findings of Harris, Hayter and Allender (2008), Johnston et al., (2011), Molin et al., (2016), as discussed in the CIS (Chapter 2), who perceived that referral of PR was easy to overlook, as although aware of the benefits, the associated barriers discouraged referral.

As a result of the lack of knowledge surrounding the programme, or which patients would be most suitable, this appeared to evoke anxiety and concern in the current study within secondary care, about being asked to make a referral to PR. It was apparent that there was worry associated with making an incorrect referral, and the HCPs interviewed would rather have someone instruct them on the process or prefer someone from the respiratory team to make the ultimate decision. This evidences how a lack of knowledge surrounding a particular aspect of care can impede HCPs' confidence in carrying out tasks. The suggestion of a referral checklist was offered by one GN, who discussed how a checklist is completed as standard when a patient arrives with alcohol excess, and that a similar system may be beneficial for those who arrive on the ward with COPD. This type of tool may be useful, as referral processes for PR currently vary nationwide, and are dictated by the service (BTS, 2013). Similar issues within the literature have surrounded referral to cardiac rehabilitation, however suggestions included better education with regards to the programme for those working in secondary care, and making referral automatic upon discharge (Arena et al., 2012). Although, automatic referral may not always be viable for



those admitted to hospital with COPD, raising awareness or, as suggested in the current study using a checklist, may ensure that patients eligible do not miss the opportunity to attend.

Some in secondary care in the current study discussed what they perceived the referral criteria would entail, however they admitted that these were merely assumptions. It was apparent that doctors in secondary care had slightly greater levels of awareness of PR than GPs; a distinct difference from PNs having much greater knowledge than GPs in primary care. The doctors in secondary care also discussed how they probably would refer to the programme, however were unsure if this would be actioned by telephone, email or if they needed a referral form. Thus, evidencing the need for greater knowledge surrounding the referral process.

The sub-ordinate theme *facilitators to referral* was only identified within primary care. Although many of the HCPs described and focused upon the issues and barriers surrounding PR, some GPs and PNs described particular aspects which aided referral. These often were the opposite of the issues discussed under the difficult referral sub-ordinate theme and concentrated on the logistical aspects. Similar to the findings of a systematic review by Cox et al., (2017), a simple referral process was considered as one of the greatest facilitators to referral. Electronic self-populating referral forms were praised in the current study for their simplicity, and reduction of time previously associated with completing and faxing documentation to the PR team. Electronic referrals have transformed the healthcare service, providing improved communication between primary and secondary care and made distribution more effective (Kim et al., 2009; Straus et al., 2011). Other facilitators within the current study were highlighted, and included having contact details of someone who could be approached regarding questions surrounding referral criteria; this was something highlighted as lacking for those in secondary care. In addition, one PN discussed how a new diagnosis of COPD acts as a reminder for her to initiate a referral, and admitted that she is '*much more thorough with it, with the newly diagnosed*' (PN 5). Although this PN acknowledges that a new diagnosis instigates a referral, if she does not remember to refer those who have had COPD for some time, this disadvantages those patients in accessing the service.

Overall, it was evident that referral procedures differed over the North West of England, with the service responsible for the format of the referral, and how much information they require. It was deemed that those who had a simplistic referral process and support from their local

team, were much more likely to refer than those in an area with a changeable service and little information or assistance.

## **5.5 CHAPTER SUMMARY:**

This chapter aimed to synthesise the findings with the literature discussed within the Introduction Chapter (Chapter 1) and CIS (Chapter 2), as well as drawing upon the wider body of literature. Similarities and differences between the findings of the current study and the literature have been highlighted, alongside commonalities and divergences amongst different HCP professional groups, and primary and secondary care, in keeping with IPA (Smith, Flowers & Larkin, 2009). Original contributions to knowledge have been identified and acknowledged throughout the discussion and will be further focused upon in Chapter 7.

It should be acknowledged that literature directly pertaining to HCPs perceptions of PR as a management strategy for patients with COPD has never been the emphasis of any previously conducted study. Data was therefore extracted in the CIS from studies with a wider focus and has been drawn upon in this chapter. Whilst designing the current study the National PR Audit (2015), highlighted that there was a lack of referrals to PR in England, however the reasons surrounding this were unknown. The audit concluded this may be as a result of a lack of HCP knowledge and awareness of PR, yet these were merely assumptions due to the lack of current literature. This further emphasises that this is a unique body of work, with the ability to inform policy and practice as discussed in Chapter 7, and to also further underpin the findings of the CIS.

This study aimed to explore the perceptions of HCPs working in primary care and on general medical wards in secondary care surrounding PR as a management strategy for patients with COPD. No previous research has focused upon and included the perceptions of HCPs working in these two areas, therefore the current study aimed to bridge this gap in the literature. It is perceived that the current study met the objectives. New knowledge has been highlighted in relation to HCPs' illness perceptions, and the potential these may have to influence a referral to PR. In addition, the perceived barriers and facilitators to referral have been displayed, alongside HCPs organisational and referral pathway perceptions. The subsequent chapter details the researcher reflections documented throughout the PhD, and aims to offer insight into personal researcher thoughts throughout the duration of the study. The final chapter will offer strengths, limitations and recommendations for research, practice and policy, building upon the findings explored within this discussion.

## **CHAPTER 6: RESEARCHER REFLECTIONS**

### **6.1 INTRODUCTION:**

This chapter aims to provide the reader with an overview of my personal journey throughout the study as the researcher. As reflexivity is a prominent aspect of IPA and phenomenological research, developing a level of self-awareness and reflecting upon experiences throughout the duration of the study was considered imperative (Smith, Flowers & Larkin, 2009). This process was facilitated by a researcher reflexive diary as recommended by Smith, Flowers and Larkin (2009), which was used at every stage of the research to note any personal thoughts, feelings, observations or explanations.

I conscientiously noted down personal reflections from the commencement of the research design process, through until completion of the study. Within this chapter it will therefore not be possible to discuss all of the reflections detailed within the diary, however some of the most pertinent extracts have been provided to evidence my thoughts and feelings captured at particular moments in time. As a result, this is the only chapter within the thesis which will be written in first person, however it was perceived imperative that my voice as the researcher was documented.

The diary served most useful during the participant interviews, and many of the entries written during this time were drawn upon to assist with interpretation of participants' accounts during the analysis stage. Reflexivity allowed me to draw upon my own experiences and perceptions of PR, and document any change in these opinions throughout the research process. The personal reflection within this chapter will hopefully serve to increase the rigour of the study (Smith, Flowers & Larkin, 2009).

### **6.2 DOCUMENTED REFLECTIONS THROUGHOUT THE STUDY:**

Upon commencement of the study I was worried about the prospect of interviewing HCPs, due to not having a HCP background myself. On reflection this was not something I should have been anxious about, as I had previously interviewed GPs during my Psychology MRes. I was, however, nervous about interviewing different HCPs working in both primary and secondary care, and felt somewhat a sense of imposter syndrome, wondering whether they would respect me, or even participate in my research, given my non-professional background. Prior to each interview I introduced myself as a PhD student with a psychology

background and, to my surprise, this appeared to assist me in establishing a rapport with the HCPs.

Within the initial interviews it became very apparent that I was not always familiar with some of the medical terminology that some of the HCPs used, particularly with regards to acronyms. This resulted in me entering my own personal battle about whether I should probe HCPs with regards to this and ask them to explain certain concepts in further detail, or if this would suggest to HCPs that I was not suitable to be conducting the interviews. Initially this was a challenge and I was reluctant to acknowledge my unfamiliarity, however I decided to make HCPs aware that there may be some aspects I may ask them to explain in further detail, to provide extra context. Given they were aware of my non-HCP background, they each accommodated this, and I felt this enabled me to gain richer data. This also reduced any potential power imbalances which are sometimes seen during interviews between two HCPs, or someone who is perceived more knowledgeable (Råheim et al., 2016). I believe that those who admitted to a lack of knowledge surrounding PR often did so because they felt comfortable during the interview, and in the knowledge that I was not there as a HCP, nor to judge them in any way.

In June 2017, I was invited to a Roundtable Discussion on PR at the BLF Head Office in London. I felt privileged, yet nervous that my research had been recognised and I had been invited to provide my views on ways to increase uptake to PR at such an early stage in my career. These views are demonstrated in the diary entry excerpt below:

*Diary Entry: Attendance at the BLF Head Office PR Round Table Discussion 5<sup>th</sup> July, 2017.*

*'I am on the train to London Euston as I write. I was incredibly shocked to receive an email a few weeks ago from the Chief Operating Officer from the BLF, inviting me to attend the Round Table Discussion. At that moment in time I thought I had probably been entered on to a mailing list and been invited by mistake, so replied politely stating that I would love to attend, however proceeded to tell the Chief Operating Officer that I was a PhD student at Edge Hill University and my research focused upon HCPs' perceptions of PR. He replied to say that he knew about my research after meeting with his North West Development manager and that he also followed me on Twitter. To this day I am still astonished that I have been invited to provide my views. I am incredibly anxious as I have never done anything like this before, yet am really excited at the same time. I have been sent an agenda for the day's discussion and have pre-planned some points which I can discuss, I am sure*

*that the nerves will settle once I have navigated my way across London and met everyone at the BLF Head Office.'*

I was able to provide suggestions and disseminate the findings I had gained up to that point, highlighting the barriers and facilitators to PR which HCPs encounter. The topic of changing the name 'PR' was discussed at length, and at this point I had not conducted many interviews in secondary care, however after interviewing those working on general medical wards, HCPs also discussed confusion surrounding the name of the programme, with regards to what it entails and who it would be suitable for. It was positive to contribute towards, and hear that the views of those in attendance were similar to the HCPs who participated in the study. The outcome of the discussion was that the name PR should be changed to something which better captures the outcomes of the programme and empowers patients, for example breathe better. It was however viewed that this would be a complex process as the term PR is used worldwide, thus the implications of such change would be much greater than the impact on just the UK.

After conducting a few interviews in secondary care it became apparent that some were unaware of PR. This was an unexpected finding and on 12<sup>th</sup> July 2017 I wrote: *Some HCPs have never heard of PR, should I let them participate?* This reflection was initiated by a GN who asked at the end of the interview with regards to PR 'So *what is it?* (GN 2), even after conducting the CIS I did not think that I would ever have anticipated HCPs either during, or subsequent to the interview, to ask what the programme was, as they had never heard of it. Others in secondary care admitted towards the beginning of the interview that they did not have much knowledge of the programme, I had not expected this response, and I could not understand at that moment why they had self-selected to take part. Was it because someone who worked at the hospital distributed the email and they felt as though they were helping them out? Were they enthusiastic about research? I interviewed a couple of HCPs who admitted to either no knowledge or a scarcity of knowledge about the programme, and wondered if I had made the correct decision. I reflected upon this for a few days and came to the decision that all HCPs had received a participant information sheet and decided themselves to participate after reading it; this was their decision to take part. I believe that it would have been unjust not to allow those who were unaware of PR prior to the interview to take part if they wished to do so, as their voice would have been missing from the data. I had decided from the outset that even if HCPs had limited experience or knowledge of the programme, this was still their individual experience of it, I had not expected for HCPs to have never heard of it at all. Previous literature, especially the National PR Audit (2015), highlighted a lack of referrals to the programme, thus I deemed that interviewing those who

were previously unaware of PR or lacked knowledge, may have been able to provide further insight, or offer explanation.

Opposed to those working in primary care who preferred to be interviewed at a suitable time over the telephone, those on general medical wards favoured face to face interviews. Due to the need to wait for research passports to be obtained prior to going on site to conduct face to face interviews in secondary care, data collection had ended in primary care, before interviewing those on general medical wards. The prospect of interviewing those within a hospital setting and in their place of work was initially unnerving, as prior to this, thankfully, I have had very little personal experience of hospitals. The setting was therefore alien to me, and one thing that I noticed whilst conducting interviews on general medical wards was the noise, trollies constantly going back and forth, machines making various different noises, patients shouting and HCPs rushing about. HCPs were always made aware that I understood if there was an incident where a patient had become unwell, they had to leave immediately. I did not realise the impact that this would have on me until it occurred. In a diary entry on 15<sup>th</sup> August 2017 I wrote: *'I was conducting an interview with a GN today and then all of a sudden alarms started ringing. I did not know what was going on, however immediately, mid interview the GN stood up from where she was seated and said 'I've got to go' and started to run down the corridor, almost as though she was classically conditioned to the alarm. What felt like an hour had passed, although I am sure that it could have been no longer than five minutes the GN returned calm, collected although a little out of breath. She informed me that it had been a false alarm although they thought a patient was having a cardiac arrest. I informed her that we could leave the interview if she wished, however she was insistent on finishing it. I felt as though it took me a good few minutes to compose myself, I have never experienced this kind of intensity, however the GN continued as though nothing had happened. This was normal to her, it was not to me and I worried I had affected the quality of the interview.'*

On reflection and after analysing the interview I realised that it was good and the standard was comparable to others conducted, it was my inexperience with that particular setting which impacted upon my confidence. After conducting more interviews on general medical wards I began to realise that these interruptions were part of conducting research in a real life setting. For example, another interview was disturbed as a nurse needed to talk to relatives of a patient in the family room, where I was interviewing a doctor. Due to a lack of quiet space, this interview therefore only reconvened 20 minutes later.

### **6.3 REFLECTIONS ON THE RESEARCH AS SOMEONE WHO HAS CARED FOR A RELATIVE WITH COPD:**

I first became aware of PR in 2015, as a result of my Grandad not being offered the opportunity to attend the programme. Therefore, prior to the PhD I only ever had knowledge of the programme that I had read about online. I can admit that even after deciding to focus the PhD on PR, I still had limited knowledge about the aims of the programme and its content. My knowledge and understanding of the programme has developed throughout the course of the PhD, and my beliefs surrounding all patients having the same level of opportunity to attend PR have strengthened.

Visiting the programme myself during my PhD and seeing it first hand, was an experience which I will never forget; I found this both inspiring and emotional. I wrote in a diary entry on 14<sup>th</sup> June 2016: *'today has not been easy, although I think about Grandad every day, he has been in my thoughts today more so than ever'*. It was great to see patients involved in the exercises, providing encouragement to each other and benefiting from the programme. The PR team allowed me to be involved with the programme and talk to patients about their experiences of COPD and attending the programme. Although, some patients discussed finding the exercise difficult, they all said that they had seen physical improvements, and the camaraderie and friendships made were endearing to observe. I had time to talk to those delivering the session and they reaffirmed the importance of the study, highlighting that there were certain GPs who refer patients *'all the time'* and others who *'they have never had a referral from'*. The physiotherapists delivering the service stated that they would be keen to see the findings of my study, as it would be interesting to identify the reasons why some HCPs refer frequently and others not at all. This day in particular made me realise the importance of the programme to the patients who attend, and how a lack of referrals from some HCPs disadvantages patients who may gain from attendance. I also appreciated the importance my research could have on practice, and how it could assist those delivering the programme to increase referrals from certain HCPs. Whilst, I thoroughly enjoyed the day, in particular gaining an insight into the programme and hearing the need for my research, when I returned home I felt emotional that this was something my Grandad did not have the opportunity to experience.

Although, I was aware from my own personal experience of caring for my Grandad that there were some HCPs who had never heard of PR, I did not expect so many HCPs to admit this. I always wanted this research to raise public awareness of PR through dissemination or patient and public involvement, I did not, however, expect that some of the

interviews would serve as increasing HCPs understanding or awareness of PR. It was not by any means the aim of the research to educate HCPs, and throughout the interview they provided their views on the programme. However, after the interview ended many reflected upon their experiences and said that they were either going to find out more about PR, or consciously try to make an effort to make more referrals than they do currently. I want to reiterate that this was never my intention, however after realising the extent of the lack of referrals made to PR, did feel a sense of pride that, although very small, my research had made a difference. If only one HCP who I had interviewed, who was either knowledgeable or lacked knowledge of PR, made an extra referral as a result of participating then, I feel that the research has been more than worthwhile.

I could see the disappointment in some HCPs who I interviewed that had never heard of the programme or thought to refer to it, and as someone who had cared for a relative with COPD I sympathised with them. Many wanted to do the best they could for all of their patients, however there was a reason for this lack of knowledge and appreciation of the programmes benefits, which many often attributed to diminished education on PR. It was clear to see the strain that both the HCPs and NHS were under and this was highlighted in the interviews. There was the requirement for HCPs to be aware of many different programmes and services within general medicine, and I started to feel that ultimately there was a reason that they lacked knowledge of PR, and it appeared to be due to a lack of communication from the service or during training. Although I remained impartial throughout the interviews, and HCPs were encouraged to tell their story, after recruitment ended and reading back over all of the transcripts, I did sympathise with those who were unaware of the programme.

#### **6.4 REFLECTIONS UPON COMPLETION OF THE STUDY:**

The experiences of PR during the PhD, for example observing the programme first hand, talking to patients who have previously attended PR at a dance event and local BLF Breathe Easy Group, alongside hearing HCPs views, have therefore shaped my perceptions of the programme. Overall, I believe that the programme is advantageous and that the psychological benefits and education patients gain from attendance is just as important and worthwhile as any physical improvements. A quote from one of the PNs that has remained with me throughout this journey is that '*it's quality of life, pulmonary rehab.*' (PN 1), and this is something which I maybe did not fully realise prior to the study, however is something I believe to be true now. I perceive that HCPs often do not refer to the programme, either because they are unaware of the benefits, unsure of how to refer, do not perceive it as their



job, or know that there is a programme available for them to refer to. This therefore highlights the need for greater education and communication surrounding PR and this is something that I will take away from this research.

I have questioned upon completion of this study whether I should have interviewed those who worked on respiratory wards in secondary care. This is something which I consider would have added further depth and perspective to the research, and has been discussed in further detail as a suggestion for future research in Chapter 7. I also acknowledge that I could have combined the findings from those working in primary care and those in secondary care, rather than analysing them separately however I perceived them to be very different working environments and therefore different experiences. This was discussed with supervisors early in the analysis phase and it was therefore perceived beneficial to analyse them individually and draw comparisons. On reflection, I believe that this was the correct choice to make as Smith, Flowers and Larkin, (2009), discuss that the principles of IPA should be used to guide analysis, however can be modified to meet the needs of the researcher.

It is also acknowledged that in IPA the researcher has to acknowledge when they consider the research 'good enough', as many spend too long trying to find perfection, when this is often not possible (Smith, Flowers & Larkin, 2009). In hindsight this is something which I may have pondered upon for too long, however it is considered that this was due to it being the first time which I had used IPA, and I believe that I would be more confident if I was to use this approach again. Others may perceive that the sample size is too large for IPA, however the ability to refer to PR was the homogenous factor, and it was therefore viewed that gaining perspectives from different professional groups would enable similarities and differences to be identified between groups. Sample size in IPA is now often influenced by how the researcher wishes to compare different accounts (Pietkiewicz & Smith, 2014), therefore the sample size was considered appropriate.

Throughout the course of the research people often questioned if I found it difficult to understand the respiratory literature, and if I had been accepted by the respiratory community, given my non-professional background. This was a question which initially I was unsure how to answer, and on many occasions made me question if I was the most suitable person for this project. However, I believe that my prior personal experiences gave me the drive and determination to learn about COPD, and network with key figures in the field; others without my experience may have not had this determination. Some also asked if I would be able to incorporate psychology into the project, and I do feel that the research

allowed me to combine both respiratory and psychology effectively, and the findings have been presented and accepted by both psychologists and respiratory audiences.

This PhD to me, was about taking a real world issue that I identified with, and turning it into a project which had the potential to make a difference to the lives of those with COPD, no matter how small. I believe that this has already partially been achieved through presenting my research at conferences, a HCP study day and at patient events, along with being accepted for the BTS Winter Meeting in December 2018. I hope that I have given the HCPs who gave their time to speak to me about their experiences of PR a voice, and that from this research positive change can occur. This project means far more to me than the award of a PhD, it has enabled something positive to come out of unfortunate circumstances, and on a personal note that is something which I will always be grateful for.

## **6.5 CHAPTER SUMMARY:**

This chapter has explored some of my own personal researcher reflections documented throughout the course of the PhD. I have found this chapter quite cathartic to write, as it has allowed me to reflect upon the reasons I conducted the research, my personal background, thoughts and experiences throughout data collection and analysis, and opportunities to disseminate throughout the research process. It has also enabled me to provide explanation for some of the choices made. I have also detailed how my personal thoughts on PR have changed and developed throughout the course of the PhD. I hope that I have captured the individual voices and perceptions of the participants interviewed within this study, providing readers with enough information to build a clear picture of each participant.

The final chapter of the thesis will discuss the strengths, limitations and recommendations for future research, education, policy and practice, based upon the findings of the current study.

## **CHAPTER 7: STRENGTHS, LIMITATIONS AND RECOMMENDATIONS FOR FUTURE RESEARCH, PRACTICE AND POLICY**

### **7.1 INTRODUCTION:**

This chapter will explore the strengths and limitations of the current study, discussing aspects in relation to both the empirical research and the CIS. As the CIS informed the research question, and decisions made within the empirical research, the choice was taken to discuss them together. This chapter will aim to provide greater clarity to the choices made, whilst highlighting the implications and importance of the findings, dissemination to date and future dissemination plans before offering recommendations for future research, practice and policy, and lastly providing a final word to close the thesis.

In order to highlight the strengths and limitations, Yardley's (2000) four key characteristics of what constitutes a good piece of qualitative research will be used to provide structure to the chapter. The four key characteristics encompass: *sensitivity to context, commitment and rigor, transparency and coherence, and impact and importance* (Yardley, 2000). Adhering to this guidance is recommended by Smith, Flowers and Larkin (2009) who also provide some suggestions of their own in relation to ensuring a commitment to rigour within IPA research, these will also be drawn upon with instances highlighted throughout.

### **7.2 STRENGTHS AND LIMITATIONS:**

Smith, Flowers and Larkin (2009), promote the use of Yardley's (2000) approach of assessing qualitative research as it offers general guidance. They perceived other forms of criteria are unsuitable for IPA, due to adopting a checklist approach which appears to have oversimplified some of the understated aspects of qualitative research, resulting in them being overlooked. The advice provided by Yardley (2000), is perceived as simplistic whilst comprehensive; it is inclusive of all qualitative designs, allowing quality to be established in a range of different ways (Smith, Flowers & Larkin, 2009).

#### **7.2.1 Sensitivity to Context:**

The first aspect which Yardley (2000) explores in relation to sensitivity of context is that of the researcher having an awareness and becoming familiar with the literature in relation to both the methods adopted, and any previous similar empirical research in the area. This is referred to as the theoretical context of the research and was adhered to by providing a

background to the research in Chapter 1, whilst offering a comprehensive overview of both COPD and PR, alongside literature pertaining to patients' perceptions of PR. This introduction to the topic was provided in order to situate and provide context to the research. It was also decided to conduct a CIS on HCPs perceptions of PR as a management strategy for patients with COPD, in order to establish what research had previously been conducted in the area, and ultimately provide a rationale for conducting the research.

The findings from the CIS (Chapter 2) and the literature discussed within the background chapter helped to inform the research question and guide thinking in the empirical study. It may appear that these two chapters constitute a substantial amount of the thesis, however it was deemed important to conduct a CIS, as it became evident that no study, in its entirety, had previously explored HCPs' perceptions. A systematic approach was therefore required, which allowed synthesis of different methodological approaches to ensure that, as far as possible any literature regarding HCPs perceptions of the programme was included.

It was further perceived that detailing IPA research methodology literature within Chapter 3, assisted with providing context as to why this was chosen as the most suitable approach. Adopting a sensitive approach to pre-existing literature and methodological choices is perceived as beneficial by Smith, Flowers and Larkin (2009), as it provides the reader with additional clarity. They also add that providing considerable literature assists with positioning the findings in relation to previous research, although they acknowledge that literature not previously mentioned should also be interwoven into the discussion to add further context to new findings. This approach was adopted as when carrying out qualitative research it is often difficult to predict what participants will choose to discuss, therefore any novel or unexpected findings were later contextualised in the discussion chapter in relation to literature not previously explored in the first two chapters.

Attention was also given to the suitability of IPA as the specific approach, and it could be argued that 27 is a particularly large sample size for IPA (Brocki & Wearden, 2006), and as a consequence some of the commitment to an ideographic approach may be lost. Smith, Flowers and Larkin (2009), however, promote the use of a homogenous sample, and as HCPs were recruited from four distinct professional groups: GPs, PNs, doctors working on general medical wards and nurses working on general medical wards, with the homogenous factor being the ability to refer to PR, it was deemed that recruitment would cease once no new information emerged from each group. This supports the view of Smith and Eatough (2012) who suggest that there is no definitive answer with regards to the correct number of participants in IPA, as data collection should be driven by the richness of the data obtained

and is also dependent upon how the researcher wishes to compare and contrast different accounts (Pietkiewicz & Smith, 2014). Therefore the sample size for this study was justified after consideration of the narrow focus of the research topic, and the desire to explore perceptions from a variety of professional backgrounds and clinical settings.

In addition, IPA promotes recruitment of a purposeful sample of individuals who hold lived experiences of a phenomenon, however these individuals are often perceived difficult to access (Smith, Flowers & Larkin, 2009). However, using a gatekeeper within secondary care enabled the recruitment of those working on general medical wards, allowing individual perspectives to be gained; in keeping with the ideographic nature required to conduct IPA (Smith, Flowers & Larkin, 2009). Recruiting from general medical wards in secondary care allowed any potential comparisons in practice to be drawn against the findings in primary care. The perceptions of HCPs in relation to PR as a management strategy for patients with COPD has previously not been captured within the literature, thus representation from different professional groups captures a wider range of views and experiences.

During data collection, sensitivity to the participant is regarded as important to make them feel comfortable, with careful management of any perceived imbalances of power (Smith, Flowers & Larkin, 2009). This requires the researcher to provide the participant with a greater sense of power than may have been previously displayed in qualitative research, where they may have been perceived as merely a subject of the research (Yardley, 2000). This is often facilitated through conversational style discussion and careful consideration of the impact of the researcher's actions, gender, or background (Yardley, 2000). Prior to the study and during the initial interviews, as discussed in the reflections chapter, it was considered a potential weakness that interviews were being conducted as a non-HCP. There was a worry surrounding how rapport would be established with the HCPs interviewed, however this in fact appeared to facilitate conversation, as HCPs often provided a number of examples and did not assume any shared knowledge, resulting in rich data collected. It was hoped that acknowledging being a non-HCP prior to the interview, would put participants at ease. Many HCPs discussed quite frankly and openly about their experiences, and in some instances their lack of knowledge surrounding PR, highlighting that no party considered themselves as an expert in the area.

Socio-cultural setting is also perceived important in relation to participants' understanding and perceptions of a phenomenon (Yardley, 2000). In the current study all participants were recruited from the North West of England from either two large hospital trusts, or a number of locations within primary care in the North West Coast CCG area, or Greater Manchester

CCG area. The locations which HCPs were recruited from in primary care were diverse in respect of deprivation. It was perceived that all participants held similar characteristics in the respect of being qualified HCPs, and therefore will have had similar training, education and experiences. It could be proposed that the findings could be culturally specific to the North West of England, although little is known about the difference in perceptions elsewhere in the UK. Many demographic details were collected from participants, as seen in table 6 and 7 in Chapter 4, although it could be considered a weakness that details in relation to participants' culture or geographical location with regards to nursing or medical training were not obtained.

Prior personal experiences of caring for a relative with COPD, who was not given the opportunity to attend PR, could be considered as a bias, due to having potential pre-conceived ideas or views regarding the topic, however these personal experiences are regarded as a strength in IPA (Smith, Flowers & Larkin, 2009). Adopting a double hermeneutic approach promoted in IPA research however, enabled participants to try to make sense and communicate their experiences, whilst the researcher aimed to interpret these (Smith & Osborn, 2008). In an attempt to remain sensitive, all participants were made aware that there was no right or wrong answers to any of the questions asked, and they were encouraged to provide their honest views on the topic. Each HCP was entitled to their own views and, as discussed within the reflections chapter the adoption of IPA provided new insight into the topic, with prior views of PR as a researcher ultimately modified as a result.

It is claimed that a well conducted piece of IPA research will be most sensitive to the data collected (Smith, Flowers & Larkin, 2009). This is due to the nature of IPA, whereby attention is focused upon ensuring that any claims made during the analysis are grounded within the data. It is therefore advocated that a high quality IPA study should have a significant number of verbatim quotes used to support any interpretations, allowing the individuals' voices to be heard and providing enough detail for the reader to make their own assessment (Smith, Flowers & Larkin, 2009). This is further promoted as good practice by Willig (2013), who believes that it enables the reader to establish themselves if the data 'fits' with interpretations made. A number of participant quotations were therefore provided within the findings chapter to demonstrate and support the interpretations made (Chapter 4).

The findings may have been enhanced by carrying out member checking. The process of member checking would have allowed participants to provide further comments on the transcripts in order to assess the accuracy and validate findings in relation to their lived

experiences (Birt et al., 2016). This was however decided against, as those who participated often found it difficult, given their busy schedule, to find adequate time to conduct the interview, therefore the potential additional pressures that member checking would have added was not considered plausible. Consideration was also given to those who suggest caution should be taken with member checking, as participants reflecting upon their interview and changing their views could impact upon the quality of the data collected, and therefore advocate the use of a second interview instead to corroborate responses (Morse, 2018). A second interview would have not been viable given the HCPs' heavy workload, and may have potentially resulted in participants not taking part. Therefore, it was perceived that a middle ground was found using respondent verification whereby, on occasion, participants were asked during the interview if they could provide additional detail, in order to add clarity, and to ensure that researcher interpretations were an accurate representation of their perceptions.

### **7.2.2 Commitment and Rigour:**

The second aspect to be considered in relation to the research is commitment and rigour. Yardley (2000), suggests that commitment to the research is evidenced via an in-depth immersion with the research process and topic, and adds that it is often beneficial if researchers can draw upon their own experiences throughout, for example being a carer or HCP themselves. It could therefore be seen as an advantage that holding such significant prior experiences of caring for a family member with COPD, enabled the creation of this research and lead thinking both through the design and reflection process of the study. It was deemed that without holding these previous experiences the current study and research question, which was based upon a personal lived experience, would not have come to fruition. These experiences ignited a passion and interest in the topic, and this prolonged engagement with the topic area is perceived as beneficial (Yardley, 2000).

Rigour pertains to how thorough a study has been conducted (Smith, Flowers & Larkin, 2009). In the context of Yardley's (2000) guide, rigour is related to the ability of the data to tell the full story and is not dependent upon sample size; it is associated with completeness and data saturation. It should be noted here that some researchers are uncomfortable with the term data saturation, due to it being a term developed for grounded theory, with no clear guidance on how to use it for other qualitative approaches and currently a number of different definitions are available (O'Reilly & Parker, 2012). However, Smith (2004), highlights that saturation can occur within IPA, and the current study adopted the notion that this is achieved when no new ideas or concepts emerge from the data (O'Reilly &

Parker, 2013). Consideration was also paid to the point when a representative picture of the data could be drawn, as suggested by Smith & Osborn, (2015b), with recruitment ending at this point.

As IPA aims to collect the perceptions of individuals who all have experience of a particular phenomenon, purposeful recruitment is promoted to increase rigour and obtain a homogenous sample (Smith, Flowers & Larkin, 2009). A limitation of this study is that HCPs self-selected to participate in the research, and therefore those who did not offer to participate may have held different perceptions to those interviewed. Through adopting a '*multi-perspectival*' approach as promoted by Smith Flowers and Larkin (2009, pg 52), this did evidence individual perceptions of different HCPs, however displayed that there were common findings and divergences amongst professional groups. This study, as with other qualitative research does not aim to offer any generalisability to HCPs working in other locations, as this would not be possible given the nature of the sample. It does, however, offer the individual experiences of HCPs working in one of four professional groups within the North West of England. It could be viewed that if HCPs working on a general medical ward in a different hospital in the North West of England were interviewed, or HCPs working in primary care, for example, in the Midlands or South of England, they may have held different perceptions. It would therefore be beneficial to conduct larger scale research to test the findings more generally and establish HCPs' perceptions of PR, in a number of locations.

Yardley (2000) adds that the rigour of a study can be increased by using triangulation within data collection, and this can be achieved through collecting data from different sources, and uses the example of doctors and nurses. It was therefore perceived an advantage of the study that the perceptions of those working in primary care (GPs and PNs) and those working on general medical wards in secondary care (doctors and GNs) were gained, to provide a well rounded understanding of the research area. A limitation however, may be viewed as the lack of representation from those working on respiratory wards, and others who deliver the PR service. It was considered that those working on respiratory wards would have a good understanding of PR and therefore interviewing them would add little to what was already known; upon reflection this may have been naive. One of the gatekeepers who distributed the participant information email to eligible participants in secondary care, discussed at the end of data collection how she believed that interviewing those who worked on respiratory wards may have added an extra dimension to the research. As a respiratory consultant herself, and as a result of the lack of knowledge evidenced in primary and secondary care, she believed it may have been interesting to establish HCPs'



understanding of PR from those who worked specifically on the respiratory wards. This suggestion was noted and may be an avenue for exploration in the future.

Rigour within IPA research is achieved through the quality of the data collected and the researcher establishing the correct position during data collection, of building a rapport with the participant yet remaining objective, whilst identifying areas during the interview where probes could be used to '*dig deeper*' (Smith, Flowers & Larkin, 2009, pg 181). It is proposed that this process is facilitated through the researcher using their intuition (Yardley, 2000), a skill enhanced from interviewing GPs during an MRes, however this took a few interviews to settle back into, along with adapting to interviewing different HCPs. The skill of *digging deeper*, exploring participants' perceptions in greater detail, asking them to provide an example of why they felt a particular way, came with confidence. When this approach was adopted, richer data was gathered and enabled the interviews to feel more relaxed and conversational.

During data analysis Yardley (2000) advises extensive consideration and contemplation in order to produce enlightened and well informed interpretations. It was considered a strength that this research was conducted over a three year period, with analysis occurring concurrently with data collection, and data collection being completed a year prior to submission of the thesis. The appropriate time required to consider the data and the interpretations made was therefore available. This supports Smith, Flowers and Larkin (2009), who advocate that strong IPA research should move beyond the descriptive and provide interpretations offering insight into the perceptions of individual participants, whilst discussing them within the wider context of the theme. A further advantage was that peer validation of the findings was conducted by the supervisory team. This ensured agreement of the quotations provided under each super-ordinate and sub-ordinate theme and reduced any potential bias.

The findings section of this thesis may be considered by some as lengthy, however within IPA research it is advocated that enough room is provided to explore themes in detail, rather than to discuss a greater number of themes and only highlight surface findings (Smith, 2011). It is further advocated that in larger studies the prevalence of the theme should be displayed within the findings in some way. Therefore, the choice to include table 9 and table 11 was taken, which evidences the systematic approach adopted for data analysis, and displays which participants, and how many, discussed a super-ordinate theme or sub-ordinate theme. Although it is understood that all the quotes in relation to a theme cannot be used within IPA research, particularly within larger studies, the sample should be equally

drawn upon. It was a priority to ensure that each participants' individual perceptions and views were heard within the study, and this was achieved by making sure each participant had been fairly represented within the narrative. It was also considered important to include table 12 prior to the narrative, to capture how often all of the participants referred to PR, and what their general perceptions of the programme were. This was considered beneficial given the sample size, as it was viewed that it would enable the reader to gain a concise representative overview and profile of each participant prior to reading the narrative.

### **7.2.3 Transparency and Coherence:**

The third principle detailed by Yardley (2000) encompasses transparency and coherence. Transparency relates to the comprehensiveness of the documentation of the research process (Smith, Flowers & Larkin, 2009). This often involves transparency in how participants were recruited, how the data was collected and a detailed overview of how the data was analysed, providing enough information for someone to replicate the research if they wished to do so (Yardley, 2000). Within IPA research it is suggested that this transparency is often gained from the presentation of these details, with tables suggested for ease of understanding (Smith, Flowers & Larkin, 2009). This approach was adopted whereby tables and diagrams were used to display the response rate, and participation from the invitation letter in primary care (Figure 5), the step-by-step process of IPA data analysis undertaken (Figure 6), and also details of how the super-ordinate themes and sub-ordinate themes were developed (Table 8 and 10), with the occurrence of these themes throughout the data also displayed (Table 9 and 11). Further clarity was added by including the participant recruitment letter and email, participant information sheets, consent forms and the semi-structured interview topic guide, to provide the reader with an understanding of the types of questions asked. The aim was to ensure that every aspect of the research was as transparent as possible, and a further method suggested by Yardley (2000), is to make the anonymised data from the study available to other researchers. This is something which was adopted, and approval to enact this should a request be received from another researcher, was approved by the University Ethics Committee and the HRA. All participants were made aware of this and agreed to this during the consent procedure.

Although, the CIS is considered as informing the empirical research, the clear systematic documentation of the review process was perceived as beneficial. As with the empirical research, the methodology was clearly documented with inclusion and exclusion criteria, and the search strategy used to identify papers, and the number of papers retrieved at each stage. Examples of the data extraction forms, and a completed example were provided in

the appendices along with the quality appraisal tool adapted from Hawker et al., (2002). This transparency and the providing of examples enabled all aspects of the review process to be documented.

Transparency can be further added through the use of researcher reflexivity (Yardley, 2000), and this is considered a key component of IPA research (Smith, Flowers & Larkin, 2009). This process can be first seen within the preface which explains the reasons for undertaking the current research. These motivations for conducting a piece of research are considered important by Yardley (2000) as it often adds insight into the rationale for undertaking the project, which is important for the reader to consider. A researcher reflexive diary was also kept from commencement of the research process, through to the end of the study. Some of the prominent reflections documented have been highlighted in the researcher reflections chapter (Chapter 6), with excerpts taken from the diary included. It was viewed that capturing this level of detail would be advantageous as it is important for the reader to understand the researcher's thought processes throughout the study, and offer insight into key decisions made during the research process (Koch, 1999). Furthermore, due to the nature of qualitative research, which adheres to the notion that experiences are often shaped by assumptions, behaviour and goals, it is valuable to reflect upon these during the research process, to allow the reader to assess any impact they may have made on the research (Yardley, 2000).

Coherence is assessed by the suitability of the research question in relation to the methodological approach adopted, and the analysis (Yardley, 2000). Within IPA research, Smith, Flowers and Larkin (2009), suggest that the reader is often best positioned to judge this, therefore it is important for the researcher to consider themselves in the shoes of the reader whilst writing the thesis. They add that the researcher should ask themselves if the findings present a coherent argument, and in addition divergences should be recognised and discussed appropriately, as they are often the richest source of data. Thus, similarities should be identified within the data, however it is important to discuss contradictions or distinctive findings, as this adheres to maintain individuals' experiences at the heart of the analysis (Smith, 2011). These similarities and differences were identified in individuals' perceptions and were synthesised to form a narrative. It was perceived advantageous that the Findings Chapter (Chapter 4) highlighted where there was agreement or disagreement between professional groups, or between primary and secondary care, yet it was also useful to highlight individuals who perhaps had different experiences, and thus held different perceptions. As IPA focuses upon the experience of the individual it was important to include

a number of quotes within a theme, and this was viewed as a strength, to enable the reader to hear the voices of those interviewed.

Further consideration of the coherence of the research occurred through the refinement of themes within the findings. Smith, Flowers and Larkin, (2009) advise that this occurs during the drafting and re-drafting of the findings section to ensure that discrepancies or novel findings within the data are highlighted, yet analysis still flows. This process of writing the findings chapter, whilst further refining, is considered simultaneous and assists with articulation. This process was further aided by meetings with the supervisory team to discuss the suitability of each theme, how it was positioned, and the information included within it. The supervisory team were also involved when the super-ordinate and sub-ordinate themes were initially formed to offer an objective view, which led to development and re-development, and they also commented upon draft chapters of the thesis and as a whole, to ensure clarity was maintained throughout.

It was important to discuss within the methodology section how IPA involves the participant making sense of their own experiences and the researcher interpreting this. As a result the reader also has to try to make sense of the researcher's interpretations. It was perceived a strength of the research that this was highlighted as it provides the reader with an understanding of the IPA process, and evidences that the study has been carried out in accordance with the key principles of IPA. Upon reading the thesis the reader should be convinced that they have a comprehensive understanding of the individual experiences of those who participated in the research (Smith, 2011).

#### **7.2.4 Impact and Importance:**

The last characteristic Yardley (2000) proposes contributes to a good piece of qualitative research, is that of impact and importance. It is argued that the impact that the findings of the research have is often the most important component and what others judge the research on (Smith, Flowers & Larkin, 2009). The impact and necessity of the research can be questioned in many ways through assessing the objectives and findings, and this can often only be determined by the community who the findings are applicable to (Yardley, 2000).

The usefulness and potential impact of the study has also been highlighted, due to those working within healthcare, respiratory and health psychology taking an interest in the findings. The research has already been disseminated at the BLF Head Office Roundtable

PR Discussion in July 2017, after being personally invited to provide information on HCPs' perceptions of PR, and what could potentially be done to increase uptake to the programme. Subsequent to this the study was disseminated to HCPs in attendance at the North West BLF Study Day June 2018. The interest and support the BLF have shown for the research highlights its significance, and the potential it may have to inform future research and policy, although it is acknowledged that further research would be required due to the limited sample drawn upon. Further acceptance of the research was gained, after presenting a research poster at the British Psychological Society Division of Health Psychology Conference in Cardiff, in September 2017, evidencing the interdisciplinary interest in the research. In addition to this, the research will continue to be disseminated post PhD, and has just been accepted for an oral presentation at the prestigious BTS Winter Meeting 2018. It is also anticipated that publications in peer reviewed journals will be derived from this research; the CIS has already been written up and is ready for submission. Furthermore, patient and public involvement has occurred throughout the course of the PhD, as it was perceived important to meet patients and to also give something back to the community. After invitation from Professor Ann Caress, a meet the researcher stand was held at a respiratory dance event at the University of Manchester in association with the BLF. It was invaluable to talk to patients about their experiences of PR, highlight the research being undertaken into respiratory conditions and have an involvement in the dancing, whilst observing the benefits gained. It is hoped that this has evidenced the wide impact and interest received for the research to date, emphasising the perceived importance of the project from HCPs, psychologists and a national charity.

It is hoped that increasing knowledge of HCPs perceptions in such a way will have a positive impact upon awareness of the programme amongst HCPs, the understanding of HCPs perceived barriers and facilitators to the programme, and the need for better education surrounding PR. This new knowledge highlighted does however require reinforcement via further research, and has been discussed in further detail in section 7.4.1. This is supported by the views of Yardley (2000), who discusses that qualitative research often has the potential to present unique findings which provide insight and understanding to a topic, however given the small numbers of participants recruited need further reinforcement. It was perceived that the depth of HCPs individual experiences discussed within this research could not have been gained using a different approach, whether that had been thematic analysis or a quantitative technique. Therefore, it is viewed that the study achieved what it desired and has increased the very limited knowledge base surrounding HCPs' perceptions of PR.

### **7.2.5 Additional Aspects Considered:**

The analysis was organised using NVivo 11 ® (QSR International, 2015), as it was perceived convenient to view data all in one place, with easy manoeuvrability of quotes between super-ordinate and sub-ordinate themes to ensure correct placing. It was also considered useful that the software displayed how many participants were represented under each super-ordinate and sub-ordinate theme, alongside the number of associated references. This allowed clear documentation and depiction of the occurrence amongst individual cases as advocated by Smith, Flowers, and Larkin (2009), and Smith (2011), when working with larger sample sizes in IPA. Although, all transcripts were uploaded to NVivo 11 ® (QSR International, 2015), and annotations were added, it was not deemed to be as straightforward to view these within the software package as it was using hard copies of the transcripts, an example of this can be seen in appendix 18. Nevertheless, organising the data into themes was exclusively carried out in NVivo 11 ® (QSR International, 2015), as it was viewed that this was the most convenient way to organise large quantities of data.

### **7.3 ORIGINAL CONTRIBUTIONS TO KNOWLEDGE:**

Although the original contributions to knowledge have been highlighted within the discussion chapter (Chapter 5), it was considered important to summarise these as lasting thoughts before conclusion of the thesis.

This study focused upon HCPs perceptions of PR as a management strategy for patients with COPD. As discussed within the CIS there is no research in its entirety which establishes HCPs' views of the programme. Data was therefore extracted from studies with a slightly different focus, in order to provide an original insight into what is currently known. This new contribution was formed after interpreting and synthesising research from HCPs who had the ability to refer to PR or delivered the programme, therefore a large range of views were displayed within the CIS. In many instances these papers also included data from both HCPs and patients, therefore data was extracted to solely include HCPs views. There was a scarcity of research available which focused upon and addressed the perceptions of HCPs, in particular those working on general medical wards in secondary care. The research question for the empirical study was therefore considered justified, in order to produce a piece of research which solely focused upon HCPs' perceptions of the programme, and synthesise the views of those working in primary and secondary care. This

therefore was the first study to specifically focus on the perceptions of HCPs in relation to their views on PR as a management strategy for patients with COPD.

Within primary care HCPs focused more upon the psychological symptoms of the disease and believed that this caused or worsened breathlessness. Conversely, those in secondary care placed focus upon the physical symptoms of the disease and how they perceived these caused a burden to the patients' lives. Previous literature has referred to both the physical and psychological impact of COPD, however no literature prior to this has seen the views of those in primary care centred around the psychological impact of the condition, with minimal reference to the physical symptoms. Upon embarking on this research it was not expected that COPD illness perceptions would constitute a super-ordinate theme, however it was perceived that potentially this has previously been the missing piece in the jigsaw, as they have the potential to explain HCPs' perceptions of PR. It was therefore considered vital that COPD illness perceptions were included to create a clearer picture of HCPs views of the programme.

PNs were considered to have the greatest knowledge surrounding PR and as a result were the ones most likely to refer. Taking this into account, all HCPs admitted to lacking knowledge of the programme in some way. An original finding was displayed within the interviews from secondary care, as it became apparent that those working on general medical wards were knowledgeable about other forms of rehabilitation, such as cardiac and stroke rehabilitation, and often made assumptions that PR would be a similar concept, as many had never heard of the programme. Although some of the previous literature explored within the CIS highlighted that a few HCPs were unaware that they could refer to PR, no prior research has established such a strong understanding of other forms of rehabilitation combined with a lack of awareness of PR.

Furthermore, it does not appear that those working in secondary care have previously discussed that COPD patients should be managed within the community, due to holding the perception that nothing could be done to help them in hospital. This was based upon the view that COPD could not be fixed nor cured. As a result the condition was considered to add a burden to the NHS and secondary care in particular due to the frequent nature of patient presentation. It is therefore perceived that such strong negative views in relation to COPD patients being admitted to general medical wards have not been evidenced elsewhere. This notion of frequent attendance and the need for medical intervention could also impact upon HCPs perceptions of PR, although this requires further exploration.

Another finding which was of interest surrounded patient access to the programme, and discussion that the inverse care law could act as a barrier to PR. It was viewed that those who may require or benefit from the service the most, possibly are the ones who do not have access to it. This was only referred to by one doctor, so therefore is not considered an original contribution to knowledge, however it was considered important to highlight, as it has not previously been referred to within the literature, and may be an interesting consideration in the future. Similarly, being an expert patient, someone who has been diagnosed and managing their condition for some time, was considered as a barrier to PR. This has also not previously been attributed as a reason for patients not to attend the programme.

Probably one of the most significant original findings to be displayed was the consistent view amongst those working in secondary care that PR was missing from the medical and nursing curricula. HCPs blamed the medical or nursing curricula for not adequately discussing the programme, or the local PR team for not providing them with the correct information. It was perceived that if the programme had been mentioned within the pre-registration curricula at university, or greater focus had been placed upon it, then there would be better awareness of the programme and its aims. This responsibility has not previously been placed upon university education and the local service, nor regarded as a reason for non-referral to PR. Therefore this is a unique finding, which has not previously been regarded as a barrier to PR by other HCPs, however it was considered that this lack of teaching could potentially result in a lack of awareness and provide explanation to a lack of referrals to PR. This is an aspect which future research should focus upon. Furthermore with regards to HCPs understanding of the programme, it was evident that some confusion surrounded the word '*rehabilitation*'. This is another novel finding which has not been discussed by HCPs in other studies. However, once again this is a prominent finding which may offer explanation as to HCPs perceptions and confusion surrounding the programme, and which patients they consider would be suitable.

It is evident that many of the original findings with regards to PR arose from the interviews conducted with HCPs working on general medical wards, and therefore is an area requiring further exploration. The findings discussed in Chapter 4 and also the CIS provide new insight and add to the limited body of literature currently available. The recommendations that have arisen as a result of conducting this research are explored in further detail below.



## **7.4 RECOMMENDATIONS:**

The recommendations made from the current study have been explored and summarised under four distinct headings below: *recommendations for future research, recommendations for education, recommendations for practice, and recommendations for policy.*

### **7.4.1 Recommendations for Future Research:**

This study offers new insight into HCPs' perceptions of PR and offers a number of avenues for potential future exploration. Conducting larger scale research which incorporates the views of those working in other areas of the UK, would enable a clearer picture to be established regarding the perceptions of those working outside of the North West of England. It would also be beneficial to carry out a survey of those working in primary care and secondary care across the UK, to assess if the findings could be generalised, and highlight beliefs and understanding with regards to PR amongst a larger group of HCPs. Furthermore, it would be advantageous to assess if HCPs' perceptions differ based upon how effectively their PR service runs, and the perceived quality of information and communication they receive from them. The views of those working on respiratory wards would add further insight, as it would be interesting to determine if their knowledge or understanding of the programme is also lower than expected. Research is required to establish their awareness and perceptions of the programme, and how often they refer patients to it.

Given that HCPs discussed how there had been a lack of teaching or exposure to PR during their medical or nursing degrees, additional research is required surrounding how PR is incorporated into the medical and nursing curricula. It would therefore be beneficial to establish current undergraduate students' understanding and perceptions of the programme, as this could lead to potential improvement of the curricula. Further depth could be added by assessing the views of PR amongst those who teach nursing and medical students, as this is something which may impact on students' perceptions of the programme, and has not previously been explored. It would also be worthwhile to investigate how much emphasis is placed upon other non-pharmacological approaches used for different conditions, compared to PR, as HCPs in the current study in secondary care discussed how they had greater understanding of cardiac and stroke rehabilitation.

As a result of the lack of understanding and knowledge highlighted surrounding PR, and details about their local programme, it may be of worth to create educational sessions on PR for HCPs, delivered by those who run the local service, and assess whether providing this programme specific information increases referrals to the programme.

Lastly, there is a need for future research to involve patients who have recently been referred to PR. This could be carried out using either interviews, focus groups, or conducting a large scale survey to gather patients' perceptions of PR prior to attending the programme. This would add a further dimension, which is currently lacking in the area, by ascertaining patients understanding of PR from the information provided at referral and whether they perceived enough information was given and how they felt prior to attendance.

#### **7.4.2 Recommendations for Education:**

Although not anticipated upon commencement of the research, education surrounding PR, or a lack of, could be attributed to many of the HCPs' perceptions of the programme. Therefore, an increase in PR education was considered as a potential gateway to a greater number of referrals, by providing HCPs with the confidence and knowledge of how to refer to the programme.

There is a clear need for greater incorporation of PR into the medical and nursing curricula as HCPs, especially those in secondary care could not recall being taught about the programme. Furthermore, educating HCPs how to effectively and convincingly communicate the benefits of non-pharmacological management strategies to patients could increase uptake to the programme. This would assist HCPs with removing some of the concern surrounding exercise and may reduce the number of DNAs.

Education provided directly from the local service would be considered useful, to ensure that HCPs have good awareness of their local programme. This could be offered by simply emailing HCPs with updates in relation to the local programme, such as the location, times, day on which the programme is delivered, what the programme consists of, and how many weeks patients will be expected to attend. It may also be beneficial for those who deliver the service to arrange an appropriate time to visit GP surgeries and hospital trusts, in order to provide advice on the programme and details of any updates.

Lastly, raising awareness amongst both patients and HCPs via posters and advertisements would be beneficial. If patients are aware of PR, and that they are able to attend, more may ask HCPs to refer them if they have not already been offered the service. All of the suggestions in relation to recommendations surrounding education have the ability to positively impact upon the number of referrals made to PR.

#### **7.4.3 Recommendations for Practice:**

It is acknowledged that changes to practice would not, and should not, be made based upon the findings of one study, however the suggestions highlighted below are aspects for consideration.

Better communication between the service and HCPs with the ability to refer to the programme is required. This includes greater feedback for referring HCPs, on how patients have progressed throughout the programme. Many PNs in primary care felt disappointed over the level of information required from the service, and felt devalued when they only received minimal information regarding whether the patient had completed the programme or not. It was suggested that more referrals may be made to the programme if a summary was received regarding whether any improvements had been observed throughout the programme, for example in exercise capacity or the 6MWT.

Having clear guidance available of referral criteria for the local programme and making the referral process simplistic were identified as key facilitators to referral within the current study; this was also identified in some of the papers within the CIS. PR services therefore need to ensure that HCPs are knowledgeable of how to refer to their programme, and the process is straightforward and easily completed within the constraints of an appointment. Similarly, HCPs suggested they lacked information from the service to offer patients, to allow them to make informed choices with regards to PR. Providing HCPs with patient resources would be easy for PR services to implement, and may provide HCPs with greater confidence in making a referral, as they are aware that the information they send home with the patient has come direct from those who deliver the programme.

The suggestions offered with regards to practice are relatively easy to implement and have been drawn from the findings of the current study. Future research conducted with regards to HCPs' perceptions of PR would build a more substantial evidence base for further practice related recommendations.

#### **7.4.4 Recommendations for Policy:**

Greater awareness is required amongst HCPs with regards to both the COPD Guidelines (NICE, 2010; GOLD, 2018) and the PR Guidelines (BTS, 2013). HCPs need to know that these guidelines are available and how to access them. This awareness would assist with understanding where PR is placed within a COPD patient's management, and why it is recommended as a non-pharmacological approach.

Potentially incorporating greater information into the guidelines surrounding the management of COPD and referral to PR, when the patient also has other comorbidities may be beneficial. As COPD patients often present with a number of associated conditions, further clarification in this respect may improve referral to PR. It is however acknowledged that the NICE (2010) COPD guidelines are due for update in 2018, with publication expected in December 2018, therefore it is not yet clear which aspects of the guidelines will have been modified, and further consideration may be required after this date.

#### **7.5 FINAL WORD:**

Upon commencement of this research it was apparent that referrals to PR were lacking, however the reasons for this were unknown (National PR Audit, 2015). This research has explored the perceptions of GPs and PNs in primary care, and doctors and GNs working on general medical wards. It is concluded that for COPD patients, chance of referral to PR is as certain as spinning a wheel of fortune. This is as a result of which HCP the patient sees on which day, what perceptions they hold in relation to COPD as a disease, and also their beliefs and understanding of PR. It is considered that HCPs enter a PR downward spiral, with those working on general medical wards never making a referral to the programme, due to a culmination of a lack of knowledge, awareness or appreciation of PR, alongside either being unaware how to refer or deferring referral responsibility. Those in primary care might exit the PR downward spiral, however this was only those who were committed to referring patients to the programme, and was most often PNs.

It is hoped that this research will contribute to the limited literature surrounding HCPs' perceptions of PR and add a unique perspective and potential explanation as to why the National PR Audit (2015) concluded that referrals to PR were lacking. It is hoped that this study emphasises the perceived lack of education and awareness surrounding PR and how, as a result, this can impact upon HCPs understanding or perceptions of the programme.

Lastly, it is hoped that this research will enable current education, policy and practice to be further questioned.

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## APPENDICIES:

### Appendix 1: Medical Research Council Dyspnoea Scale

<b>Grade 1</b>	Are you ever troubled by breathlessness except on strenuous exertion?
<b>Grade 2:</b>	(If yes) Are you short of breath when hurrying on the level or walking up a slight hill?
<b>Grade 3:</b>	(If yes) Do you have to walk slower than most people on the level? Do you have to stop after a mile or so (or after $\frac{1}{4}$ hour) on the level at your own pace?
<b>Grade 4:</b>	(If yes to either) Do you have to stop for breath after walking about 100 yds. (or after a few minutes) on the level?
<b>Grade 5:</b>	(If yes) Are you too breathless to leave the house, or breathless after undressing?

\*Used with permission of the Medical Research Council (2018)

## Appendix 2: Systematic Search Strategy

### CINAHL Search Strategy:

#	Query	Limiters/Expanders	Last Run Via	Results
S25	S14 AND S24	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	62
S24	S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	259,431
S23	AB belief* OR perception* OR view* OR opinion* OR attitude* OR satisf* N3 "healthcare provider*"	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	205,748
S22	AB belief* OR perception* OR view* OR opinion* OR attitude* OR satisf* N3 consultant*	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	205,721
S21	AB belief* OR perception* OR view* OR opinion* OR attitude* OR satisf* N3 registrar*	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	205,715

S20	AB belief* OR perception* OR view* OR opinion* OR attitude* OR satisf* N3 doctor*	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	205,884
S19	AB belief* OR perception* OR view* OR opinion* OR attitude* OR satisf* N3 physician*	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	206,452
S18	AB belief* OR perception* OR view* OR opinion* OR attitude* OR satisf* N3 nurse*	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	207,520
S17	AB belief* OR perception* OR view* OR opinion* OR attitude* OR satisf* N3 practitioner*	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	205,884
S16	AB belief* OR perception* OR view* OR opinion* OR attitude* OR satisf* N3 "healthcare prof"	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	205,729
S15	(MH "Attitude of Health Personnel+")	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search	72,451



			Database - CINAHL Complete	
S14	S8 AND S13	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	896
S13	S9 OR S10 OR S11 OR S12	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	7,583
S12	TI PR	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	765
S11	AB PR	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	5,664
S10	TI "Pulmonary rehab*"	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	944
S9	AB "Pulmonary rehab*"	Search modes - Find all my search terms	Interface - EBSCOhost Research	997

			Databases Search Screen - Advanced Search Database - CINAHL Complete	
S8	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	18,730
S7	TI "chronic airflow obstruction*"	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	24
S6	AB "chronic airflow obstruction*"	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	33
S5	TI "chronic obstructive pulmonary disease*"	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	5,669
S4	AB "chronic obstructive pulmonary disease*"	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	8,056

S3	TI "chronic respiratory disease*"	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	144
S2	AB "chronic respiratory disease*"	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	443
S1	(MH "Pulmonary Disease, Chronic Obstructive+")	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	14,420

MEDLINE Search Strategy:

#	Query	Limiters/Expanders	Last Run Via	Results
S25	S14 AND S24	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	26
S24	S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	158,981
S23	AB (belief* OR perception* OR view* OR opinion* OR attitude* OR satisf*) N3 "healthcare provider"	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	491
S22	AB (belief* OR perception* OR view* OR opinion* OR attitude* OR satisf*) N3 consultant*	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	388
S21	AB (belief* OR perception* OR view* OR opinion* OR attitude* OR satisf*) N3 registrar*	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	76

S20	AB (belief* OR perception* OR view* OR opinion* OR attitude* OR satisf*) N3 doctor*	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	3,168
S19	AB (belief* OR perception* OR view* OR opinion* OR attitude* OR satisf*) N3 Physician*	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	10,642
S18	AB (belief* OR perception* OR view* OR opinion* OR attitude* OR satisf*) N3 Nurse*	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	10,146
S17	AB (belief* OR perception* OR view* OR opinion* OR attitude* OR satisf*) N3 "practitioner"	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	2,769
S16	AB (belief* OR perception* OR view* OR opinion* OR attitude* OR satisf*) N3 "healthcare prof"	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	679
S15	(MH "Attitude of Health Personnel+")	Search modes - Find all my search terms	Interface - EBSCOhost Research	141,870

			Databases Search Screen - Advanced Search Database - MEDLINE	
S14	S8 AND S13	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	2,037
S13	S9 OR S10 OR S11 OR S12	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	55,843
S12	TI PR	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	4,521
S11	AB PR	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	52,043
S10	TI "pulmonary rehab*"	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced	1,395

			Search Database - MEDLINE	
S9	AB "pulmonary rehab*"	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	2,394
S8	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	67,907
S7	TI "chronic airflow obstruction*"	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	239
S6	AB "chronic airflow obstruction*"	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	451
S5	TI "chronic obstructive pulmonary disease*"	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	15,906

S4	AB "chronic obstructive pulmonary disease**"	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	34,700
S3	TI "chronic respiratory disease**"	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	796
S2	AB "chronic respiratory disease**"	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	2,216
S1	(MH "Pulmonary Disease, Chronic Obstructive+")	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	47,008



PsychINFO Search Strategy:

#	Database	Search term	Results
1	PsycINFO	exp "PULMONARY EMPHYSEMA"/	83
2	PsycINFO	exp "BRONCHIAL DISORDERS"/	150
3	PsycINFO	exp "CHRONIC OBSTRUCTIVE PULMONARY DISEASE"/	1206
4	PsycINFO	exp "LUNG DISORDERS"/	3894
5	PsycINFO	exp REHABILITATION/	69863
6	PsycINFO	("chronic respiratory disease*").ti,ab	128
7	PsycINFO	("chronic airflow obstruction*").ti,ab	5
8	PsycINFO	("pulmonary rehabilitation*").ti,ab	155
9	PsycINFO	(PR).ti,ab	2984
10	PsycINFO	(1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7)	73699
11	PsycINFO	(8 OR 9)	3113
12	PsycINFO	(10 AND 11)	188
14	PsycINFO	(belief* OR perception* OR view* OR opinion* OR attitude* OR satisf* N3 healthcare professional).ab	694966
15	PsycINFO	(belief* OR perception* OR view* OR opinion* OR attitude* OR satisf* N3 practitioner).ab	694966
16	PsycINFO	(belief* OR perception* OR view* OR opinion* OR attitude* OR satisf* N3 Nurse).ab	694966
17	PsycINFO	(belief* OR perception* OR view* OR opinion* OR attitude* OR satisf* N3 physician).ab	694966

18	PsycINFO	(belief* OR perception* OR view* OR opinion* OR attitude* OR satisf* N3 doctor).ab	694966
19	PsycINFO	(belief* OR perception* OR view* OR opinion* OR attitude* OR satisf* N3 registrar).ab	694966
20	PsycINFO	(belief* OR perception* OR view* OR opinion* OR attitude* OR satisf* N3 consultant).ab	694966
21	PsycINFO	(belief* OR perception* OR view* OR opinion* OR attitude* OR satisf* N3 healthcare provider).ab	694966
22	PsycINFO	(14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21)	694966
23	PsycINFO	(12 AND 22)	28

### Appendix 3: Data Extraction and Quality Appraisal Form

#### Data Extraction and Quality Appraisal Form:

<b>Title:</b>	
<b>Authors:</b>	
<b>Year:</b>	<b>Journal:</b>
<b>Volume:</b>	
<b>Issue:</b>	
<b>Country of Origin:</b>	
<b>Research Question:</b>	
<b>Aims of the Study:</b>	
<b>Method/ Design:</b>	
<b>Participants and Inclusion/ Exclusion Criteria:</b>	
<b>Data Collection Methods:</b>	
<b>Data Analysis:</b>	
<b>Findings/ Results/ Pertinence to the Research Question</b> (What are Healthcare Professionals' Perceptions of Pulmonary Rehabilitation as a Management Strategy for Patients with COPD?):	

**Summary of Relevance to Healthcare Professionals Perceptions of Pulmonary Rehabilitation:**

<b>Quality Appraisal:</b>	<b>Good (4)</b>	<b>Fair (3)</b>	<b>Poor (2)</b>	<b>Very Poor (1)</b>	<b>Comments:</b>
Abstract and title					
Introduction and aims					
Method and data					
Sampling					
Data analysis					
Ethics and bias					
Results					
Transferability/ generalisability					
Implications/ usefulness					
Relevance to research question					
<b>Additional comments:</b>					
<b>Total:</b>					

## Appendix 4: Example of Completed Data Extraction Form and Quality Appraisal

### Quality Appraisal and Data Extraction Form:

<b>Title:</b> Factors affecting the offer of pulmonary rehabilitation to patients with chronic obstructive pulmonary disease by primary care professionals: a qualitative study.	
<b>Authors:</b> Harris, D., Hayter, M. & Allender, S.	
<b>Year:</b> 2008	<b>Journal:</b> Primary Health Care Research & Development
<b>Volume:</b> 9	
<b>Issue:</b> 4	
<b>Country of Origin:</b> UK (North Midlands)	
<b>Research Question:</b> What factors affect the offer of pulmonary rehabilitation to patients with COPD by healthcare professionals?	
<p><b>Aims of the Study:</b></p> <ol style="list-style-type: none"> <li>1. To understand health professionals' experiences of referring patients for pulmonary rehabilitation.</li> <li>2. To understand the barriers and facilitators health professionals face when offering pulmonary rehabilitation.</li> </ol>	
<p><b>Method/ Design:</b></p> <p>Qualitative research design: grounded theory.</p>	
<p><b>Participants and Inclusion/ Exclusion Criteria:</b></p> <p>Purposive sample of 21 participants who refer patients for pulmonary rehabilitation: Nine GP's, seven practice nurses, two GP registrars, two community matrons and one healthcare assistant.</p> <p>Healthcare professionals from three GP practices were recruited.</p> <p>Inclusion criteria: General practitioners, practice nurses, healthcare assistants and community matrons.</p>	
<p><b>Data Collection Methods:</b></p> <p>Participants took part in five focus groups at the practice where they worked, facilitated by a healthcare professional and a member of the research team. The questions included asking participants about their involvement with COPD patients, their knowledge of referring patients to the programme, guidance that they provide to patients, and the perceived barriers and facilitators to patients accepting this advice. The topic guide was</p>	

amended throughout the study, dependent on the responses given from previous focus groups. The focus groups were transcribed verbatim.

**Data Analysis:**

Grounded theory was a simultaneous process that occurred whilst data collection was taking place. A sample of the codes given were checked by two researchers to ensure agreement, and to increase rigour. Two of the participants a GP and practice nurse contributed to respondent validation.

**Findings/ Results/ Pertinence to the Research Question (What are Healthcare Professionals' Perceptions of Pulmonary Rehabilitation as a Management Strategy for Patients with COPD?):**

Practice Nurses and GP's believed that there was a lack of knowledge amongst healthcare professionals with regards to PR, they were unsure of what happens at the programme and how to refer. Other healthcare professionals perceived that the wait time was too long, and therefore would not consider referral. There is also the perception that there is too much paperwork involved in making a referral and that it takes too long. In keeping with the time issues, some viewed that they do not have sufficient time to discuss the prospect of attending PR in a standard consultation. There was also a lack of clarity amongst healthcare professionals about whose role it was to help COPD patients manage their condition, with practice nurses feeling under pressure and GPs' perceiving that it is not their role to manage COPD.

Nurses found it difficult to communicate with patients with COPD, as the patients have a low awareness of COPD and PR. Finally, healthcare professionals discussed that patients place an emphasis on medication, therefore the idea of PR needs to be sold to the patient, so that they can see other benefits rather than just that of their health.

It was evident that many of the GPs did not deal with many of the management or treatment options for patients with COPD, except when they were having an exacerbation. A number of the nurses felt that they had sole responsibility for the management of patients with COPD.

**Summary of Relevance to Healthcare Professionals' Perceptions of Pulmonary Rehabilitation:**

Overall the study discusses healthcare professionals' perceptions of PR for those working in primary care, including the referral process and their views of patient's perceptions of the programme. Healthcare professionals in general found the referral process problematic, in relation to issues with time, whose role it was to make the referral and communication issues with the patients.

**Assumptions that the Researchers Draw from their Findings:**

Although healthcare professionals are aware of some of the advantages of PR, healthcare professionals may be reluctant to refer patients due to the limited capacity on the programme, long waiting lists, absence of information and overall perception of a challenging referral process. The attitudes that healthcare professionals have towards PR may impact on the way that they deliver information about the programme to patients, potentially acting as a barrier.





<b>5. Data analysis:</b> Was the description of data analysis sufficiently rigorous?		
Good	(4)	Clear description of how the analysis was done. Qualitative studies: Description of how themes derived/ respondent validation or triangulation. Quantitative studies: Reasons for tests selected hypothesis driven/ numbers add up / statistical significance discussed.
Fair	(3)	Qualitative: Descriptive discussion of analysis. Quantitative: Descriptive discussion of analysis.
Poor	(2)	Minimal discussion about analysis.
Very Poor	(1)	No discussion of analysis.
<b>6. Ethics and bias:</b> Have ethical issues been addressed, and what necessary ethical approval gained? Has the relationship between researchers and participants been adequately considered?		
Good	(4)	Ethics: Where necessary issues of confidentiality, sensitivity, and consent addressed. Bias: Researcher was reflexive and / or aware of own bias.
Fair	(3)	Lip service was paid to above (i.e., these issues were acknowledged)
Poor	(2)	Brief mention of issues.
Very Poor	(1)	No mention of issues.
<b>7. Results:</b> Is there a clear statement of findings?		
Good	(4)	Findings explicit, easy to understand, and logical in progression. Tables, if present, are explained in text. Results relate directly to aims. Sufficient data are provided to support findings.
Fair	(3)	Findings mentioned but more explanation could be given. Data presented relate directly to results.
Poor	(2)	Findings presented haphazardly, not explained, and do not progress logically from the results.
Very Poor	(1)	Findings not mentioned, or do not relate to aims.
<b>8. Transferability and generalisability:</b> Are the findings of this study transferable (generalisable) to the wider population?		
Good	(4)	Context and setting of the study is described sufficiently to allow comparison with other contexts and settings, plus high score in question 4 (sampling)
Fair	(3)	Some context and setting described, but more needed to replicate or compare the study with others, PLUS fair score or higher in question 4.
Poor	(2)	Minimal description of context / setting.
Very Poor	(1)	No description of context / setting.
<b>9. Implications and usefulness:</b> How important are these findings to policy and practice?		
Good	(4)	Contributes something new and / or different in terms of understanding / insight or perspective. Suggests ideas for further research. Suggests implications for policy and / or practice
Fair	(3)	Two of the above (state what is missing in comments)
Poor	(2)	Only one of the above (state what is missing in comments)
Very Poor	(1)	None of the above

10. <b>Relevance to the research question:</b> What are Healthcare Professionals' Perceptions of Pulmonary Rehabilitation as a Management Strategy for Patients with Chronic Obstructive Pulmonary Disease (COPD)?		
Good	(4)	Very applicable to the review: Study as a whole discusses healthcare professionals' perceptions of pulmonary rehabilitation as a management strategy for patients with COPD. Provides a contribution to knowledge.
Fair	(3)	The focus of the research may not be solely around healthcare professionals' perceptions of pulmonary rehabilitation, however this aspect was explored adequately, and adds to existing knowledge on the topic.
Poor	(2)	Very brief mention of healthcare professionals' perceptions of pulmonary rehabilitation.
Very Poor	(1)	No mention of healthcare professionals' perceptions of pulmonary rehabilitation.

\*Adapted from Hawker et al., (2002).

Appendix 6: Example of how Synthesising Arguments and Synthetic Constructs were Formed.

General Perceptions of PR		
Synthesising Argument:	Synthetic Construct:	Supporting Quotes/Extracts:
<p>Unsure of the benefit</p>	<p>Negative attitude</p> <p>Main focus of considerations was on medical treatments rather than programmes during pulmonary rehabilitation (Hain et al., 2016)</p> <p>"I am not really sure what any kind of rehabilitation would come into this. I am not sure there is that in" (Johnson et al., 2015) → the concern of the benefits gained from attending pulmonary rehabilitation</p>	<p>"the accurate content and title of pulmonary rehabilitation was being low value rehabilitation was correct" (32) related (rehabilitation) was not clear" (Hain and Nelson, 2008, pp 348) → quote quote (Hain), not from participant</p> <p>"another 15/17 saying they are neutral about the benefits of pulmonary rehabilitation" (Hain and Nelson, 2008, pp 348) → quote quote (Hain), not from participant</p> <p>"only 5/8 thought rehabilitation was useful or very useful for COPD patients" (Hain and Nelson, 2008, pp 348) → quote quote (Hain), not from participant</p> <p>(Johnson et al., 2015, pp 321)</p>
<p>The programme is positive</p>	<p>Increase in confidence</p> <p>- Allow patients to build friendships with others with the same condition (Wachter et al., 2015)</p> <p>- The patients can create a bond / friendship with others in the same situation (Hain et al., 2016)</p>	<p>"I think fear is the biggest thing when they're first coming into the programme... what they're in the programme thinking and what decisions... it really does help with their Patient Anxiety"</p> <p>"Many [COPD participants] are very anxious about exercise... to start with I'm not going to do it... so they can feel more confident about exercising" (Wachter et al., 2015, pp 162)</p> <p>(Johnson et al., 2015, pp 322)</p> <p>(Hain et al., 2014, pp 505)</p> <p>(Hain et al., 2014, pp 505)</p>
<p>Perception of patients referred to pulmonary rehabilitation</p>	<p>Lack motivation</p> <p>Belief that patients would be unmotivated to attend pulmonary rehabilitation (Hain et al., 2014)</p> <p>(not willing to try PR) / patients feel depressed and frustrated could not manage pulmonary rehabilitation (Hain et al., 2014)</p> <p>- Health care professionals discussed how you have to ease the patients into the sessions to motivate and encourage them (Wachter et al., 2015)</p> <p>- Health care professionals are more to motivate and get patients they're doing well (Wachter et al., 2015)</p>	<p>Perception patients do not want to attend PR</p> <p>"He lives in a town camp... and he's just got more important things than coming to an exercise programme... 50 lots of buses use that rather than pure motivation" (Johnson et al., 2016, p 111)</p> <p>"I think there are some who have a certain level of motivation... they're not going to do it... they're not going to do it... they're not going to do it" (Hain et al., 2014, pp 505)</p> <p>"I think sometimes need to accept that patients won't change their behaviour if they're not motivated" (Hain et al., 2014, pp 505)</p> <p>4. Aides revealed that many positive men COPD do not attend pulmonary rehabilitation after an offer has been made (Coster et al., 2016)</p> <p>- Patients should want to be motivated to increase their skills. (Hain et al., 2015)</p> <p>The Psychological effects of COPD are just as important as the physical ones. Pulmonary rehabilitation assists patients with depression, low self-esteem and those who feel demotivated about a reason of getting (Hain et al., 2016, pp 1934)</p>
	<p>Exercise / Unable</p> <p>Analysis suggests COPD patients in relation to exercise (Wachter et al., 2015)</p> <p>Healthcare professionals were worried about asking COPD patients to exercise (Johnson et al., 2014, pp 11)</p>	<p>"The are many fails to attend because they lack it to do it [ ] they say yes but then they don't show up anyway [ ] maybe the explanation is the other. Or maybe they do not think they benefit enough from the sessions" (Hain et al., 2016, pp 1934)</p> <p>Some of the patients who are COPD participants are depressed [ ] for patients to participate they need more energy so I think that may be the reason's main COPD [ ] are not able to attend PR at the health center (Hain et al., 2016, pp 1935)</p>



# Barriers to Referral Cont...

Synthesising Argument:	Synthetic Construct:	Supporting Quotes/Extracts:
<p>Practical Barriers</p>	<p>Transport and Location</p>	<p>"It was difficult to get the GP for some people, and some of them were older so they had to organise transport and it was difficult for them every time. The public transport is not good... to take the bus is a nightmare." (Cochrane et al., 2016, pp 9).</p> <p>"We need a transport and someone to sit around the car waiting for you or if you're going to shop yourself and another person they get to the first time, it means that they're going to be stuck and unable to leave." (Johnson et al., 2013, pp 321).</p> <p>"The main professional groups that patients consult are GPs, nurses and health visiting in order. Patients also use physiotherapists, podiatrists, hearing aid dispensers, opticians, dentists, counsellors and dietitians. The most common reasons for consulting are respiratory symptoms, followed by musculoskeletal, mental health, and general health concerns. The most common reasons for consulting are respiratory symptoms, followed by musculoskeletal, mental health, and general health concerns. The most common reasons for consulting are respiratory symptoms, followed by musculoskeletal, mental health, and general health concerns." (Johnson et al., 2016, pp 112).</p> <p>"The main professional groups that patients consult are GPs, nurses and health visiting in order. Patients also use physiotherapists, podiatrists, hearing aid dispensers, opticians, dentists, counsellors and dietitians. The most common reasons for consulting are respiratory symptoms, followed by musculoskeletal, mental health, and general health concerns. The most common reasons for consulting are respiratory symptoms, followed by musculoskeletal, mental health, and general health concerns." (Johnson et al., 2016, pp 112).</p> <p>"The main professional groups that patients consult are GPs, nurses and health visiting in order. Patients also use physiotherapists, podiatrists, hearing aid dispensers, opticians, dentists, counsellors and dietitians. The most common reasons for consulting are respiratory symptoms, followed by musculoskeletal, mental health, and general health concerns. The most common reasons for consulting are respiratory symptoms, followed by musculoskeletal, mental health, and general health concerns." (Wilson et al., 2007, pp 1707).</p> <p>Difficult for patients to attend (Johnson et al., 2011) because of issues with travel. pp 663</p> <p>Barrier due to the distance where the pulmonary rehabilitation is run. (Nolan et al., 2016).</p>
	<p>Long Waiting Lists</p>	<p>"I think if people go on a waiting list for a long time for anything, by the time they're called up quite often that procedure to go and do something about it might have changed." (Johnson et al., 2013, pp 321).</p> <p>"the waiting lists are very long, it's too much for them." (Cochrane et al., 2016, pp 9).</p> <p>"When I rang... it would be 6 months before the patient could get... There's a long waiting list for the pulmonary rehab which makes you think... (Hains, Hayler and Allender, 2008, pp 284)</p> <p>Barrier: Long waiting lists (Johnson et al., 2011)</p>
	<p>Complicated Referral Process</p>	<p>"A single point of referral contact for PR services was suggested in four meetings... I think you do have to do for me to be able to... just refer to somebody... (Johnson et al., 2013, pp 322)</p> <p>"the patients had many forms, many things to do at the same time and it means them overwhelmed... a lot of patients are over 65 or 70 and it's too much for them." (Cochrane et al., 2016, pp 9)</p> <p>"we had to request many things, blood tests, spirometry, referrals to cardiologist, dietician, allied health professions, sometimes psychiatry or psychology." (Cochrane et al., 2016, pp 9).</p> <p>Problematic referral process, in relation to issues with time, whose role it is to make the referral and communication issues with patients (Hains, Hayler and Allender, 2008).</p> <p>Difficult referral process (Johnson et al., 2011)</p>

## Appendix 7: Study Selection Form

### Study Selection Form:

**Aim of the Systematic Review:** To identify studies which contain healthcare professionals' perceptions of pulmonary rehabilitation as a management strategy for patients with chronic obstructive pulmonary disease (COPD).

**Study Title:**

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**Date of Study:**        /        /

**Date Reviewed:**        /        /

**Authors:**

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<b>Inclusion Criteria:</b>	<b>Inclusion criteria met (✓)</b>
1. The study establishes HCPs' perceptions of PR as a management strategy for patients with COPD; in full or as part of a larger study.	
2. The article is written in the English language.	
3. The study has been conducted within the last 30 years (1988-2018).	
4. Primary research study with a clear and detailed method.	

<b>Exclusion Criteria:</b>	<b>Paper excluded (✓) *</b>
1. Any paper which does not include healthcare HCPs' perceptions of PR as a management strategy for COPD, or only includes patients' perceptions.	
2. Any paper that was unavailable in the English language.	
3. Any study conducted prior to 1988.	
4. Discussion, review papers, or studies without a clearly stated methodology.	

\*If any box is ticked under the paper excluded heading, then the paper will not be included in the systematic review.

**If excluded, list reasons why:**

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## Appendix 8: University Ethical Approval Letter

Edge Hill  
University

Emma Swift

6<sup>th</sup> May 2016

Dear Emma,

Thank you for submitting your research ethics application '*Healthcare Professionals' Perceptions of Pulmonary Rehabilitation as a Management Strategy for Patients with Chronic Obstructive Pulmonary Disease (COPD)*' (Project Ref: FOSH143) to the Faculty of Health & Social Care Research Ethics Committee.

I have pleasure in informing you that the Committee recommended that your study is granted Faculty of Health & Social Care research ethics approval, subject to the following conditions:

1. Ethical approval covers only the original study for which it is sought. If the study is extended, changed, and / or further use of samples or data is needed the Committee Administrator, Daniel Brown, must be contacted for advice as to whether additional ethical approval is required.
2. (NHS studies only) NHS Research governance processes must be adhered to. An application must be made to the HRA for approval for the research to be conducted in the NHS. All NHS R&D departments (in Trusts where data is being collected) will also need to be approached for Trust permission to proceed.
3. If the project requires HRA approval and/or NHS ethical approval, please forward evidence of the approval(s) to Daniel Brown ([browdan@edgehill.ac.uk](mailto:browdan@edgehill.ac.uk)) before commencing the study
4. The Principle Investigator is responsible for ensuring that all data are stored and ultimately disposed of securely in accordance with the Data Protection Act (1998) and as detailed within the approved proposal.
5. The Principle Investigator is responsible for ensuring that an annual monitoring form and an end of study form, where appropriate, is sent to the Committee Administrator ([browdan@edgehill.ac.uk](mailto:browdan@edgehill.ac.uk)). The form will be sent to you at the appropriate time by the Committee Administrator.

The study documentation that has been reviewed and approved is detailed below:

<doc title>	<version no & date>
Participant Letter	V2, 22/03/2016
Participant information sheet	V2, 22/03/2016
Topic Guide	V2, 22/03/2016

Participant email	V1, 15/02/2016
Consent form	V1, 14/01/2016
Proposal for ethics	

Yours sincerely



Louise Cope  
Acting Chair Faculty of Health & Social Care  
Research Ethics Committee

## Appendix 9: HRA Approval Letter



Health Research Authority

Miss Emma Swift  
Edge Hill University, Faculty of Health and Social Care  
St Helens Road  
Ormskirk  
L39 4QP

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

26 August 2016

Dear Miss Swift,

### Letter of HRA Approval

**Study title:** Healthcare Professionals' Perceptions of Pulmonary Rehabilitation as a Management Strategy for Patients with Chronic Obstructive Pulmonary Disease (COPD).  
**IRAS project ID:** 208153  
**REC reference:** 16/HRA/4075  
**Sponsor:** Edge Hill University

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

#### Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

*Appendix B* provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.



It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from [www.hra.nhs.uk/hra-approval](http://www.hra.nhs.uk/hra-approval).

### Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

### After HRA Approval

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](http://www.hra.nhs.uk), and emailed to [hra.amendments@nhs.net](mailto:hra.amendments@nhs.net).
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](http://www.hra.nhs.uk).

### Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application

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procedure. If you wish to make your views known please email the HRA at [hra.approval@nhs.net](mailto:hra.approval@nhs.net). Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

#### HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is **208153**. Please quote this on all correspondence.

Yours sincerely

Thomas Fairman  
HRA Assessor

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

Copy to: *Dr Nikki Craske, Edge Hill University, (Sponsor Contact)*  
*Faye O'Keeffe, University Hospital of South Manchester NHS Foundation Trust,*  
*(Lead NHS R&D Contact)*

## Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

<i>Document</i>	<i>Version</i>	<i>Date</i>
IRAS Application Form [IRAS_Form_15082016]		15 August 2016
Letters of invitation to participant [Invitation Letter for Primary Healthcare Professionals]	Version 2	22 March 2016
Letters of invitation to participant [Invitation Email for Healthcare Professionals in Secondary Care ]	Version 1	15 February 2016
Other [Client Information Letter (Insurance document)]		
Other [Certificate of Indemnity ]		
Other [Client Information Letter - 2016 Renewal - EL and PL]		03 August 2016
Other [Client Information Letter - 2016 Renewal - Professional Indemnity]		25 August 2016
Other [HRA Schedule of Events]	2	26 August 2016
Other [HRA Statement of Activities]	2	26 August 2016
Participant consent form	2	25 August 2016
Participant information sheet (PIS)	3	25 August 2016
Research protocol or project proposal [Research Proposal ]	Version 2	22 February 2016
Summary CV for Chief Investigator (CI) [Emma Swift CV]	1	11 July 2016
Summary CV for student [Emma Swift CV]		
Summary CV for supervisor (student research) [Dr Carol Kelly CV]		
Summary CV for supervisor (student research) [Professor Mary O'Brien CV ]		
Summary CV for supervisor (student research) [Dr Sarah Peters CV]		

## Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

**For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) sections in this appendix.***

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Dr Nikki Craske, Edge Hill University, ([crasken@edgehill.ac.uk](mailto:crasken@edgehill.ac.uk), 01695650925)

### HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The sponsor has submitted the HRA Statement of Activities and intends for this to form the agreement between the sponsor and study sites.  The sponsor is not requesting, and does not require any additional contracts with study sites.
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional

Section	HRA Assessment Criteria	Compliant with Standards	Comments
			indemnity provided by their medical defence organisation covers the activities expected of them for this research study
4.3	Financial arrangements assessed	Yes	No application for external study funding has been made. No study funding will be provided to sites, as detailed at Schedule 1 of the Statement of Activities.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Not Applicable	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

#### Participating NHS Organisations in England

*This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.*

All participating NHS organisations will undertake the same study activities. There is therefore only one study site 'type' involved in the research.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at [hra.approval@nhs.net](mailto:hra.approval@nhs.net). The HRA will work with these organisations to achieve a consistent approach to information provision.

### Confirmation of Capacity and Capability

*This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.*

NHS organisations in England that are participating in the study **will be expected to formally confirm their capacity and capability** to host this research.

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capability will be confirmed is detailed in the Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) section of this appendix.
- The Assessing, Arranging, and Confirming document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

### Principal Investigator Suitability

*This confirms whether the sponsor's position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England, and the minimum expectations for education, training and experience that PIs should meet (where applicable).*

A Principal Investigator should be appointed at study sites.

GCP training is not a generic training expectation, in line with the [HRA statement on training expectations](#).

### HR Good Practice Resource Pack Expectations

*This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken.*

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If research activities will be conducted at Alder Hey Children's NHS Foundation Trust by researchers without a pre-existing contractual relationship with the trust then the a Letter of Access should be sought. In addition the following reengagement checks would be necessary

- Occupational Health Clearance
- Criminal Record Check

#### **Other Information to Aid Study Set-up**

*This details any other information that may be helpful to sponsors and participating NHS organisations in England in study set-up.*

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

## Appendix 10: Research Passport

### Research Passport Application Form – Version 3 01/09/2012

Please refer to the guidance notes before completing the form.

Section 1 - Details of Researcher To be completed by Researcher			
1.	Surname: Swift	Prof <input type="checkbox"/> Dr <input type="checkbox"/> Mr <input type="checkbox"/> Mrs <input type="checkbox"/>	
	Forename(s): Emma	Miss <input checked="" type="checkbox"/> Ms <input type="checkbox"/> Other <input type="checkbox"/>	
	Home Address:		
	Work Tel: 01695 654352 emma.swift@edgehill.ac.uk	Mobile:	Email:
2.	Date of birth:	Gender: Male <input type="checkbox"/> Female <input checked="" type="checkbox"/>	
	Ethnicity: British	National Insurance number:	
3.	Professional registration details, if applicable (Doctors undertaking any form of medical practice should confirm they have a licence to practise). N/A <input checked="" type="checkbox"/>		
4.	Employer: Edge Hill University		or place of study: Edge Hill University
	Work Address/Place of Study: Edge Hill University Faculty of Health and Social Care St Helens Road Ormskirk Lancashire L39 4QP		
	Post or status held: PhD Student and Graduate Teaching Assistant		
Section 2 - Details of Research To be completed by Researcher			
5.	What type of Research Passport do you need? Project-specific <input checked="" type="checkbox"/> Multi-project <input type="checkbox"/>		
	If you will be conducting one project only please complete the details below. If you anticipate that you will be undertaking more than one project at any one time, please give details in the Appendix.		
	Project Title: Healthcare Professionals' Perceptions of Pulmonary Rehabilitation as a Management Strategy for Patients with Chronic Obstructive Pulmonary Disease (COPD). 2016SU009		
	Project Start Date: 01/09/16		End Date: 31/08/18
	Proposed start and end-date of 3-year Research Passport:		
	Start Date: 01/09/16		End Date: 31/08/18
	NHS organisation(s):	Dept(s):	Proposed research activities:
Trust	NHS Foundation	Researcher is working on NHS premises only (no access to identifiable data).	



		Researcher requires direct contact with staff only but no access to patients (e.g. staff interviews).	
NHS Foundation Trust		Researcher is working on NHS premises only (no access to identifiable data). Researcher requires direct contact with staff only but no access to patients (e.g. staff interviews).	
Greater Manchester Clinical Research Network (CRN)		Researcher is working on NHS premises only (no access to identifiable data). Researcher requires direct contact with staff only but no access to patients (e.g. staff interviews).	
<b>Section 3 – Declaration by Researcher</b> <i>To be completed by Researcher</i>			
6.	Have you ever been refused an honorary research contract?	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>	
	Have you ever had an honorary research contract revoked?	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>	
If yes to either question, please give details:			
I consent to the information provided as part of this Research Passport and attached documents being used, recorded and stored by authorised staff of the NHS organisations where I will be conducting research.			
Signed:		Date: 30/08/16	
When Sections 1-3 have been completed, the researcher should forward the form to the appropriate person to complete Section 4.			

<b>Section 4 - Suitability of Researcher</b>	
<i>To be completed by researcher's substantive employer, e.g. line manager, or academic supervisor</i>	
7. a	Will this person's research activity mean that they may be undertaking regulated activity with children and/or adults as defined in the Safeguarding Vulnerable Groups Act 2006, as amended (in particular by the Protection of Freedoms Act 2012)? (please use the Research Passport algorithm to make this judgement)
	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>
7. b	I am satisfied that the above named individual is suitably trained and experienced to undertake the duties associated with the research activities outlined in this Research Passport form.
	Signed: _____ Date: 19 <sup>th</sup> July 2016
	Name: Carol Kelly Job Title: Senior Lecturer
	Department and Organisation: Postgraduate Professional Education
	Address: Edge Hill University, St Helens Road, Lancs, L39 4QP
	Tel No: 01695 657090 Email: kellyc@edgehill.ac.uk
	Managerial responsibility for the applicant: Director of Studies
<i>When Section 4 has been completed, the researcher should forward the form to the appropriate person to complete Section 5.</i>	
<b>Section 5 - Pre-engagement checks</b>	
<i>To be completed by the HR department of the researcher's substantive employer or registry at place of study</i>	
8.	Does the above named individual's research involve Regulated Activity with children and/or adults as defined in the Safeguarding Vulnerable Groups Act 2006, as amended (in particular by the Protection of Freedoms Act 2012)?
	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
	If yes to the above, has the above named individual been checked against ISA barred lists for adults and/or children, as appropriate and have you received confirmation via the criminal record disclosure that the person is not barred from working with adults and/or children? (NB individuals who are barred from working with adults or children must not undertake a regulated activity in the NHS with the vulnerable group from which they are barred, and you must not submit a Research Passport form in such cases).
	Checked against: ISA Adults List? Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input checked="" type="checkbox"/>
	ISA Children's List? Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input checked="" type="checkbox"/>
	Can you confirm that a clear criminal record disclosure has been obtained for the above-named individual, with no subsequent reports from the individual of changes to this record? NB for Regulated Activity this must be an enhanced level criminal record check. For non-regulated activity, ensure the criminal record check is at the mandated level.
	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input checked="" type="checkbox"/>
	<i>If yes, please provide details of the clear disclosure:</i>
	Date of disclosure: _____ Type of disclosure: _____
	Disclosure No.: _____ Organisation that requested disclosure: _____
9.	Have the pre-engagement checks described below been carried out with regard to the above-named individual and is confirmation of the necessary checks, including any required satisfactory documentary evidence, available in the employing organisation's/place of study's records?
	▪ Employment/student screening:
	o ID with photograph Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
	o two references Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
	o verification of permission to work/study in the UK Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
	o exploration of any gaps in employment Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
	▪ Evidence of current professional registration Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input checked="" type="checkbox"/>
	▪ Evidence of qualifications Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
	▪ Occupational health screening / clearance Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
	Is the named individual on a fixed term contract or is the contract end imminent? Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
	Please indicate current contract end-date Date: 31.08.2018
	Signed: _____ Date: 18/07/2016
	Name: KAREN DANIEL Job Title: HR ADMIN PARTNER
	Organisation: EDGE HILL UNIVERSITY Department: HR
	Address: ST HELENS ROAD, ORMSKIRK, L39 4QP
	Tel No: 01695 657 236 Email: karen.daniel@edgehill.ac.uk
<i>Please return the form to the researcher.</i>	

<b>Section 6 - Instructions to applicants</b>	
<i>To be completed by Researcher</i>	
<i>Please indicate which of the following documents are attached to this Research Passport:</i>	
Current curriculum vitae, including details of qualifications, training and professional registration (please use the template C.V. at <a href="http://www.rdforum.nhs.uk/docs/template_cv.doc">http://www.rdforum.nhs.uk/docs/template_cv.doc</a> )	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
Researcher's copy of criminal record disclosure. NB where research involves regulated activity with children and/or adults as defined in the Safeguarding Vulnerable Groups Act 2006, as amended (in particular by the Protection of Freedoms Act 2012), the disclosure must include confirmation of a check against the appropriate ISA barred list(s).	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input checked="" type="checkbox"/>
Evidence of occupational health screening / clearance	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>
Appendix – List of projects and amendments	Appendix numbers:  N/A <input checked="" type="checkbox"/>

*Please send the completed form and original documents to the Lead R&D office. The completed form and original documents will be returned to you. This package of documents will be used to validate your completed Research Passport form. You may then, and where relevant, provide the Research Passport to other NHS organisations.*

**You must inform all NHS organisations that have received this Research Passport of any changes to the information supplied above. Failure to do so may result in withdrawal of your honorary research contract or letter of access. As part of the quality control procedures for the Research Passport, random checks on the accuracy of the information held on this Research Passport may be made.**

<b>Section 7</b> This section should be completed by HR in the Lead NHS organisation, only if additional checks are undertaken			
The following additional checks have been completed:			
N/A			
Having confirmed that the necessary additional pre-engagement checks have been completed, I am satisfied that the above named researcher is suitable to carry out the duties associated with their research activity outlined in this Research Passport.			
Signed:		Date:	
Name:		Job Title:	
Organisation:		Department:	
Email:			
<b>Section 8 - For Office Use Only</b>			
<i>This section should be completed by the NHS R&amp;D office that received the initial application. The NHS R&amp;D office must countersign and date retained photocopies of the documents. The grey section must be completed before the form is returned to the applicant.</i>			
CV reviewed?	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>	Training?	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/> <i>cel</i>
Evidence of qualifications?	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>	Appendix pages reviewed?	Numbers: 1
Professional registration details reviewed?	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input checked="" type="checkbox"/>	Occupational health clearance reviewed?	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input checked="" type="checkbox"/>
Criminal record disclosure reviewed?	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input checked="" type="checkbox"/>	Date of disclosure:	Disclosure No:
For regulated activity as defined in the Safeguarding Vulnerable Groups Act 2006, as amended (in particular by the Protection of Freedoms Act 2012), did the criminal record disclosure confirm a satisfactory check against the appropriate ISA barred list(s)			Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input checked="" type="checkbox"/>
Enter Electronic Staff Record Number (if issued):			
Confirmation of valid Research Passport:			
Project specific <input checked="" type="checkbox"/> 1. Three-year <input type="checkbox"/>		Other End date <input checked="" type="checkbox"/> Date: 31.8.18 <i>(contract end date)</i>	
Signed:		Date: 12.9.16	
Name:			
NHS Organisation Name and contact details			
Date Honorary Research Contract/letter of access issued (delete as appropriate)			
12.9.16			

*If required, this section should be added to the Research Passport Form and completed by each NHS R&D office receiving the valid Research Passport. The original Research Passport form and documents should be returned to the applicant.*

Has the Research Passport been validated by a Lead NHS organisation and is this validation acceptable to this NHS organisation? Yes <input type="checkbox"/> No <input type="checkbox"/>			
CV reviewed?	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>	Training?	Yes <input type="checkbox"/> No <input type="checkbox"/>
Evidence of qualifications?	Yes <input type="checkbox"/> No <input type="checkbox"/>	Appendix pages reviewed?	Numbers:
Professional Registration details reviewed?	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>	Occupational health clearance reviewed?	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>
Criminal record disclosure reviewed?	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>	Date of disclosure:	Disclosure No:
For regulated activity as defined in the Safeguarding Vulnerable Groups Act 2006, as amended by the Protection of Freedoms Act 2012, did the criminal record disclosure confirm a satisfactory check against the appropriate ISA barred list(s)			Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>
Checked Electronic Staff Record: Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>			
Signed:			Date:
Name:			
NHS organisation name and contact details:			
Date honorary research contract/letter of access issued ( <i>delete as appropriate</i> )			

**Passport Appendix. List of projects and amendments**

Appendix Number:

*If you are applying for a three-year Research Passport, please use this section to enter details of projects and activities that will be covered by this Research Passport. Once you have a validated Research Passport, you may add details of subsequent projects during the three years that this Research Passport is valid.*

*If you are applying for a project-specific Research Passport, but need to add further sites to the project, please enter the details below.*

*Whenever you add further details, the full Research Passport and accompanying documents must be submitted to the relevant NHS organisations.*

Title: Health Care Professionals Perceptions of Pulmonary Rehabilitation as a Management Strategy for Chronic Obstructive Pulmonary Disease (COPD)		Start Date: 01/09/16	End Date: 31/08/16
NHS organisation(s):	Dept(s):	Proposed research activities:	Manager in NHS organisation:
North West Coast Clinical Research Network (CRN)		Researcher is working on NHS	

**Amendments to the Research Passport**

*Please state what these are, e.g. they might be a change in name or employment details, or a change in research activities.*

*Please check with the NHS organisation where you are undertaking your research if you are unsure whether you will need to submit new evidence of pre-engagement checks on a new Research Passport form, which will need to be validated by the NHS organisation(s) hosting your research.*

Date	Old Details	New Details	Office use only NHS R&D contact details and signature

**To add more projects please copy this page or download further blank pages. Each appendix page should be numbered.**

*For office use only:  
A photocopy of the appendix should be retained whenever any amendments or additions to the appendix are made.*

## Appendix 11: Confirmation of Non-substantial Amendment

**From:** Emma Swift [<mailto:Emma.Swift@edgehill.ac.uk>]

**Sent:** 24 April 2017 12:02

**To:** FAIRMAN, Thomas (HEALTH RESEARCH AUTHORITY) [REDACTED]

**Subject:** Re: IRAS 208153 Healthcare Professionals' Perceptions of Pulmonary Rehabilitation (1)

Dear Thomas,

### RE: IRAS 208153. Healthcare Professionals' Perceptions of Pulmonary Rehabilitation (1)

Following our recent telephone conversation, I would just like to inform you that after suggestion from a gatekeeper in secondary care, the researcher may accompany the gatekeeper to wards where eligible healthcare professionals work, to inform them about the study in person. On these occasions recruitment will be the same as outlined, information about the study will be left with the health professionals and they will make contact with the researcher if they want to take part. This is solely to raise awareness of the project and I already have letters of access from all of my sites.

Thank you once again. Please do not hesitate to contact me should you require any further information.

Kind Regards,

Emma Swift

---

**From:** AMENDMENTS, Hra (HEALTH RESEARCH AUTHORITY)

**Sent:** 02 May 2017 09:23

**To:** 'Emma.Swift@edgehill.ac.uk'

**Cc:** [REDACTED]; [REDACTED]; FAIRMAN, Thomas (HEALTH RESEARCH AUTHORITY)

**Subject:** FW: IRAS ID: 208153 - NSA #1- Healthcare Professionals' Perceptions of Pulmonary Rehabilitation (1) - Category C amendment

Dear Emma,

<b>IRAS Project ID:</b>	208153
<b>Short Study Title:</b>	Healthcare Professionals' Perceptions of Pulmonary Rehabilitation (1)
<b>Date complete amendment submission received:</b>	24/04/2017
<b>Amendment No./ Sponsor Ref:</b>	NSA #1- researcher accompanying gatekeeper to inform HCP of study
<b>Amendment Date:</b>	24/04/2017

Thank you for submitting the above referenced amendment. In line with the [UK Process for Handling UK Study Amendments](#) I can confirm that this amendment has been categorised as:

- **Category A** - An amendment that has implications for, or affects, ALL participating NHS organisations

You should now provide this email, together with the amended documentation, to the research management support offices **and** local research teams at your participating NHS organisations in England.

If you have participating NHS organisations in Northern Ireland, Scotland and/or Wales, you should communicate directly with the relevant research teams to prepare them for implementing the amendment, as per the instructions below. You do not need to provide this email or your amended documentation to their research management support offices, as we will pass these to the relevant national coordinating functions who will do this on your behalf.

Subject to the three conditions below, you will be able to implement the amendment at your participating NHS organisations in England **35 days after you notify them of the amendment**. A template email to notify participating NHS organisations in England is provided [here](#).

- You may not implement this amendment until and unless you receive all required regulatory approvals, including REC favourable opinion where applicable, (for participating organisations in England, please see 'Confirmation of Assessment Arrangements' below). You should provide regulatory approvals to the research management support offices and local research teams at your participating NHS organisations in England, plus to local research teams at any participating NHS organisations in Northern Ireland, Scotland or Wales\*.
- You may not implement this amendment at any participating NHS organisations which inform you within the 35 day period that they require additional time to consider the amendment, until they notify you that the considerations have been satisfactorily completed.
- You may not implement this amendment at any participating NHS organisation that informs you that it is no longer able to undertake this study.

**Note:** you may only implement changes described in the amendment notice or letter.

If you receive required regulatory approvals (for participating organisations in England, please see 'Confirmation of Assessment Arrangements' below) after the 35 days have passed, you may then immediately implement this amendment at all participating NHS organisations that have not requested additional review time, or are no longer able to undertake this study.



There is no need for you to receive a letter of confirmation from the participating organisation that the amendment can be implemented, as the intended date of implementation is communicated through the above process. However, you may be able to implement this amendment ahead of the 35 day deadline, if all necessary regulatory approvals are in place and the participating organisation has confirmed that the amendment may be implemented ahead of the 35 day date.

\* Where the study involves NHS organisations in Northern Ireland, Scotland or Wales, the HRA will forward regulatory approvals to the relevant national coordinating function to distribute to their research management support offices.

### **Participating NHS Organisations in England – Confirmation of Assessment Arrangements**

#### **Further to the details above, I can confirm that no HRA assessment of this amendment is needed.**

- If this study has HRA Approval, this amendment may be implemented at participating NHS organisations in England once the conditions detailed in the categorisation section above have been met
- If this study is a pre-HRA Approval study, this amendment may be implemented at participating NHS organisations in England that have NHS Permission, once the conditions detailed in the categorisation section above have been met. For participating NHS organisations in England that do not have NHS Permission, these sites should be covered by HRA Approval before the amendment is implemented at them, please see below;
  - If this study is awaiting HRA Approval, I have passed your amendment to my colleague in the assessment team and you should receive separate notification that the study has received HRA Approval, incorporating approval for this amendment.

Please do not hesitate to contact me if you require further information.  
Kind regards

Alka Bhayani  
HRA Approvals - Amendments Coordinator

**Health Research Authority**  
HRA, Ground Floor, Skipton House, 80 London Road, London, SE1 6LH  
E: [hra.amendments@nhs.net](mailto:hra.amendments@nhs.net)  
[www.hra.nhs.uk](http://www.hra.nhs.uk)

---

AMENDMENTS, Hra (HEALTH RESEARCH AUTHORITY)

<hra.amendments@nhs.net>

Tue 02/05, 09:25

Sorry All

The subject line should read Category A (now amended) and not Category C as below. Apologies for the oversight.

Many thanks, Alka

## Appendix 12: University Ethics Amendment Letter

Edge Hill  
University

Emma Swift

10<sup>th</sup> May 2017

Dear Emma,

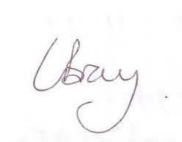
Thank you for submitting your revised ethics documentation for '*Healthcare Professionals' Perceptions of Pulmonary Rehabilitation as a Management Strategy for Patients with Chronic Obstructive Pulmonary Disease (COPD)*' (Project Ref: FOSH143) to the Faculty of Health & Social Care Research Ethics Committee.

I have pleasure in informing you that I have reviewed your amended documents and approved the changes made to your research.

The study documentation that has been reviewed and approved is detailed below:

<doc title>	<version no & date>
Participant Letter	<b>V2, 22/03/2016</b>
Participant information sheet	<b>V3, 25/08/2016</b>
Topic Guide	<b>V2, 22/03/2016</b>
Participant email	<b>V1, 15/02/2016</b>
Consent form	<b>V2, 25/08/2016</b>
Proposal for ethics	<b>V3, 24/04/2017</b>

Yours sincerely



Dr Lucy Bray

Acting Chair of Faculty of Health & Social Care Research Ethics Committee Edge Hill University  
St Helens Road  
Ormskirk  
Lancashire  
L39 4QP  
[brayl@edgehill.ac.uk](mailto:brayl@edgehill.ac.uk)

## Appendix 13: Participant Invitation Letter Primary Care – Version 2

**Edge Hill  
University**

Emma Swift BSc (Hons), MRes  
Office H116  
Faculty of Health and Social Care  
Edge Hill University  
St Helens Road  
Ormskirk  
L39 4QP

Tel: 01695 654352

Email: [emma.swift@edgehill.ac.uk](mailto:emma.swift@edgehill.ac.uk)

Dear Dr/ Mr/ Mrs/ Miss,

I am a PhD student at Edge Hill University, studying in the Faculty of Health and Social Care. I am conducting a study into healthcare professionals' perceptions of pulmonary rehabilitation as a management strategy for patients with chronic obstructive pulmonary disease (COPD). I would very much appreciate your participation in this research.

The research involves a short interview (between 20-40 minutes), of your views on the topic. This can be conducted at a time suitable for yourself, either over the telephone or face to face at the surgery where you work.

If you are interested in taking part, I have included a participant information sheet which gives a more detailed overview of the study. I would be grateful if you could complete the form below and return it in the pre-paid envelope provided. Alternatively please feel free to respond on the email address provided above.

Thank you for taking the time to read this letter, and if you have any questions please do not hesitate to contact me on the email address or telephone number provided above.

Yours Sincerely,

Emma Swift

-----  
Would you like to participate in the above mentioned research?

Yes

No

[GP/practice nurse  
name and address]

If yes please could you provide your contact details, and suitable contact times.

Contact telephone number: \_\_\_\_\_

Email address: \_\_\_\_\_

Please list the most suitable times for contact:

\_\_\_\_\_  
\_\_\_\_\_

Thank you,

Emma Swift

**Healthcare Professionals' Perceptions of Pulmonary  
Rehabilitation as a Management Strategy for Patients with  
Chronic Obstructive Pulmonary Disease.**

(IRAS ID: 208153)

**Participant Information Sheet:**

You are being invited to take part in a research study to establish healthcare professionals' perceptions of pulmonary rehabilitation as a management strategy for patients with chronic obstructive pulmonary disease (COPD). The information sheet aims to give an overview of the study and provide answers to commonly asked questions. Before you decide whether you would like to take part it is important for you to understand why the research is being conducted and what your involvement will entail. Please take time to decide whether you would like to take part, and discuss with others if you wish. If you have any further questions please do not hesitate to contact a member of the research team, details of which can be found at the bottom of this information sheet. Thank you for taking the time to read this.

**Who will conduct the research?**

The research will be carried by the primary researcher Emma Swift (PhD student, Edge Hill University, Faculty of Health and Social Care), as part of her PhD.

Dr Carol Kelly (Director of Studies), Professor Mary O'Brien both from the Faculty of Health and Social Care at Edge Hill University, and Dr Sarah Peters from the University of Manchester, School of Psychological Sciences, are also members of the research team.

**What is the purpose of the study?**

The aim of the study is to explore healthcare professionals' perceptions of pulmonary rehabilitation as a management strategy for patients with COPD. Both healthcare professionals working in primary care and secondary care, who have the ability to refer COPD patients to the pulmonary rehabilitation will be invited to take part. We would like to establish perceptions of the programme and whether or not healthcare professionals refer COPD patients to it. It is hoped that the findings of the study will increase understanding of the facilitators and barriers to referrals to the pulmonary rehabilitation programme. The purpose of carrying out this study is to also write the results up as a thesis for the primary researchers' (ES) PhD.

### **Why have I been chosen?**

A large proportion of healthcare professionals working in GP surgeries and in hospital trusts within the North West of England have been invited to take part. This information sheet has been sent to healthcare professional who have the ability to refer to the pulmonary rehabilitation programme. If you do decide to take part, there will be approximately 40 other healthcare professionals involved in the study.

### **Do I have to take part?**

No. Your participation in the research is voluntary. You are also free to withdraw from the study at any time during the interview, and up to seven days after, without any given reason. If you decide to withdraw the researcher will stop the interview, and any data collected will not be included in the study if you do not want it to be.

### **What will happen if I decide to take part in the study?**

If you wish to take part in the research after reading this information sheet the researcher will ask if you have any questions. If you are still happy to take part then the researcher will ask you to give consent. This will be verbally for telephone interviews and in writing for face to face interviews. The primary researcher (ES) will carry out the interview, which is expected to last between 20-40 minutes, on your views surrounding the topic. The interview will be audio digitally recorded, with your permission, and will take place at a time suitable for yourself, either over the telephone, or face to face at the practice or hospital where you work, or at Edge Hill University if you prefer.

### **Will my taking part in this study be kept confidential?**

The interviews will be transcribed verbatim, and at this point any identifying information that you may provide, such as names and places, will be removed. Your transcript will be allocated a non-identifying number which only the primary researcher will be able to link to you. Any personal details such as your name and where you work will be held securely in accordance with the Data Protection Act (1998), and separately from the anonymised interview transcripts.

Data will be stored on a secure electronic server (computer) at the university, with access restricted to the research team. Data will be kept for 10 years, after which point it will be destroyed. Any hard copies of consent forms or transcripts will be kept in a locked filing cabinet in the primary researcher's office, which only the research team has access to. The audio recordings will be kept until the end of the study, at which point they will be deleted. The only exception would be if the researcher considered that there was a disclosure of unsafe practice, in which case the primary researcher would refer this information to the supervisory team.

Anonymised data will be made available for sharing with other researchers should a request be received by the research team. In this case anonymised transcripts would be sent to those whom requested it, with your permission.

### **What will happen to the results of the research study?**

It is anticipated that the study will be disseminated through publication in academic journals, and presented at conferences. The results will also be disseminated back to the healthcare professionals who take part, in the form of a report. Should any of your words be used as quotes in any reports or publications arising from this study, (with your permission), a non-identifying number will be used e.g. GP 1. The results will be written up as part of a thesis for a PhD.

### **Who has reviewed the study?**

Permission has been granted by Edge Hill University Faculty of Health and Social Care Research Ethics Committee. NHS Research Management and Development (R and D) Permission has also been granted.

### **What if there is a problem?**

If you wish to discuss any aspect of the study please feel free to contact the primary researcher Emma Swift via email: [emma.swift@edgehill.ac.uk](mailto:emma.swift@edgehill.ac.uk) or telephone: 01695 654352.

Or alternatively the Director of Studies Dr Carol Kelly via email: [kellyc@edgehill.ac.uk](mailto:kellyc@edgehill.ac.uk) or telephone: 01695 657090.

If you feel that you would prefer to speak to someone outside of the research team, please feel free to contact: Professor Clare Austin, Associate Dean for Research and Innovation in the Faculty of Health and Social Care at Edge Hill University on [austincl@edgehill.ac.uk](mailto:austincl@edgehill.ac.uk), or alternatively via telephone 01695 650772.

**Thank you for taking the time to read this participant information sheet. If you would like any further information about the study, or have any questions then please feel free to contact the primary researcher or director of studies on the email address or telephone numbers provided above.**

## Appendix 15: Invitation Email for Distribution in Secondary Care – Version 1

Edge Hill  
University

Dear Dr/ Mr/ Mrs/ Miss,

I am a PhD student at Edge Hill University, studying in the Faculty of Health and Social Care. I am conducting a study into healthcare professionals' perceptions of pulmonary rehabilitation as a management strategy for patients with chronic obstructive pulmonary disease (COPD). I would very much appreciate your participation in this research.

The research involves a short interview (20-40 minutes), of your views on the topic. This can be conducted at a time suitable for yourself, either over the telephone, or face to face at the hospital where you work.

If you are interested in taking part, I have attached a participant information sheet which gives a more detailed overview of the study. I would be grateful if you could reply to this email by contacting me on the email address provided below, to express an interest in the study, or decline participation.

Thank you for taking the time to read this email, and if you have any questions please do not hesitate to contact me on the email address or telephone number provided below.

Yours Sincerely,

Emma Swift

BSc (Hons) (Psychology), MRes (Psychology)  
PhD Student/ Graduate Teaching Assistant  
Office H116  
Faculty of Health and Social Care  
Edge Hill University  
St Helens Road  
Ormskirk  
L39 4QP  
01695 654352  
[Emma.Swift@edgehill.ac.uk](mailto:Emma.Swift@edgehill.ac.uk)

**Appendix 16: Consent Form – Version 2**

**Healthcare Professionals' Perceptions of Pulmonary Rehabilitation as a Management Strategy for Patients with Chronic Obstructive Pulmonary Disease**  
(IRAS ID: 208153)

**Research Consent Form:**

**Please  
initial box**

I confirm that I have read and understood the information sheet for the above study dated 25/08/16, version 3, and that I have had the time to consider participation in the study. I have had the opportunity to ask any questions, and these have been answered satisfactorily.

I understand that my participation is voluntary, and that I have the right to withdraw both during the interview and at any point up to seven days after the interview, without any given reason.

I agree to the interview being audio digitally recorded.

I agree to the use of any anonymised quotes being used in the thesis, or any publications which arise from the research.

I agree to my anonymised data being shared with other researchers in the future.

I agree to take part in the above research.

**Signed:**

Name of participant:

Signature:

Date:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Name of researcher taking consent:

Signature:

Date:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_



## **Appendix 17: Interview Topic Guide – Version 2:**

### **Topic Guide:**

#### **Demographic Information:**

How long have you been (a practicing GP, registered nurse, consultant, registrar) for?

Is there any area of medicine that you specialise in, or are particularly interested in?

What is your experience with respiratory conditions?

#### **Pulmonary Rehabilitation and COPD:**

Can you tell me what you know about pulmonary rehabilitation? [Probe for knowledge of the programme in their area, and how often they refer COPD patients]

Do you think there are any benefits that a COPD patient may experience from attending pulmonary rehabilitation? [Probe for examples]

Do you consider there to be any drawbacks or disadvantages that a COPD patient might experience from attending pulmonary rehabilitation? [Probe for examples]

What information have you received about pulmonary rehabilitation? [Probe for where or who they received the information from, whether they received enough information, how useful they found the information and how they feel that it could be improved]

Do you give or present information to COPD patients, regarding pulmonary rehabilitation? [If so probe for what information is provided to the patient. If no, probe for why not, and what could be done to change this]

#### **The referral to pulmonary rehabilitation:**

Thinking back can you tell me about a time when you referred a COPD patient to pulmonary rehabilitation, or when you considered it? [Probe for why they referred the patient, and what symptoms prompted them to refer. If they considered referral but decided not to refer, probe for why]

What would influence your decision to refer a COPD patient to pulmonary rehabilitation? [Probe for examples]

What might deter you from referring a COPD patient to pulmonary rehabilitation?

**Feedback on pulmonary rehabilitation:**

Thinking back has there been an instance where you have referred a patient to, or know a patient who has attended, pulmonary rehabilitation and they have given you feedback on the programme? [If so probe for patients reported perceptions of the programme, did they finish the programme, if not ask do they know the reasons why?]

In summary, what are your views on the effectiveness of pulmonary rehabilitation as a management strategy for patients with COPD?

**Thank the participant for taking part in the study and ask if they have any questions that they wish to ask.**

## Appendix 18: Example of Initial Analysis of Transcript

Participant ID:	Gender:	Years in Practice:	Specialism:	List Size:	Area:	Age:	Length of Interview:
Practice Nurse 1	Female	46	General Practice	8119	Greater Manchester CCG	69	21mins 17secs

I: and how useful do you think the information was that they provide in that course then, or do you think there's anything that could be improved?

P: It was very useful because erm it was just one session, and that session included some advice on where to put things in the kitchen so that you're not reaching high and things like that. There was some light exercise going on, and, and quite a bit of education, you know... erm like reassurances, and, it was just very interesting because there was one chap er with, he was only in his mid-fifties, very, very advanced COPD and his exercise involved standing up from a chair ... but it's something that he was more proficient at, through going through rehab he'd struggled and he could do it, and then I thought yeah and you know, if this goes on long enough maybe he'd be able to do just that little bit more. So I think its quality of life, erm pulmonary rehab. → PR increases quality of life. } observed benefits

I: Yeah, definitely.

P: (inaudible).

I: So, do you feel there could sort of be any improvement on the information that you receive as a practice nurse then?

P: Oh yes.

I: What sort...

P: If they give us, if they give us a programme of what the actual course involves, then we can give the patients an idea of what the course involves, and they then can make an informed decision rather than being sent somewhere where there's a sketchy sort of idea of what happens, and it is that informed consent to a referral. → Requires further information on programme content

I: yeah that's great. So do the patients that you refer to the programme then, do you give or present any information to them regarding pulmonary rehabilitation, before they attend?

P: No ...

I: or is it just sort of all verbal?

P: It's all verbal, and there's no sort of little handbook or anything like that, no, it would be nice for a booklet that outlines the programme erm, and you know, then the patient knows what to expect, and you think about these people who have become isolated, they are going into a group, they don't know what to expect, they don't know what's going to happen, so they're anxious... → Present info to patients verbally. → Anxious / patients need to be informed / know what to expect.

I: Yeah.

P: and then they start shallow breathing, and then they start dyspnoea, and,, it's, it's just something, yeah, it's quite complicated if you think about it. → Anxious worsens symptoms, need to reassure / put patients minds at rest.

*Handwritten notes:*  
 - Knowledge gained from attending PR session / course content  
 - If HCPs are informed / knowledgeable about PR in their area, patients can make an informed decision  
 - Suggestion of improvement - but

Participant ID:	Gender:	Years in Practice:	Specialism:	List Size:	Area:	Age:	Length of Interview:
Practice Nurse 1	Female	46	General Practice	8119	Greater Manchester CCG	69	21mins 17secs

I: um

P: whereas if they know what they're going into, at least they've got, you know, they're, they're not so anxious. They'll still be anxious, but not quite so anxious.

I: Um. Thank you. So my next few question are just going to be on the referral process to pulmonary rehabilitation. So

P: Yes

I: thinking back can you tell me about a time when you referred a COPD patient to pulmonary rehabilitation, or when you considered it?

P: ... Er well, it happens every week.

I: Well if you think about sort of, you don't have to give any names but sort of a particular patient, can you just give me a few examples of the sort of process that you'd go through, why you'd referred that patient, what symptoms prompted you to refer, that sort of thing?

Example of patient discussion regarding PR.

P: It's erm, okay so this is Joe Bloggs and he'd, yeah [laughter], he was overweight, and, and taking very little exercise because of his breathing, not because of pains in his legs or anything, because of his breathing, erm so we had a little discussion about his weight and er we do have a health trainer coming in, so they do the weight management part of things, erm, and then I offered pulmonary rehab, and he said what's that [laughter], so I yo-, and this is where it gets stuck you see, because I said well it's a series of erm meetings at [name of health centre], and, and they help you with breathing exercises, and erm moving around, and, this it gets very, very difficult because it comes across that the health professional really does not know what she's is talking about... → Lack of knowledge on how to sell / describe the programme, increases HCP's anxiety

I: Yeah.

P: and, and I'm, I am the only nurse who's actually gone to pulmonary rehab, to see what happens. → Gone out of way to gain knowledge.

I: So do you think more then could be offered to the healthcare professionals, to sort of give them a better idea then of what they're, what they are trying to sell to the patient?

Lack of information / knowledge.

P: Yes, because if we'd got an outline of the programme, and just sort of a standard outline of the programme, nothing exotic you know, we could say well this is what pulmonary rehab is and this is what you know, this is how long this, we don't even know how long a session lasts. → Requires further information from service to increase our confidence / make our job easier

I: Right, okay.



Participant ID:	Gender:	Years in Practice:	Specialism:	List Size:	Area:	Age:	Length of Interview:
Practice Nurse 1	Female	46	General Practice	8119	Greater Manchester CCG	69	21mins 17secs

P: Yeah, so this is week one, week two, week three, week four, and then all, all, so even just a print out, we haven't even got a, a booklet to give them...

I: Right, okay.

Requires more information for Patients (suggestion).

P: Yeah.

I: That's great, thank you. Erm, so do you think that patients, what do you think patients understanding of the programme is then? Before they are sort of referred, COPD patients?

Faith / hope that something will work (psychological benefits).

P: I, I think it's, it's hope, the patients have hope that the pulmonary rehab will improve their breathing, because this is what they perceive as the big problem, is the breathing. So they're hoping, erm that you know that, that something will improve that.

I: That's great, thank you. So is there anything that might deter you from referring a COPD patient to pulmonary rehabilitation?

P: No.

I: No.

P: Nothing at all. → would refer all patients to PR.

I: Right okay.

P: Yeah, we send, we also send a copy of the spirometry, erm along with everything else, so it's, you know, it's, it seems like a one way road of information, that we send loads of information about medication, spirometry, history, all this sort of stuff, erm and we either get patient attended pulmonary rehab, or patient failed to attend, and that's the feedback we get.

→ Imitation / work load / de-valued by PR service as they receive limited information back.

I: So do you get nothing other than that then?

P: No, it's then just asking them just asking the patients how it went on.

→ Have to rely on feedback from patients

I: Right okay. Are you able to follow that information up with the patient, or is that just something that you leave then at that point?

P: Er, we probably talk, but it's, it's twelve months then until their next review, and pulmonary rehab comes up again.

→ Limited contact with COPD patients

I: Right okay, and are you allowed to re-affair at that point?

P: Oh yes, yeah, yeah...

I: Yeah, so thinking back

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P: Even if they, sorry, even if they've done part of, part of the pulmonary rehab erm and they want to go back, then we will refer them back.

I: That's great, thank you. So thinking back as there been an instance where you have referred a patient or know a patient who has attended pulmonary rehabilitation, and they have give you feedback personally on the programme?

P: Oh yes, yeah. Erm, and I would say in the majority of cases it is very positive feedback. → Most patients are positive about the programme.

I: So what sort of things do they report? Sort of what are their perceptions of the programme, once they have attended?

P: It's that confidence thing, ah they show you how to do this, they show you how to do that, and you know it's a lot better now. It's, these people erm, they, I think they see it, they eventually enjoy the social part of it as well, they're meeting the same people every week and, and getting to know each other, yeah it's, it's positive, and yeah. → chance to meet others in the same situation / friendship / social benefits  
 ↑ increased positivity / confidence building / ability / psychological benefits.

I: That's great, thank you. Do most patients finish the programme then that you speak to?

P: No. [laughter] Short answer [laughter]. Er some will do the first, and sometimes the second part of the programme and, and then not go back. → Large drop out rate.

I: Do you know the reasons why for that?

P: Because they find it too much. But then often they're like, erm I, I don't, I've never really, when we are doing an annual review we've got thirty minutes to cover everything, so to actually go into it in depth, erm is pretty much an impossibility. But - s workload if, I, I always again offer pulmonary rehab, and then, it, it might come out at that second you know offer, yeah, well yeah I will go back because [name of man] was ill, you know some sort of family crisis, or I wasn't very well, and then I didn't feel like going back because I'd missed a week. So ... → Events happened patient dropped out, did not want to go back, but will go back after.  
 ↑ Reasons for drop out.  
 ↑ Lack of time in consultation  
 ↑ Passionate positive about PR.

I: Are they sort of the main reasons then, that they don't finish the programme?

P: Yeah, yeah. There's some sort of interruption, and they've missed a week, or you know, or what will they say when they go back [laughter]. → Patients worry about missing a session, therefore drop out.

I: That's great. So just in summary, can I just ask what your views are on the effectiveness of pulmonary rehabilitation as a management strategy for patients with COPD?

P: It's an essential I think, because we sit there and, we, we give advice, we give medication, we can't, that, that's just part of, of caring for somebody with COPD isn't it, you know so I think pulmonary rehab sort of completes the picture, this holistic

↳ Positive attitude to PR / part of the complete care for a patient with COPD