

**Exploring Patients' Perceptions  
Following an Acute Exacerbation of  
Chronic Obstructive Pulmonary  
Disease to Inform Tailored Strategies  
to Enhance Pulmonary Rehabilitation**

Thesis submitted for the degree of

Doctor of Philosophy

at the University of Leicester

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2014

## **ABSTRACT**

### **Exploring Patients' Perceptions Following an Acute Exacerbation of Chronic Obstructive Pulmonary Disease to Inform Tailored Strategies to Enhance Pulmonary Rehabilitation**

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**Background:** Patient attrition to Pulmonary Rehabilitation (PR) is significant. Whilst biomedical variables have been examined as potential predictors, their explanatory power is not substantial and increasingly psychological constructs have been considered as determinants of PR adherence.

**Aim:** This thesis aimed to increase understanding of how PR can be facilitated and enhanced for patients following hospitalisation with an acute exacerbation of Chronic Obstructive Pulmonary Disease (COPD) by exploring issues around patient access, engagement and assessment of psychological appraisals.

**Methods:** An observational mixed-methods design was utilised informed by a review of the published literature and a retrospective observation of stable patients. Participants in the prospective studies had recently been hospitalised with an acute exacerbation of COPD. *Qualitative component:* Patients who refused a referral to PR participated in in-depth interviews exploring appraisals of an exacerbation. Transcripts were subjected to Interpretative Phenomenological Analysis. *Quantitative component:* Questionnaires relating to illness perceptions, mood, health status and self-efficacy were completed soon after hospital discharge. At six months acceptance and uptake of PR was documented. Cluster analysis was conducted using the domains of the Illness Perceptions Questionnaire-Revised.

**Results:** *Qualitative component:* Conceptual themes included: 'Construction of the self', 'Relinquishing control' and 'Engagement with others'. *Quantitative component:* Three distinct illness profiles exist in patients following an acute exacerbation of COPD: '*in control*', '*disengaged*' and '*distressed*'. There were no differences between 'clusters' in acceptance or uptake of PR.

**Conclusion:** Adherence to post-exacerbation PR is poor and may reflect the intense emotional distress reported by patients following an acute exacerbation of COPD. Health care professionals need to be mindful of how they address patients who, during a period of vulnerability, are sensitive of perceived dismissive behaviour. Targeted psychological strategies which enhance partnership working and trust, address intense fear and elicit control may be beneficial in reducing distress and supporting uptake of PR.

## **ACKNOWLEDGEMENTS**

The completion of this thesis would not have been possible without the support and expertise of several people.

Firstly, I would like to thank my supervisors Dr Noelle Robertson and Professor Sally Singh who, by sharing their experience, have taught me a wealth of new skills. I am also very grateful to have been offered the wonderful opportunity to conduct this work.

In addition to my supervisory team I would like to thank Lindsay Apps for her qualitative expertise, Dr Chris Graham for his support in conducting the cluster analysis, Dr John Bankart for his statistical advice and Dr Michael Steiner for helping me to organise my thoughts.

I feel very lucky to have completed my PhD in such a constructive work environment where I am surrounded by many friends all of whom have offered support and advice on a daily basis. Thank you to the Respiratory Early Discharge Scheme nurses for assisting with recruitment and to Victoria Willott and Gillian Doe for helping to gather the six month follow up data.

The quality of this research was greatly improved by the advice and comments provided by the Patient Public Involvement group members. Thank you for all your time and thoughtful discussion.

I cannot express enough gratitude to my parents for instilling in me the belief that if you work hard enough anything is possible and for giving me every opportunity to achieve my ambitions. Thank you also to my fiancé Dan for all the support, even accompanying me across the world so I can pursue a career in research.

Finally, I am hugely thankful to all the patients who gave up their time to complete the study, particularly during a period when they were acutely unwell. These people participated in the hope that findings may help future patients.

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## **LIST OF ABBREVIATIONS**

Basal Metabolic Rates (BMR)  
Beck Anxiety Inventory (BAI)  
Beck Depression Inventory (BDI)  
Behaviour Change Wheel (BCW)  
Body Mass Index (BMI)  
Brief Assessment Schedule for Depression Cards (BASDEC)  
Centre for Epidemiological Studies-Depression (CES-D)  
Chronic Obstructive Pulmonary Disease (COPD)  
Chronic Respiratory Questionnaire (CRQ)  
Chronic Respiratory Questionnaire-Self Reported (CRQ-SR)  
Cognitive Behavioural Therapy (CBT)  
Common Sense Model (CSM)  
Endurance Shuttle Walk Test (ESWT)  
Forced Expiratory Volume in One Second (FEV<sub>1</sub>)  
Forced Expiratory Volume in One Second/Forced Vital Capacity (FEV<sub>1</sub>/FVC)  
General Practitioner (GP)  
Hospital Anxiety and Depression Scale (HADS)  
Illness Perceptions Questionnaire (IPQ)  
Illness Perceptions Questionnaire-Revised (IQP-R)  
Intervention Mapping (IM)  
Improving Access to Psychological Therapies (IAPT)  
Incremental Shuttle Walking Test (ISWT)  
Interpretative Phenomenological Analysis (IPA)  
Inter Quartile Range (IQR)  
Long Term Oxygen Therapy (LTOT)  
Medical Research Council (MRC)  
Mindfulness Based Stress Reduction (MBSR)  
Mindfulness Based Cognitive Therapy (MBCT)  
Minimal Clinically Important Difference (MCID)  
Myocardial Infarction (MI)  
Patient and Public Involvement (PPI)

Patient Information Sheet (PIS)  
Physical Activity Level (PAL)  
Profile of Mood State (POMS)  
Pulmonary Rehabilitation (PR)  
Randomised Controlled Trial (RCT)  
Reciprocal Translational Analysis (RTA)  
Respiratory Early Discharge Scheme (REDS)  
Saint George's Hospital Respiratory Questionnaire (SGRQ)  
Saint George's Hospital Respiratory Questionnaire - COPD (SGRQ-C)  
SenseWear PRO<sup>2</sup> Armband (SWM)  
Short Burst Oxygen Therapy (SBOT)  
Six Minute Walk Test (6MWT)  
State-Trait Anxiety Inventory (STAI)  
Standard Deviation (SD)  
The Common Sense Model (CSM)  
The Critical Appraisal Skills Programme (CASP)  
The Pulmonary Rehabilitation Adapted Index of Self-Efficacy (PRAISE)  
The Transactional Model of Stress and Coping (TMSC)  
Tuberculosis (TB)  
United Kingdom (UK)

## **LIST OF PUBLICATIONS/ABSTRACTS**

Below is a list of papers and abstracts arising from this thesis:

### **Publications**

1. Harrison, S. L., Apps, L., Singh, S. J., Steiner, M. C., Morgan, M. D. L., Robertson N. (2013). “Consumed by breathing” – A critical interpretative meta-synthesis of the qualitative literature. *Chronic Illness*, 10 (1): 31-49.
2. Harrison, S. L., Greening, N. J., Williams, J. E. A., Morgan, M. D. L., Steiner, M. C., Singh S. J. (2012). Have we underestimated the efficacy of pulmonary rehabilitation in improving mood? *Respiratory Medicine*, 101 (6): 838-844.
3. Harrison, S. L., Robertson, N., Graham, C. D., Williams, J. E. A., Steiner, M. C., Morgan, M. D. L., Singh, S. J. (2013). Can we identify patients with different illness schema following an acute exacerbation of COPD: A cluster analysis? *Respiratory Medicine*, 108 (2): 319-328.
4. Harrison, S. L., Apps, L., Singh, S. J., Steiner, M. C., Morgan, M. D. L., Robertson N. ‘We are not worthy’ – Understanding why patients decline pulmonary rehabilitation following an acute exacerbation of COPD. *Disability and Rehabilitation*, available online. 1-7.



## **Abstracts**

### Oral presentations

1. Harrison, S. L., Robertson, N., Graham, C. D., Williams, J. E. A., Steiner, M. C., Morgan, M. D. L., Singh, S. J. (2012). Using psychological profiling to identify vulnerable populations following an acute exacerbation of COPD. Presented at the Postgraduate Conference, School of Psychology, University of Leicester.

### Poster presentations

2. Harrison, S. L., Robertson, N., Williams, J. E. A., Steiner, M. C., Singh, S. J. (2012, September). Does pulmonary rehabilitation (PR) influence patients' perceptions of disease? Presented at the meeting of the European Respiratory Society congress. Vienna, Austria.
3. Harrison, S. L., Apps, L., Steiner, M. C., Singh, S. J., Robertson, N. (2012, September). "Consumed by breathlessness" - A critical interpretative synthesis. Presented at the meeting of the European Respiratory Society congress. Vienna, Austria.
4. Harrison, S. L., Greening, N. J., Williams, J. E. A., Singh, S. J. (2010, December). Is a pulmonary rehabilitation (PR) programme effective in reducing severe symptoms of anxiety and depression in patients with COPD? Presented at the British Thoracic Society Winter meeting, London, UK
5. Harrison, S. L., Apps, L., Singh, S. J., Steiner, M. C., Morgan, M. D. L., Robertson N. 'We are not worthy' – Why do patients decline pulmonary rehabilitation following an acute exacerbation of COPD? Presented at the American Thoracic Society International conference, 2014.

# **Chapter 1**

## **1. INTRODUCTION**

### **1.1. Chronic Obstructive Pulmonary Disease**

Chronic Obstructive Pulmonary Disease (COPD) is an umbrella term which encompasses a number of respiratory conditions most commonly caused by the effects of tobacco smoking, including chronic bronchitis and emphysema. There is considerable variation in the course of the disease although COPD is characterised by progressive airflow limitation resulting in symptoms such as; shortness of breath on exertion, a chronic cough, regular sputum production and a frequent wheeze (National Institute for Clinical Excellence, 2010). COPD is a major cause of morbidity and mortality; by 2020 it is estimated to become the third leading cause of death worldwide due to the rising incidence of COPD in women and the effect of an aging population (Mannino, 2002; Murray & Lopez, 1997; Soriano et al., 2000).

COPD is a costly disease both to society and to the individual. The greatest proportion of COPD-related costs is accounted for by acute exacerbations resulting in hospitalisation. Acute exacerbations are defined by a change in patients' baseline symptoms beyond day to day variability (American Thoracic Society / European Respiratory Society Task Force, 2004). Despite medical intervention approximately one third of patients will have recurrent symptoms within 14 days often resulting in a readmission to hospital (Emerman, Effron, & Lukens, 1991; Miravittles et al., 2000). Following an admission to hospital physical activity levels are significantly reduced affecting health-related quality of life and leading to associated psychological co-morbidities (Donaldson, Wilkinson, Hurst, Perera, & Wedzicha, 2005; Pitta et al., 2006a; Seemungal et al., 1998; Gruffydd-Jones, Langley-Johnson, Dyer, Badlan, & Ward, 2007).

## **1.2. Personal background**

My academic and professional background has inevitably influenced the content of this thesis. I believe that information regarding my position as a researcher will assist with the understanding and contextualisation of the research I have conducted.

In 2006 I completed my undergraduate bachelor degree in psychology and sports-science (BSc honours). I then went on to complete my postgraduate masters degree in physiotherapy (MSc pre-registration) which also awarded me with registration as a health care professional.

I was employed at an acute trust in the East Midlands as a research physiotherapist January 2009 working within the Pulmonary Rehabilitation (PR) department. As well as my research responsibilities I assisted in the delivery of the PR service: assessing and discharging patients, delivering exercise classes and giving educational talks. My interest in psychology shaped the way I approached my clinical role; paying particular attention to patients' psychological state and their readiness to engage in PR.

Although my intensive involvement in the clinical service inevitably diminished during the course of my PhD, throughout the process I was an integral part of the team and kept informed of current developments within the department and wider hospital setting.

## **1.3. Pulmonary Rehabilitation**

PR is central to the management of patients with COPD. As well as improving exercise tolerance it has been shown to be effective in reducing breathlessness, increasing health related quality of life and improving symptoms of anxiety and depression (Griffiths et al., 2000; Lacasse et al., 2002). The benefits of PR in patients whose COPD is stable has led to its expansion for more vulnerable disease populations. Patients who attend PR following an acute exacerbation are less likely to experience a readmission to hospital (Puhan, Scharplatz, Troosters, Walters, & Steurer, 2009; Seymour et al., 2010).

Despite the documented benefits, there are difficulties recruiting to, and poor attendance at, PR programmes particularly following an acute exacerbation (Eaton et al., 2009; Puhan et al., 2011; Seymour et al., 2010). This is perhaps a consequence of PR programmes being primarily developed for stable patients and the additional clinical demands of patients following an acute exacerbation being less scrutinised. Socio-demographic and clinical variables have been shown to be poor predictors of attendance to PR and it has been suggested that psychological variables may have greater predictive value (Fischer et al., 2007). The most influential theoretical framework utilised in a predictive capacity is the Common Sense Model (CSM) (Leventhal, Nerenz, & Steele, 1984). The CSM proposes that experience of symptoms provokes a process of ‘meaning making’ for individuals and the creation of cognitive and emotional representations. The ways in which patients adopt and adapt these illness representations shapes subsequent health behaviour.

#### **1.4. Illness perceptions**

The role of illness perceptions has been explored fairly extensively in patients whose COPD is stable using the Illness Perceptions Questionnaire-Revised (IPQ-R). Illness perceptions which attribute many symptoms, perceive a low sense of control and possess strong emotional representations are associated with poorer health outcomes; increased disability, reduced health related quality of life and higher anxiety and depression (Kaptein et al., 2009). To date, no research has investigated patients’ illness perceptions following an acute exacerbation. This is particularly surprising considering patients’ illness perceptions following significant acute health - related events have been shown to affect disease management in other chronic conditions such as diabetes (Skinner et al., 2011) and post myocardial infarction (Alsen, Brink, Persson, Brandstrom, & Karlson, 2010; French, Cooper, & Weinman, 2006).

An investigation into the value of illness perceptions in predicting PR engagement in patients whose COPD is stable found that ‘treatment control’ significantly differed between individuals who adhered to a PR programme and patients who were unable (Fischer et al., 2009). However, predicting engagement in PR is complex, it may be that a combination of illness perceptions is able to account for the variance in health-promoting behaviour between individuals with COPD. Psychological profiling has not

been applied in COPD and may be helpful in identifying tailored psychological strategies to enhance PR.

### **1.5. Thesis aim and objectives**

The overall aim of this thesis is to increase understanding of how a PR intervention can be facilitated and enhanced for patients following hospitalisation with an acute exacerbation of COPD by exploring issues around patient access, engagement and assessment of patients' psychological appraisals.

Underpinning this aim are a number of research questions:

1. What does the current literature tell us regarding how patients respond to, appraise and understand acute exacerbations of COPD resulting in hospitalisation?
2. What is the interaction between psychological symptoms and PR?
  - a. Specifically, how successful is PR, delivered in its current form, in addressing symptoms of anxiety and depression, which are severe?
  - b. What is the utility of the Hospital Anxiety and Depression Scale (HADS) in identifying patients who successfully complete PR and those who are unable?
3. What is the acceptance and uptake of PR delivered following an acute exacerbation of COPD?
4. How do patients who decline PR appraise acute exacerbations of COPD?
5. Can a measure of illness perceptions offer additional value in understanding psychological status in patients following an acute exacerbation of COPD?
  - a. What are patients' illness perceptions measured using the IPQ-R following hospitalisation with an acute exacerbation of COPD?
  - b. Can we identify clusters of patients with distinct illness perceptions following hospitalisation with an acute exacerbation of COPD?
  - c. Do patients' illness perceptions have utility in explaining variance in health behaviour following an acute exacerbation of COPD?

### **1.6. Chapter summaries**

Chapters 2, 3, and 4 present a comprehensive review of the literature which informs and contextualises this work. Chapter 2 describes the study population and the focus of

disease management strategies in patients with COPD. By detailing the impact of symptoms associated with the disease and the manner in which interventions designed to promote physical activity are delivered, the chapter justifies why further examination of this patient group is warranted.

Although psychological support is currently recommended for patients with COPD the manner in which this support is delivered has been given little consideration. Chapter 3 provides a critical review of salient psychological models highlighting the appropriateness of tailoring psychological strategies for patients with COPD around the concepts endorsed by the CSM. A rationale for the exploration of patients' illness perceptions following an acute exacerbation is provided with reference to a narrative evaluation of current published evidence documenting the value of illness perceptions in predicting engagement in disease-promoting behaviour in other chronic conditions as well as in patients whose COPD is stable. The IPQ-R, a measure used to assess patients' illness perceptions, has been found to be useful in the development of behavioural interventions.

With reference to the information presented in the proceeding chapters describing the difficulties in engaging patients in PR following an acute exacerbation of COPD, Chapter 4 focuses on developing strategies to assess the needs of these patients. An argument is advanced that by tailoring interventions to the specific concerns and beliefs of a population the likelihood of successfully promoting behaviour change is greatly enhanced. Two frameworks which promote tailoring treatment through a phased approach are described and the adoption of an Intervention Mapping (IM) framework serves to inform the remaining content and structure of this thesis.

Chapters 5 and 6 constitute; a meta-synthesis of the existing qualitative literature and a retrospective analysis of data derived from the HADS. Information gleaned from these preliminary investigations is argued to increase understanding of the needs of the population, in accordance with the IM framework, and assess the extent to which patients' needs are currently being met.

The current literature observes that following an acute exacerbation patients report heightened levels of distress questioning the appropriateness of PR, delivered in its

current form, for this vulnerable population. Distress appears to be construed by patients' appraisals of the acute event advocating the usefulness of assessing patients' illness perceptions following an acute exacerbation of COPD to help inform psychological interventions designed to mitigate distress.

Currently, PR programmes are not tailored to meet the specific demands of patients with heightened levels of psychological morbidity and it is therefore unsurprising that PR has limited efficacy in addressing severe symptoms of anxiety and depression. The HADS is the routinely applied tool to assess psychological morbidity in patients with COPD, yet it may not be the best tool to explain adherence to PR. Considering conclusions drawn from the meta-synthesis (Chapter 5) and the strengths of the IPQ-R in informing the development of tailored psychological interventions (Chapter 3) the IPQ-R was selected to assess psychological status in patients following an acute exacerbation.

Chapter 7 provides a rationale for adopting a mixed-methods approach. As the purpose of this thesis was both to explore and increase understanding, qualitative and quantitative approaches were afforded equal status. Within the qualitative division, an interpretative phenomenological approach to the qualitative research is utilised to understand patients' 'meaning making' process following an acute exacerbation influencing the decline of PR. Quantitative assessment of illness perception data will ensure psychometric robustness and facilitate numerically substantive data from a target population to enhance generalizability of findings and offer a more robust basis for potential tailoring of clinical interventions.

Although it is likely that adherence to post-exacerbation PR is compromised, indicated indirectly by knowledge of the heightened levels of distress experienced by patients following an acute exacerbation of COPD (Chapter 5), adherence rates at programmes have not been explored prospectively. Chapter 8 thus describes a prospective observational study identifying uptake and adherence to post-exacerbation PR as being poor, emphasising the importance of considering alternative ways to facilitate the delivery of PR for patients following an acute exacerbation.

Patients who refuse active interventions (PR) are also unlikely to be motivated to participate in research studies, making this population difficult to access and therefore, arguably, poorly understood. Chapter 9 presents a qualitative study, informed and analysed using Interpretative Phenomenological Analysis, exploring how patients appraise an acute exacerbation of COPD in relation to refusing PR. Patients who decline PR following an acute exacerbation of COPD appear to possess self-conscious cognitions founded in shame and stigmatisation. These cognitions seem to reflect challenges to self-worth and appear associated with reduced help-seeking and isolation. Perceived personal culpability for COPD appears to sensitise patients towards their interactions with health care professionals, construed as critical and judgemental which may increase avoidant behaviours, such as refusal of PR.

Although information retrieved using qualitative methods enables the collection of rich data (Chapter 9) quantitative research methodologies are useful for expanding the breadth and range of enquiry into the needs of patients following an acute exacerbation of COPD. Informed by a narrative review (Chapter 3) and an investigation into the utility of the dominant measure used in identifying patients who successfully complete PR and those who are unable (Chapter 6) the IPQ-R was selected to assess potential patient appraisals linked to health behaviour (uptake and attendance to PR). In Chapter 10 a cluster analysis was conducted, using domains of the IPQ-R, to establish groups of patients holding distinct beliefs. Three distinct illness schemas exist in patients following an exacerbation: *'in control'*, *'disengaged'* and *'distressed'*. These findings may be used to develop psychologically-informed interventions designed to reduce feelings of distress and perhaps facilitate engagement in PR following an exacerbation of COPD.

By adopting principles of IM this body of research presents a thorough 'needs assessment' of patients following an acute exacerbation of COPD. Chapter 11 consolidates findings to provide recommendations for the manner in which PR can be facilitated and enhanced for this vulnerable population. The role of psychological therapies, focusing on acceptance, is proposed and critically discussed. Recommendations for strategies are provided to assist health care professionals with encouraging trust and safety which may promote active partnership working and serve to facilitate engagement in PR. Any impact of such strategies on adherence to PR would be of future interest.



# **Chapter 2**

## **2. NARRATIVE REVIEW: BIOMEDICAL MANAGEMENT AND DELIVERY IN PATIENTS WITH CHRONIC OBSTRUCTIVE PULMONARY DISEASE**

This chapter introduces the reader to Chronic Obstructive Pulmonary Disease (COPD) describing in detail the characteristics of the condition and emphasising the burdens imposed both on the individual and the health care system. Engaging patients with COPD in physical activity is beneficial not only in terms of the health and wellbeing of patients but also in reducing hospital readmission rates. However, encouraging physical activity in patients with COPD is challenging due to its association with breathlessness. Currently the additional psychological requirements of patients following an acute exacerbation of COPD have been given little consideration, and greater understanding of sub-optimal adherence is needed.

### **2.1. Chronic Obstructive Pulmonary Disease**

#### **2.1.1. Definition**

COPD is characterised by chronic airflow limitation which interferes with normal breathing and is not fully reversible. Airflow limitation is associated with an abnormal inflammatory response of the lungs to noxious particles or gases, in particular those caused by smoking. As COPD progresses its later stages are characterised by acute exacerbations which are defined by a fluctuation in symptoms often resulting in an admission to hospital (Nici et al., 2006; Suissa, Dell'aniello, & Ernst, 2012). Although progressive in nature, increased knowledge and understanding of the disease process has led to current guidelines being updated to include the terms 'treatable' and 'preventable' when defining COPD emphasising the role of medical management (e.g. pharmacological agents) .

*“COPD, a common preventable and treatable disease is characterized by persistent airflow limitation that is usually progressive and associated with an enhanced chronic inflammatory response in the airways and lungs to noxious particles or gases. Exacerbations and comorbidities contribute to the overall severity in individual patients”* (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2013).

### 2.1.2. Diagnosis

#### *2.1.2.1. Spirometry*

An accurate method for measuring airflow obstruction is spirometry (measuring of breath) which is usually performed before and after bronchodilation to test reversibility and it is used by clinicians as a diagnostic tool for COPD (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2013; National Institute for Clinical Excellence, 2010). Impaired lung function is noted when Forced Expiratory Volume in One Second/Forced Vital Capacity ( $FEV_1/FVC$ ) is measured as  $<0.70$  (after maximum inspiration, when Forced Expiratory Volume in One Second ( $FEV_1$ ) is the amount of air expelled from the lungs in one second and FVC is the total amount of air a person can expel) (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2013). COPD is classified according to severity using specific spirometric cut off points:  $FEV_1/FVC <0.7$  and  $FEV_1$  % predicted less than 80% is indicative of moderate disease severity, less than 50% implies severe disease and very severe disease is classified as less than 30%. However, clinicians exercise caution when interpreting results in this manner as these cut off points have not yet been clinically validated (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2013).

#### *2.1.2.2. Symptoms and signs*

Despite its diagnostic value, lung function assessed using spirometry is a poor predictor of health status (Jones, 2001). As well as airflow limitation other factors including: severity of symptoms, exercise limitation, acute exacerbations and other systemic manifestations influence individual disease experience and underpin recommendations for a multi-dimensional assessment when diagnosing COPD (Global Initiative for

Chronic Obstructive Lung Disease (GOLD), 2013; National Institute for Clinical Excellence, 2010).

According to the National Institute of Clinical Excellence (NICE) guidelines (2010) a diagnosis of COPD ought to be considered if a patient is over the age of 35 years, has a risk factor for COPD (usually smoking) and presents with one or more of the following symptoms: breathlessness on exertion, chronic cough, regular sputum production and frequent “bronchitis” wheeze. However, patients in whom a diagnosis is considered should also be asked about: weight loss, effort intolerance, waking at night, ankle swelling, fatigue, occupational hazards, chest pain and haemoptysis (coughing of blood) (National Institute for Clinical Excellence, 2010).

In the initial stages, COPD often goes undetected as there are seldom any abnormal physical signs (Mannino, Gagnon, Petty, & Lydick, 2000; Calverley & Georgopoulos, 1998) and slight reductions in exercise tolerance are commonly attributed to the ‘normal’ process of aging (Lazarus & Harridge, 2007; Nici et al., 2006). However, as the disease progresses breathlessness becomes a common cause for concern. In order to grade the amount of breathlessness according to the level of exertion required to provoke shortness of breath The Medical Research Council (MRC) dyspnoea scale is used (National Institute for Clinical Excellence, 2010) (Table 1).

**Table 1. Medical Research Council dyspnoea scale**

	<b>MRC dyspnoea scale</b>
<b>Grade</b>	<b>Degree of breathlessness related to activities</b>
1	Not troubled by breathlessness except on strenuous exercise
2	Short of breath when hurrying or walking up a slight hill
3	Walks slower than people of the same age on the level ground because of breathlessness or has to stop for breath when walking at own pace
4	Stops for breath after walking about 100m or after a few minutes on level ground
5	Too breathless to leave the house, or breathless when dressing or undressing

### 2.1.3. Risk factors

When deliberating appropriate disease management strategies identification of risk factors for COPD is considered to be important. Much of the evidence regarding risk

factors stems from cross-sectional studies that identify associations but, to date, few studies have monitored the progression of COPD throughout its entire course. Thorn and colleagues (2007) contributed to the limited body of evidence by conducting a 32 year prospective study on Swedish women which identified stress, smoking and obesity to be associated with airway symptoms (Thorn et al., 2007). More studies of this kind on both genders are required to increase our somewhat limited understanding of COPD associated risk factors.

#### *2.1.3.1. Tobacco smoke*

The risk factor most commonly associated with COPD is cigarette smoking (US Surgeon General, 1984; Burrows, Knudson, Cline, & Lebowitz, 1977) with individuals who smoke cigarettes being more likely to develop respiratory symptoms and having a higher mortality rate associated with COPD than non-smokers (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2013). The risk of COPD-related mortality can be predicted by the age when a person starts smoking, the total number of pack years (20 cigarettes per day for one year equals one pack year) and current smoking status.

The longitudinal severity of COPD can be increased by second-hand smoke (Eisner, Jacob, Benowitz, Balmes, & Blanc, 2009) and individuals who are involuntarily exposed to tobacco smoke are more likely to develop respiratory symptoms associated with COPD (The Surgeon General, 2006). In both smokers and non-smokers the risk of respiratory symptoms is associated with the total burden of inhaled particles and gases (Dayal, Khuder, Sharrar, & Trieff, 1994; Leuenberger et al., 1994).

Although tobacco smoke is the most important risk factor worldwide (Anto, Vermeire, Vestbo, & Sunyer, 2001; Pauwels, Buist, Calverley, Jenkins, & Hurd, 2001; Silverman & Speizer, 1996) risk factors also appear to result from a gene-environment interaction (Silverman & Speizer, 1996), in part, explaining why some non-smokers develop COPD and why a proportion of people who smoke all their lives never go on to develop significant respiratory symptoms.

#### *2.1.3.2. Occupation*

Occupational exposures associated with COPD include; dust, chemical agents and fumes (Hnizdo, Sullivan, Bang, & Wagner, 2002; Matheson et al., 2005; Trupin et al., 2003) although, the effects on respiratory symptoms are still under acknowledged with occupational exposures accounting for only 10-20% of respiratory symptoms or functional impairment in patients with COPD (Hnizdo et al., 2002; Balmes et al., 2003).

#### *2.1.3.3. Genes*

The genetic risk factor most conclusively associated with COPD is a hereditary deficiency of alpha-1antitrypsin (Stoller & Aboussouan, 2005) a rare recessive genetic trait which causes defective production of alpha-1antitrypsin leading to decreased activity in the blood and lungs and deposition of excessive abnormal alpha-1antitrypsin in the protein and liver cells. Individuals with this genetic vulnerability have a high risk of developing a reduction in lung function irrespective of smoking status, although smoking does increase the risk of developing limitations in lung function and can accelerate the rate of decline. The interaction between genes and environmental exposures is demonstrated by the variability which exists between individuals in disease severity and disease progression (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2013).

#### *2.1.3.4. Infections*

The presence of severe infections in childhood has been found to have an adverse effect on lung function later in life (de Marco et al., 2011). Human Immunodeficiency Virus and tuberculosis (TB) have also been found to be associated with an increased risk of smoking-related lung disease (Crothers et al., 2011; Menezes et al., 2007). In particular, TB is a somewhat common co-morbidity in patients with COPD (Jordan, Spencer, & Davies, 2010).

#### *2.1.3.5. Socioeconomic status*

There appears to be an inverse relationship between the risk of developing COPD and socioeconomic status (Prescott, Lange, & Vestbo, 1999) but as yet, definitive associations remain unclear. Risk may be related to environmental factors such as; related poverty, poor housing, poor nutrition and environmental exposure. It has been noted that lower education and income appears to be associated with increased disease severity and functional limitations (Eisner, Blanc, et al., 2009) implying that perhaps education level is key in defining quality of disease management.

#### 2.1.4. The burden of Chronic Obstructive Pulmonary Disease

##### *2.1.4.1. Prevalence*

Approximately 210 million people have COPD worldwide (World Health Organization, 2013) and the rate of COPD in the United Kingdom (UK) population is estimated at between two and four percent (Healthcare Commission, 2006). Unsurprisingly, there is a positive relationship between COPD prevalence and age (Mannino et al., 2000) which may, partly, be accounted for by the natural decline in lung function due to the effects of aging. The prevalence of COPD is also higher in males than females (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2013) which may have been due to occupational exposures in the past but the number of females diagnosed with COPD now appears to be rising steadily.

It is likely that the widespread prevalence of COPD is currently under-appreciated (van den Boom et al., 1998). Despite the ease of diagnosis, approximately two million people remain undiagnosed in the UK (Healthcare Commission, 2006). Patients may delay investigation as early symptoms of shortness of breath, wheezing and fatigue are often ascribed to aging rather than pathology (Mannino et al., 2000). Clinicians may also be partly to blame with fewer than 50% of individuals with COPD (based on a reduction in lung function) having a doctor's diagnoses (Mannino et al., 2000).

#### *2.1.4.2. Morbidity and mortality*

COPD accounts for approximately 30,000 deaths each year in the UK (Department of Health, 2004; Healthcare Commission, 2006). It is the fourth leading cause of death worldwide and it is set to become the third leading cause of death by 2020 (Murray & Lopez, 1997). The increasing burden of COPD can, in part, be accounted for by the rising death rate in females and also by an aging population (Soriano et al., 2000) with the majority of COPD deaths occurring in patients aged over 65 years (British Thoracic Society, 2006; Department of Health, 2005; Healthcare Commission, 2006).

As COPD progresses acute exacerbations become increasingly common often resulting in an admission to hospital (Hurst et al., 2010; Suissa et al., 2012). COPD is the second largest cause of emergency hospital admissions in the UK accounting for one in eight emergency admissions (British Lung Foundation, 2007). Furthermore, almost half of all patients admitted to hospital with an exacerbation of COPD will experience at least one subsequent acute episode (Suissa et al., 2012), with approximately 30% of patients being readmitted to hospital within the first three months period (British Thoracic Society, 2006; Hurst et al., 2010).

The likelihood of being admitted to hospital for COPD increases with age due to declining lung function and increasing disease severity (Vestbo, Prescott, & Lange, 1996; Suissa et al., 2012). Men tend to be admitted more frequently than women (Chapman, 2004; Soriano et al., 2000), although in the UK a higher proportion of admissions are for females (Office for National Statistics, 2000), perhaps reflecting a culturally-specific finding regarding the help-seeking behaviour of UK males (Galdas, Cheater, & Marshall, 2005). Given the association of COPD with aging, co-morbidities may also have sufficient impact on the amount of care required by patients (Sin, Anthonisen, Soriano, & Agusti, 2006; van Wheel & Schellevis, 2006; British Thoracic Society, 2006; Boyd et al., 2005).

The World Health Organisation publishes annual statistics for selected causes of death including COPD but inconsistent use of terminology often results in COPD being labelled as a contributor to death when in-fact it is the primary cause (American Thoracic Society / European Respiratory Society Task Force, 2004; Global Initiative for

Chronic Obstructive Lung Disease (GOLD), 2013) sustaining the continued under-recognition and under-diagnosis of COPD.

#### *2.1.4.3. Economic and social burden*

COPD is a costly disease, both to the individual and to the economy. Direct costs reflecting the diagnosis and medical management of COPD are estimated to be between £810 and £930 million per year (British Thoracic Society, 2006). In the European Union equivocal costs for respiratory disease are estimated to be approximately 6% of the total health care budget with COPD accounting for 56% of these costs (European Respiratory Society, 2003). Indirect costs reflecting the consequences of disability (i.e. caregiver costs) are more informally collected making exact costs difficult to calculate, however an estimated 24 million working days are lost per annum in the UK resulting from COPD (British Thoracic Society, 2006; Department of Health, 2004; Healthcare Commission, 2006).

Unsurprisingly as the disease progresses, costs incurred inflate via increased care, increased hospital admissions and ambulatory oxygen use (Jansson et al., 2002). In developed countries a large proportion of costs can be attributed to acute exacerbations of COPD with United States data suggesting 75% of COPD costs are associated with exacerbations (Sullivan, Ramsey, & Lee, 2000). Despite medical management, patients often experience re-occurring symptoms following an acute exacerbation sufficient enough to result in hospital readmission. Indeed, patients who experience acute exacerbations of COPD have higher readmission rates to hospital than for any other disease process (Farr, 2010).

#### *2.1.4.4. Psychological burden*

As COPD become increasingly progressive there are symptoms of breathlessness on exertion, limiting day to day activities (Nici et al., 2006). The ability to sustain physical and social activities is important for patients' wellbeing and sense of identity (Williams, Bruton, Ellis-Hill, & McPherson, 2007), yet social isolation is common in patients with



COPD (Seamark, Blake, Seamark, & Halpin, 2004; Guthrie, Hill, & Muers, 2001; O'Neill, 2002) compromising quality of life and leading to psychological co-morbidity.

It is recognised that patients with COPD have a high prevalence of symptoms of anxiety and depression compared to that of the healthy population (van Ede, Yzermans, & Brouwer, 1999; Karajgi, Rifkin, Doddi, & Kolli, 1990). Estimates for the prevalence of anxiety and depression in patients with COPD are 36% and 40% respectively, although these figures are wide ranging (7% to 46% for depression and up to 49% for anxiety) due to the variety in screening tools and classification (Yohannes, Baldwin, & Connolly, 2000).

Importantly, increased symptoms of anxiety and depression have been associated with a number of adverse health outcomes in patients with COPD including; physical and functional impairment, increased symptoms, an increased risk of mortality, a reduction in quality of life, an increased risk of exacerbation and an increase in healthcare utilisation (Kim et al., 2000; Brenes, 2003; Egede, 2007; Yohannes, Roomi, Waters, & Connolly, 1998; Yohannes, Roomi, & Connolly, 1998; Yohannes, Baldwin, & Connolly, 2005; Xu et al., 2008). These associations emphasise the need for psychological assessment and intervention, yet, even in the presence of severe symptoms specialist psychological support is rarely available for patients with COPD and those interventions which have been delivered (i.e. Cognitive Behavioural Therapy (CBT)) have met with limited success in reducing symptoms of anxiety and depression (Baraniak & Sheffield, 2011).

To date, the exploration of psychological issues in patients with COPD has been mostly limited to biomedical indices, and current understanding regarding the complex psychological needs of patients with COPD is somewhat limited. Recently there has been a greater focus on patients' illness perceptions (see Chapter 3) and the importance of attending to finer grained psychological disturbances is becoming increasingly recognised. Self-conscious emotions, e.g. shame, guilt and self-blame, appear heightened in patients with COPD and are likely associated with the culpability of the disease (Plaufcan, Wamboldt, & Holm, 2012; Arne, Emtner, Janson, & Wilde-Larsson, 2007; Clancy, Hallet, & Caress, 2009). Issues concerning self-conscious cognitions in patients with COPD are discussed in greater detail in Chapter 9.

## **2.2. Physical activity and Chronic Obstructive Pulmonary Disease**

Engaging in physical activity has been advocated for older adults with at least 30 minutes of moderate activity a day recommended (Department of Health, 2010a). Physical activity appears significantly reduced in patients with COPD in comparison to both healthy older adults (Nguyen, Burr, Gill, & Coleman, 2011) and those with other chronic conditions, most notably chronic heart disease and arthritis (Tudor-Locke, Washington, & Hart, 2009). Physical activity levels appear to be further detrimentally affected following an acute exacerbation although, to date, studies have included only small sample sizes (n=17, n=20) and both in Brazilian populations (Borges & Carvalho, 2012; Pitta et al., 2006a). Yet, the importance of maintaining physical activity is reinforced given its association in patients with COPD with an increased risk of hospitalisations, reduced exercise capacity and increased mortality (Garcia-Aymerich, Lange, Benet, Schnohr, & Anto, 2006; Pitta et al., 2006a; Borges & Carvalho, 2012).

### **2.2.1. Measuring physical activity**

Physical activity in those with COPD is measured objectively by pedometers and accelerometers. Pedometers are simple, inexpensive devices that record movement in a vertical direction and provide easy-to-view data relating to step-count. However, concerns have been expressed regarding their accuracy during slow walking speeds (Turner, Houchen, Williams, & Singh, 2012). Accelerometers are more sophisticated pieces of equipment which measure movement in more than one direction and in addition to step count provide information relating to energy expenditure. These devices can display an individual's pattern, intensity and type of physical activity.

A number of different activity monitors are available which are worn for varying lengths of time. Compared to other activity monitors the SenseWear PRO<sup>2</sup> Armband (BodyMedia, Pittsburgh, US) has been found to provide a more accurate measure of moderate physical activity in patients with COPD (Langer et al., 2009; Furlanetto et al., 2010) and is sensitive to changes in different walking speeds (Hill, Dolmage, Woon, Goldstein, & Brooks, 2010; Harrison et al., 2013).

The reliability of activity monitor data is seen to depend on disease severity and the number of days used for analysis. Accuracy appears to improve the longer the monitor is worn (Nguyen et al., 2011; Hecht, Ma, Porszasz, & Casaburi, 2009) and when worn for three days activity can be detected with approximately 70-85% accuracy in patients with COPD (Tudor-Locke et al., 2005; Watz, Waschki, Meyer, & Magnussen, 2009; Steele et al., 2000). Older adults and patients with COPD seemingly engage in significantly less activity on a Sunday (Hart, Swartz, Cashin, & Strath, 2011; Tudor-Locke et al., 2005) although, physical activity is less variable in patients with more advanced disease (Watz et al., 2009; Steele et al., 2000).

### **2.3. Acute exacerbations of Chronic Obstructive Pulmonary Disease**

Acute exacerbations of COPD are defined by a worsening of patients' baseline symptoms in regard to breathlessness, cough and/or sputum production, beyond day to day variability and sufficient to warrant a change in disease management (American Thoracic Society / European Respiratory Society Task Force, 2004). As noted in the previous section, acute exacerbations are a common cause of both morbidity (Peters, Kochanek, & Murphy, 1998; Mannino et al., 2000) and mortality (Connors, Jr. et al., 1996; Fuso et al., 1995; Seneff, Wagner, Wagner, Zimmerman, & Knaus, 1995). Approximately one third of patients discharged from hospital will have recurrent symptoms within 14 days irrespective of medical management (Borges & Carvalho, 2012; Emerman et al., 1991), with 34% being readmitted to hospital and 14% mortality rate at one year follow up (Roberts et al., 2002). Readmission appears to be associated with number of previous readmissions, a greater impairment in lung function and lower levels of physical activity (Garcia-Aymerich et al., 2001). Of these factors only physical activity is amenable to influence through behavioural interventions with successful intervention to enhance physical activity affording to reduce hospital readmission rates. Recent systematic review findings indicate that small, favourable increases in physical activity occur following PR but to provoke additional changes in physical activity further support needs to be provided by practitioners who are competent in behavioural techniques (Cindy Ng, Mackney, Jenkins, & Hill, 2012).

Acute exacerbations of COPD adversely affect levels of daily activity which can last for up to one month following discharge from hospital (Donaldson et al., 2005; Pitta et al.,

2006a; Borges & Carvalho, 2012). This finding may, in part, account for the reductions in health related quality of life experienced by patients who suffer from frequent exacerbations (Seemungal et al., 1998) and is associated with significant psychosocial co-morbidities including symptoms of anxiety and depression (Quint, Baghai-Ravary, Donaldson, & Wedzicha, 2008; Kessler et al., 2006). However, despite the treatment of exacerbations being prioritised within national guidelines (National Institute for Clinical Excellence, 2010) patients' psychological status is not routinely assessed following an acute exacerbation of COPD.

A following chapter (Chapter 5) provides more detail on how patients experience an exacerbation describing rigorous synthesis of qualitative evidence exploring how patients understand, appraise and respond to acute exacerbations of COPD resulting in hospitalisation.

## **2.4. Management of Chronic Obstructive Pulmonary Disease**

### **2.4.1. Smoking cessation**

As well as being the single dominant cause of COPD, cigarette smoking is also a major risk factor for many other chronic diseases (e.g. vascular disease, cancer and osteoporosis). Smoking cessation can slow the progressive loss of lung function (Anthonisen et al., 1994; Pauwels et al., 2001; Scanlon et al., 2000) and reduce symptoms associated with COPD (Kanner, Connett, Williams, & Buist, 1999) with earlier cessation conferring greater benefit. Individuals vary in their readiness to quit smoking and therefore a patient-centred approach based on current smoking behaviour is argued for (Prochaska, DiClemente, & Norcross, 1992).

Evidence to support both pharmacological approaches (i.e. nicotine replacement therapy and anti-depressants) and non-pharmacological approaches (i.e. motivational strategies) to smoking cessation appears warranted. A Cochrane review identified five-COPD specific studies of which only two were of sufficient quality for synthesis (van der Meer, Wagena, Ostelo, Jacobs, & van Schayck, 2003). Currently, pharmacological treatment and behavioural support in combination is recommended for all smokers

making a serious attempt to quit (Fiore, 2000; National Institute for Clinical Excellence, 2010).

#### 2.4.2. Pharmacology

Pharmacological therapy, comprising of mainly bronchodilators and oral steroids, is seen to prevent and control symptoms, reduce the frequency and severity of acute exacerbations, increase health status and improve exercise tolerance. Although existing medications provide an essential role in the symptom management of COPD, current evidence indicates that they are not effective in modifying the long term decline of lung function (Man, Mustafa et al., 2004).

##### *2.4.2.1. Inhaled therapy*

Inhaled therapy encompasses bronchodilators prescribed as required for the relief of worsening symptoms or to prevent a reduction in symptoms (Higgins, Powell, Cooper, & Tattersfield, 1991; Vathenen et al., 1988). Both long acting (24 hours) and short acting (four to six hours) bronchodilators are effective in increasing exercise capacity and improving health status (Man, Mustafa et al., 2004; Mahler et al., 1999) but short acting bronchodilators are specifically prescribed for relief from daily breathlessness (Sestini, Renzoni, Robinson, Pool, & Ram 2000; National Institute for Clinical Excellence, 2010). When breathlessness persists bronchodilators should be offered in combination with corticosteroid therapy.

##### *2.4.2.2. Corticosteroid therapy*

Corticosteroid therapy can be both inhaled and orally administered. Treatment with corticosteroids is regularly used for patients with more advanced COPD and frequent exacerbations (Spencer, Calverley, Burge, & Jones, 2004; Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2013). Although current guidelines recommend the usefulness of corticosteroids in the short term, literature is limited exploring the effectiveness of long term therapy due to negative side effects arising from prolonged steroid use, such as; muscle weakness and skin bruising (Decramer & Stas, 1992; Decramer, Lacquet, Fagard, & Rogiers, 1994).

#### *2.4.2.3. Delivery devices*

The majority of medications are delivered via hand held devices, commonly known as meter-dose inhalers. Many patients find it difficult to administer medication at the same time as breathing in. To make a meter-dose inhaler easier to use a Spacer device (a plastic cylinder) permits more time to breath in the particles of medication (National Institute for Clinical Excellence, 2010). In circumstances where breathless symptoms become distressing or disabling nebuliser therapy is considered, permitting medication to be delivered directly to the lungs where it is absorbed more rapidly. Once symptoms improve nebuliser therapy is discontinued (National Institute for Clinical Excellence, 2010).

#### 2.4.3. Oxygen therapy

Oxygen therapy is a principal treatment for patients with severe COPD (American Thoracic Society / European Respiratory Society Task Force, 2004; Siafakas et al., 1995), aiming not to reduce breathlessness but to maintain oxygen at a level sufficient to preserve vital organ function. In patients whose COPD is stable oxygen can be delivered in a number of ways; for long periods during the day and night (Long Term Oxygen Therapy (LTOT)), as ambulatory oxygen (to facilitate exercise) or as Short Burst Oxygen Therapy (SBOT) to relieve symptoms.

##### *2.4.3.1. Long Term Oxygen Therapy*

LTOT is recommend for use 15 hours per day although greater benefits are accumulated over longer duration (American Thoracic Society / European Respiratory Society Task Force, 2004; National Institute for Clinical Excellence, 2010). Although the mechanisms are still unclear oxygen therapy has been seen to increase survival in patients with severe COPD (Medical Research Council Working Party, 1981)

##### *2.4.3.2. Ambulatory oxygen therapy*

Ambulatory oxygen therapy provides portable oxygen during exercise and activities of daily living via equipment that can be carried by patients. Frequently prescribed in

combination with LTOT it can also be used in isolation to improve exercise capacity. Ambulatory oxygen therapy should be considered for use in all patients whose oxygen levels drop during exercise and who benefit from the use of oxygen via; increased exercise capacity or reduced breathlessness (National Institute for Clinical Excellence, 2010).

Use of ambulatory oxygen therapy can produce improvements in exercise performance and health status and relieve symptoms of anxiety and depression in patients with COPD (Bradley, Lasserson, Elborn, MacMahon, & O'Neill, 2007; Eaton et al., 2002). However, despite the potential benefits, a substantial proportion of patients decline to use ambulatory oxygen (Eaton et al., 2002). Findings from qualitative studies indicate that patients feel under informed about the use of ambulatory oxygen, are uncertain of the benefits, embarrassed using oxygen in public and have difficulties in carrying the cylinder (Arnold et al., 2011).

#### *2.4.3.3. Short Burst Oxygen Therapy*

SBOT, despite being expensive, is a widely prescribed treatment in the UK (Okubadejo, Paul, & Wedzicha, 1994). Generally it is prescribed for those patients who remain extremely breathless despite other therapies (National Institute for Clinical Excellence, 2010). There is a lack of conclusive evidence to support SBOT but patients consistently report considerable benefits in reducing symptoms of breathlessness and recovery time following activities (Evans, Waterhouse, Carter, Nicholl, & Howard, 1986; Quantrill et al., 2007).

### **2.5. Pulmonary Rehabilitation**

Pulmonary Rehabilitation (PR), comprising an endurance-based exercise programme and disease education, is recommended for all patients with chronic respiratory diseases who are symptomatic and often have decreased daily life activities. Comprehensive PR programmes involve a patient assessment and an intervention delivered by a multi-disciplinary team over a minimum of eight weeks, with at least two sessions per week of supervised exercise and education (Spruit et al., 2013). Programmes are available in various locations including: hospital in-patient, hospital out-patient, the community and

in the home (Bolton et al; 2013; Nici et al., 2006). Even as part of supervised programmes, advice regarding home exercise is particularly important, patients are encouraged to extend their endurance exercise gradually and aim to eventually achieve 30 minutes of exercise for five days per week in line with government guidelines (Department of Health, 2004).

#### 2.5.1. Patient assessment

A comprehensive assessment consisting of subjective information and objective measures is usually undertaken prior to rehabilitation and again once the course is completed. Exercise tests provide useful markers of an individual's progress throughout the PR course. The most common exercise tests utilised in PR are the Six Minute Walk Test [6MWT (Butland, Pang, Gross, Woodcock, & Geddes, 1982)] and the Incremental Shuttle Walking Test [ISWT (Singh, Morgan, Scott, Walters, & Hardman, 1992)].

##### *2.5.1.1. Exercise tests*

The 6MWT requires the individual to walk as far as possible during six minutes around a 30 metre course and the distance covered is recorded. However, it may not be the best test of maximal exercise performance (Troosters et al., 2002). During the ISWT, walking speed is constantly increasing at one minute intervals as patients walk around a 10 meter course. Walking speed calculated from performance on the ISWT can be set at a desired training threshold and assessed by the Endurance Shuttle Walk Test (Revill, Morgan, Singh, Williams, & Hardman, 1999), a measure of exercise endurance capacity.

##### *2.5.1.2. Health status*

A number of disease-specific measures of health status are available but the two most commonly used in patients with COPD are the Chronic Respiratory Questionnaire (CRQ) (Guyatt, Berman, Townsend, Pugsley, & Chambers, 1987) and the St George's Hospital Respiratory Questionnaire (SGRQ) (Jones, Quirk, Baveystock, & Littlejohns, 1992).



The SGRQ comprises 50 items which are divided into two domains relating to symptoms and activities. The symptoms domain is concerned with patients' perceptions regarding the frequency and severity of symptoms. The activities domain assesses the impact of activities, which cause or are limited by shortness of breath, on social and psychological functioning. More recently the SGRQ St George's Hospital Respiratory Questionnaire – COPD (SGRQ-C) has been developed specifically for use in patients with COPD with fewer items (40 items) (Meguro, Barley, Spencer, & Jones, 2007). Higher scores are associated with greater limitations in health status.

The CRQ was originally interviewer-led making it time consuming to administer, therefore it was adapted into a self-reported version: the Chronic Respiratory Questionnaire-Self-Reported (CRQ-SR) (Williams, Singh, Sewell, Guyatt, & Morgan, 2001). The basic structure, content and scoring is exactly the same as the CRQ but patients are required to tick an appropriate answer on a questionnaire rather than responding to the interviewer. The CRQ-SR is used extensively for both clinical and research purposes.

Although, both measures are valid and reliable measures of health status in patients with COPD and have been found to be responsive to PR (Griffiths et al., 2000), the CRQ is more responsive than the SGRQ, especially when considering the separate scores for each domain (Puhan et al., 2007).

#### *2.5.1.3. Psychological factors*

The American College of Chest Physicians statement advocates considering psychological issues in those patients attending PR (Mahler et al., 2010). There are a variety of screening tools available for assessing psychological symptoms such as; anxiety and depression (Yohannes, Baldwin, & Connolly, 2000). Tools frequently used to screen depression in patients with chronic disease include: the Beck Depression Inventory (BDI) (Beck, Ward, Mendleson, Mock & Erbaugh, 1961) which assesses symptoms including hopelessness and irritability as well as physical symptoms such as fatigue and weight loss; the Center for Epidemiological Studies-Depression (CES-D) (Radloff, 1977) which assesses current feelings of depression (over the past week) focusing on mood as well as behaviours; and the Brief Assessment Schedule for

Depression Cards (BASDEC) (Adshead, Cody, & Pitt, 1992) which is most commonly applied to assess symptoms of depression in elderly, medial patients by presenting a series of cards to the individual and asking them to respond with 'true' or 'false' regarding their present feelings. Useful measures of anxiety include; Beck Anxiety Inventory (BAI) (Beck, Epstein, Brown, & Steer, 1988) which assesses the emotional, physiological and cognitive symptoms of depression and; the State-Trait Anxiety Inventory (STAI) (Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983) which is divided into two domains assessing state anxiety defined as anxiety about a particular event and trait anxiety which considers anxiety as a personal characteristic. It is often applied in the assessment of caregiver distress. Finally, the Profile of Mood State (POMS) (McNair, Lorr, & Doppleman, 1981) is an instrument with a broader scope, assessing affective mood state fluctuation across six dimensions including; tension-anxiety, vigour-activity, depression-dejection, fatigue-inertia, anger-hostility and confusion-bewilderment. It has been applied in both clinical populations and within sports psychology. However, in both research and clinical practice the Hospital Anxiety and Depression Scale (HADS) (Yohannes, Willgoss, Baldwin, & Connolly, 2010; Zigmond & Snaith, 1983) is one of the most frequently used tools to assess psychological morbidity in patients with COPD. It contains two subscales allowing for anxiety and depression to be assessed in combination.

The benefits of PR on symptoms of anxiety and depression in patients with COPD are well recognised (Bolton et al., 2013; Griffiths et al., 2000) and the sensitivity of the HADS to the effects of a PR programme is established (von Leupoldt, Taube, Lehmann, Fritzsche, & Magnussen, 2011). However, a meta-analysis examining the effects of PR on symptoms of anxiety and depression reported scores which were either within the normal range or reflected only mild psychological symptoms (Coventry, 2009). From such analysis it would seem that PR is effective in reducing levels of anxiety and depression in those patients with only mild symptoms: the efficacy of PR in treating more severe symptoms of anxiety and depression remains unproven. This issue is discussed in more detail in a subsequent chapter (Chapter 6) and a more detailed description of the HADS is provided.

#### *2.5.1.4. Self-efficacy*

Self-efficacy is the measure of one's ability to perform tasks and achieve goals and has been identified as an important determinant of health behaviour (Holloway & Watson, 2002). Although a number of tools are available to measure general self-efficacy in patients with chronic disease, recently a valid and reliable tool has been developed specifically for monitoring self-efficacy in response to a PR programme. The Pulmonary Rehabilitation Adapted Index of Self-Efficacy is an adapted version of the General Self-Efficacy Scale which assesses specific behaviour and lifestyle changes (Vincent et al., 2011).

#### 2.5.2. Patient intervention

##### *2.5.2.1. Exercise training*

The exercise component of PR consists of an endurance-based element and upper and lower limb strength training. Endurance training often centres on walking or cycling, however walking appears to be the most accessible form of exercise as it requires no specific or expensive equipment and it has also been found to be the most important activity to patients (Sewell, Singh, Williams, Collier, & Morgan, 2005). Aerobic training programmes are prescribed at a threshold of at least 60% of maximal exercise capacity, although exercising at higher intensity is likely to produce greater physical benefits (Nici et al., 2006; Revill et al., 1999).

In addition to breathlessness, skeletal muscle dysfunction occurring through inactivity and the systemic effect of the disease on the muscle is now recognised as an important factor in limiting exercise performance in patients with COPD (American Thoracic Society/ European Respiratory Society, 1999; Bolton et al., 2013). Strength training sessions generally involve two to four sets of six to 12 repetitions of various strength exercises performed at 50% to 85% of an individual's one repetition maximum (O'Shea, Taylor, & Paratz, 2004).

#### *2.5.2.2. Education*

The educational component of PR consists of sputum clearing methods, the management of exacerbations, relaxation/breathing control, and managing physical activity. It has been reported that PR is effective in increasing individuals' knowledge surrounding the management of their disease (Jones, Wang, Harding, Bott, & Hyland, 2008) which, in turn, may assist patients with adopting skills to self-manage their condition.

#### 2.5.3. Adherence to Pulmonary Rehabilitation

Despite the recognised benefits of PR in patients whose COPD is stable (Griffiths et al., 2000; Lacasse, Goldstein, Lasserson, & Martin, 2006) approximately 20-60% of those eligible do not complete programmes (Fischer et al., 2009; Garrod, Marshall, Barley, & Jones, 2006; Hogg et al., 2012; Selzler, Simmonds, Rodgers, Wong, & Stickland, 2012; Hayton et al., 2012). Sociodemographic data and clinical variables have been unsuccessful in explaining the variance in patient drop-out rates, however psychological variables may be more useful (Fan, Giardino, Blough, Kaplan, & Ramsey, 2008; Garrod et al., 2006; Selzler et al., 2012; Hogg et al., 2012; Fischer et al., 2009). Depression as assessed using the BASDEC and the SF36 has been shown to impact on patients dropping out of a PR programme (Garrod et al., 2006) yet, despite the frequent use of the HADS, both clinically and within research, the influence of anxious and depressed symptoms measured using the HADS has not been explored. It would appear necessary to conduct a more detailed exploration of the effects of psychological issues on adherence to PR.

The success of PR in a stable population has led to its expansion to more vulnerable disease groups, such as following an acute exacerbation. PR would appear to be beneficial for those having experienced acute exacerbations, with those completing having fewer hospital readmissions and significantly less likelihood of experiencing reoccurring symptoms as well as benefiting in terms of improved functional capacity and health status (Man, Polkey, Donaldson, Gray, & Moxham, 2004; Eaton et al., 2009; Puhan et al., 2009; Seymour et al., 2010; Puhan et al., 2011). However, difficulties recruiting to, and poor attendance at PR programmes have been demonstrated by the

lengthy recruitment periods and small patient numbers in post-exacerbation research studies (Eaton et al., 2009; Seymour et al., 2010; Puhan et al., 2011). Currently, adherence to PR has not been explored prospectively following an acute exacerbation of COPD and therefore understanding is limited regarding why patients are reluctant to attend. Notably higher levels of anxiety have been observed in those patients for whom the onset of an acute exacerbation led to them discontinuing PR (Hayton et al., 2012). Furthermore, recent research revealed that patients' health status was more influential in predicting completion of PR than actual lung function (Selzler et al., 2012), emphasising the importance of patients' perceived benefit in adherence to PR.

# **Chapter 3**

## **3. NARRATIVE REVIEW: PSYCHOLOGICAL UNDERSTANDING WITHIN CHRONIC OBSTRUCTIVE PULMONARY DISEASE**

The limited success of psychological interventions, predominantly driven by Cognitive Behavioural Therapy (CBT), currently applied in the care of patients with Chronic Obstructive Pulmonary Disease (COPD) is discussed in this chapter emphasising the need for interventions which are psychologically informed and more refined than interventions delivered at present. This chapter offers a critical narrative review of the dominant models of health behaviour in order to evaluate which beliefs may be most likely associated with health promoting behaviour (i.e. uptake of Pulmonary Rehabilitation (PR) and physical activity) in patients following an acute exacerbation of COPD. A second critical review is described in this chapter, exploring the value of illness perceptions in explaining various health outcomes in patients for whom COPD is stable. Conclusions drawn from the existing literature offers additional support for focusing the development of a behaviour change intervention on concepts from the Common Sense Model (CSM). The importance of assessing and using theory to facilitate the development of successful behaviour change interventions is discussed in greater detail in Chapter 4.

### **3.1. Psychological support**

There is recognition that those living with COPD experience an increased likelihood of psychological distress associated with the experience of intense breathlessness. Chapter 6 describes the elevated presence of anxious and depressed symptoms experienced by those with COPD compared to a 'healthy' population. National guidelines for COPD highlight the importance of conducting research to support the development of a psychological intervention (National Institute for Clinical Excellence, 2010; Department of Health, 2010b) to improve patients' life quality. Specifically, CBT has been

recommended for inclusion in the care of patients with COPD, it would appear driven by its therapeutic dominance in current public health care delivery and its evidence base for other chronic conditions. The premise of CBT is that changing maladaptive thinking leads to behavioural change. Patients are encouraged to challenge their beliefs and replace errors in thinking (i.e. magnifying negatives, minimising positives and catastrophising) with more realistic and effective thoughts, thus reducing emotional distress. CBT helps patients to challenge their way of thinking to promote adaptive; coping skills, emotions, cognitions and behaviours through a number of techniques including; education, relaxation, cognitive therapy, behaviour therapy, behavioural activation, exposure therapy and sleep management skills (Hynninen, Bjerke, Pallesen, Bakke, & Nordhus, 2010).

The effectiveness of CBT in reducing anxiety and depression in a population of patients whose COPD is stable has been systematically explored (Coventry & Gellatly, 2008). However, there is a paucity of evidence in comparison to other health conditions and results of the four randomised controlled trials (RCT), revealed findings which were either equivocal or largely negative in their alleviation of anxiety. Coventry and Gellatly (2008) attributed findings to the insufficient power of trials. Since this review a further RCT has been conducted, focusing specifically on patients whose reports of anxiety and depression are assessed as clinically significant and containing a longer follow up period. Results revealed CBT to be effective in reducing clinically significant symptoms in patients with COPD, with reductions maintained after eight months implying that CBT may be more effective in patients with psychological symptoms reaching clinical caseness (Hynninen et al., 2010). However, in routine practice, although patients with COPD commonly present with symptoms of anxiety and depression these are frequently insufficient to warrant focused intervention and by measuring only disturbance to affect (anxiety and depression) other psychological manifestations of distress, more salient to the disease, may be minimised. A finer grained assessment of psychological disturbance may be needed, recognising not simply a diagnostic approach to distress, that can inform interventions for this patient population. A growing evidence base from health psychology argues for development of an interventions guided by the manner in which patients perceive their illness (Kaptein et al., 2009).

### **3.2. Models of health behaviour**

Patients' responses to their illness and their subsequent health behaviours vary widely. Patients differ in their medication adherence, their participation in physical activity and their smoking status. By understanding and engaging with preventative health behaviours patients can influence disease outcomes including mortality and morbidity (Garcia-Aymerich et al., 2006). Research exploring psychological predictors of health behaviours can aid current theoretical understanding and help inform intervention strategies to encourage health promoting behaviour.

With the growth of health psychology as a discipline, there has been an expansion of current theories of health behaviour focusing on the adoption and maintenance of health behaviours which underpin wellbeing. Such theories include: The Theory of Reasoned Action (Ajzen & Fishbein, 1980); Theory of Planned Behaviour (Ajzen, 1991); The Social-Cognitive Theory (Bandura, 1986); The Locus of Control Theory (Rotter, 1954); The Health Belief Model (Becker, 1974; Rosenstock, 1966); The Transactional Model of Stress and Coping (TMSC) (Lazarus & Folkman, 1984); The CSM (Leventhal et al., 1984; Leventhal et al., 1997). The theories differ in their emphasis on the specific beliefs most closely associated with the decision to adapt and maintain behaviour. Although the list of theories discussed is not exhaustive, I have chosen to focus on those models most influential in shaping psychological interventions for patients with COPD (e.g. cognitive theories) and compare them to a self-regulatory theory. Processes of self-regulation are commonly associated with adherence to disease promoting behaviour across various chronic conditions.

The Theory of Reasoned Action (Ajzen & Fishbein, 1980) proposes that an individual's behaviour can be predicted by their intentions and such assumptions have been demonstrated in the exploration of smoking behaviour in patients with COPD (Schofield, Kerr, & Tolson, 2007). However, it is generally acknowledged that the Theory of Reasoned Action is limited in accounting for individual differences, failing to acknowledge that behaviour may not always be under volitional control. As a result the Theory of Planned Behaviour (Ajzen, 1991) evolved permitting the addition of behavioural control and accounting for beliefs surrounding the perceived ease or difficulty of performing a task. Meta-analytic evidence evaluating this theory's ability



to explain behaviour and intention is encouraging although not yet conclusive (Armitage & Conner, 2001).

Unlike the Theory of Planned Behaviour the Social-Cognitive Theory (Bandura, 1986) is a more dynamic model in which the reciprocal, relationship between the individual, the environment and behaviour is emphasised. Personal efficacy to perform the desired behaviour and the expected outcome are argued as the dominant constructs which influences behaviour change. Although the theory forms the basis of most self-management programmes for patients with COPD (Bourbeau, Nault, & Dang-Tan, 2004) its application appears to be more pragmatic than evidence-driven given that self-efficacy shows only modest success in predicting variance in exercise behaviour (Keller, Fleury, Gregor-Holt, & Thompson, 1999). Due to the complexity of the theory it is seldom implemented in its entirety, focusing only on certain components. This perhaps explains its limitations and serves to question this theory's usefulness in informing the development of behaviour interventions.

The Locus of Control Theory (Rotter, 1954) builds upon the concept of individual control being a behavioural determinant by suggesting that in addition to possessing feelings of control, balance of control over an individual's health is also key. In distinguishing 'active' and 'passive' control the theory argues that those who utilise 'active control' are more likely to adhere to medical treatments, taking responsibility for medications and viewing them as an essential component in the self-management of their disease. By contrast those who adopt 'passive control' of their medications simply take them as prescribed (Dowell & Hudson, 1997). Such evidence implies that to maintain active therapy (i.e. PR) "active control" is required. However, encouraging active control may be challenging in patients with COPD who can perceive external influences (e.g. oxygen therapy) as being threatening to mastery over symptoms (Katsenos & Constantopoulos, 2011), emphasising the importance of engaging patients in their treatment decisions.

The Health Belief Model (Becker, 1974; Rosenstock, 1966) adopts a rational, economic-cost benefit premise. For the purposes of explaining the model, smoking behaviour will be used as an example. The model suggests that behaviour change is dependent, in the first instance, on the individual perceiving themselves to be

susceptible to harm (e.g. ‘threat’ of a future exacerbation), or at risk of severe health consequences as a result of their behaviour (e.g. smoking is damaging to health). In deciding whether to take action the individual will consider the benefits of the proposed behaviour (quitting smoking) (e.g. improved symptoms, save money) against the costs (e.g. less social time with friends who smoke). A key weakness of this theory, in addition to its emphasis on solely rational determinants of health, is that it fails to acknowledge the positive effects of negative behaviour (e.g. the beliefs that smoking may reduce stress) and social influences are not considered. Furthermore in the majority of cases smoking behaviour is not based on a decision to smoke but an addiction to nicotine. For “risk reduction” behaviours, such as quitting smoking’ this theory is unlikely to explain change.

The models discussed thus far are highly cognitive in their focus. They are predicated on assumptions that individuals make decisions based solely on rationale assessments. However, some patients deploy avoidance as a coping strategy supporting the notion that emotions, such as fear, play a key role in modifying health behaviour. Furthermore, they assume that the decision to carry out particular health behaviour is a discrete event rather than ongoing appraisal of health and emotions and feedback from previous health behaviour. The issue of re-appraisal may be of particular importance in a disease such as COPD where patients’ disease state is fluctuating.

The TMSC (Lazarus & Folkman, 1984) and the CSM (Leventhal, Nerenz, & Steele, 1984; Leventhal et al., 1997) are arguably both problem-based models. A health threat results in two parallel processes: one cognitive the other emotional. Health-behaviour is shaped by patients coping strategies which are themselves driven by appraisals of the health threat (i.e. seeking more information) or by emotional responses (i.e. avoidance or relaxation strategies).

The TMSC proposes that individuals view a stressor as threatening to their well-being. The significance of the stressor is appraised, firstly in relation to its relevance and severity and secondly by an individual’s ability to cope with it. The CSM is similar to the TMSC but differs in its structure. Whereas the TMSC considers appraisals as being implicit to the model the CSM focuses on the appraisal of responses. In the context of acute exacerbations of COPD focus is on the appraisal of symptoms and their meanings,

such as the intensely fear-inducing experience of breathlessness. Such appraisals regarding the experience of the disease are likely to have utility when considering the development of an intervention designed to promote coping strategies (i.e. PR and physical activity) which also evoke shortness of breath.

### **3.3. The Common Sense Model**

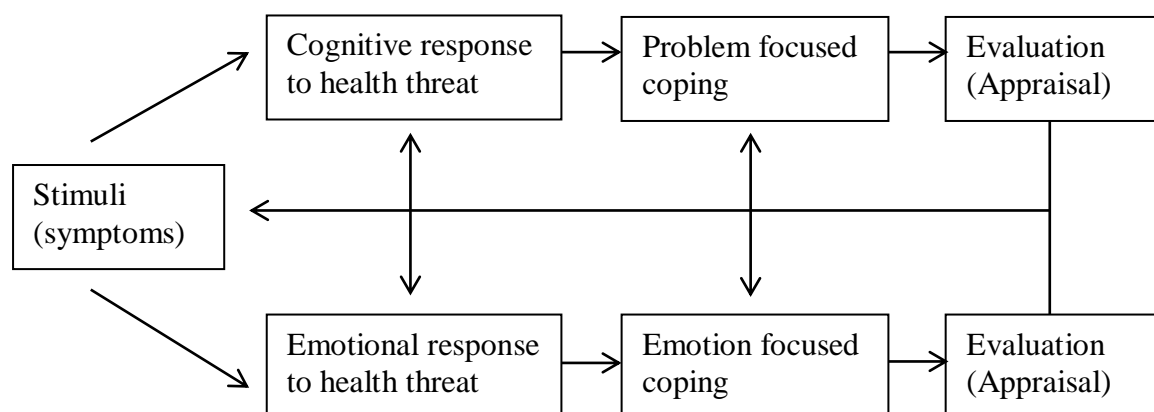
The CSM can be seen as having evolved from two longer standing models offering explanations for health-related behaviour: the Fear-Drive Reduction Model developed by Dollard and Miller (1950) and the Parallel Response Model (Leventhal et al., 1997). The Fear-Drive Reduction Model proposes that fear appraisals motivate patients to perform health promoting behaviours which reduce a sense of vulnerability to a threat (Dollard & Miller, 1950). However, the theory has greater applicability to motivation rather than sustaining behaviour given the limited duration of fear appraisals, which once addressed lose their power to affect behaviour (Leventhal & Niles, 1965). Health behaviours are not maintained as fear appraisals are not long lasting.

In acknowledging constraints on behaviour change derived from fear reduction the Parallel-Processing Model evolved (Leventhal et al., 1997). This advances Dollard and Miller's model by noting the role of fear but additionally proposing the construction of cognitive representations of such threat. Emotional and cognitive representations are processed independently. Based on the content of these representations, Leventhal and colleagues (1984) argue that individuals implement actions to manage emotions and reduce the discomfort caused by threat. It is suggested that individuals are constantly engaged in a process of self-regulation, whereby the outcome of implementing actions serves to modify illness representations associated with the experience of symptoms and their association with the illness. In this sense the model is both iterative and dynamic.

The CSM was then further developed by Leventhal and colleagues (1984) (Leventhal et al., 1984) to more precisely describe the relationship between cognitive representations and illness perceptions and has perhaps become the most influential theoretical framework explaining why there is huge variability in patients' coping and management of a condition. The CSM identifies the factors involved in the way patients' process information with regard to their disease to enable 'meaning making' and to formulate

appropriate coping strategies. Information, i.e. symptoms (stimuli), engenders cognitive and emotional representations of the illness. Illness representations are processed in parallel through three stages. Firstly the patient forms a representation of their illness by understanding and *interpreting* information. This information is gleaned from three sources: 1. Lay information accumulated by the individual and embedded in their existing knowledge. 2. Sources which individuals perceive as being significant or authoritative including; friends, family members, doctors or health care professionals. 3. Current and prior experiences which can be influenced by personality and/or cultural background. (Diefenbach & Leventhal, 1996). Secondly, the manner in which individuals *interpret* this information formulates *action* i.e. the process of help-seeking, and the development of coping and disease management strategies (Bishop & Converse, 1986). Finally, the CSM is cyclical and patients engage in the process of self-regulation by evaluating the outcomes of behaviour and appraising the efficacy of adopted strategies. This information leads to the re-formulation of illness representations, as patients re-consider their understanding and *interpretation* of information, which, in turn, shapes future *actions* and behaviour. An overview of the CSM is displayed in Figure 1.

**Figure 1. An overview of the Common Sense Model**



Patients' illness representations are formed at the onset of initial symptoms and can be altered as the disease progresses and in response to interventions and acute events. In-depth semi-structured interviews focusing on patients' illness experiences indicate that patients differ in their beliefs regarding the identity, cause, time-line and consequences

of their illness (Meyer, Leventhal, & Gutmann, 1985). Further research emphasises that patients' illness representations also incorporate beliefs regarding the cure and controllability of the disease (Lau, Bernard, & Hartman, 1989). Since the conduction of this research the CSM has been applied in the development of tools designed to assess cognitive representations of illness. Hagger and Orbell (2003) conducted a meta-analysis of 45 studies contained within the health psychology literature and found the CSM's illness representations to be valid (construct and discriminant validity). These findings offer support for both the CSM's illness perceptions and the tools used to quantify them, of which the Illness Perceptions Questionnaire (IPQ) was the most frequently utilised (Hagger & Orbell, 2003).

### **3.4. Illness perceptions**

#### 3.4.1. Assessing illness perceptions

Historically illness perceptions were assessed using in-depth semi structured interviews which aimed to address patients' experiences of their illness. Interviewing is a time consuming process which produces a variety of responses. A quantitative assessment of illness perceptions allows for data collection to be standardised and for information to be obtained from much larger sample sizes. Questionnaires had been developed in an attempt to standardise the examination of illness representations but they were not theory-based or tested in more than one disease (Lacroix, Martin, Avendano, & Goldstein, 1991). There was a clear need for a questionnaire to be produced which was theoretically based and useful in different patient groups.

##### *3.4.1.1. The Illness Perceptions Questionnaire (Weinman, Petrie, Moss-Morris, & Horne, 1996)*

Weinman and colleagues (1996) aimed to develop a tool in conjunction with Leventhal's CSM. The questionnaire was labelled the IPQ and the aspiration was that it would aid understanding regarding the nature of coping and facilitate the incorporation of self-management strategies in chronic illness (Weinman et al., 1996). The IPQ is subdivided into the five illness representation components described in the CSM:

identity (Cronbach's alpha ( $\alpha$ ) = .82), time-line ( $\alpha$  = .73), consequences ( $\alpha$  = .82), cure/control ( $\alpha$  = .73) and cause.

The IPQ has been assessed for psychometric properties in several illness groups (Weinman et al., 1996). The scales were shown to have good test-retest reliability in patients following a myocardial infarction (MI) and patients with renal disease. The pattern of correlations with other health measures supported the concurrent validity of the tool using data from the MI sample and severe asthma patients. To examine the ability of the IPQ to identify distinct illness beliefs the scale scores were compared in patients with diabetes, rheumatoid arthritis, chronic fatigue syndrome and chronic pain. Despite the similarity in symptoms between patients with chronic conditions the IPQ scores could distinguish clearly between the illness beliefs of the various patient groups. Predictive validity was examined in the MI sample across three time points (in hospital and at three and six months following discharge) and correlations obtained between IPQ scales and measures of disability, coping, health status and health distress were encouraging.

#### *3.4.1.2. The Illness Perceptions Questionnaire – Revised (Moss-Morris et al., 2002)* (Appendix B)

Despite wide application of the IPQ, concern was expressed regarding its structure and content, specifically the cure/control and timeline dimensions demonstrated some issues regarding their internal consistency, and therefore a revised version was developed: The Illness Perceptions Questionnaire-Revised (IPQ-R). The identity subscale was reused with sore throat and wheeziness added to the list of symptoms, and focus was directed towards whether a patient believed a symptom to be related to their diagnosis. New items were added to address concerns regarding the internal consistency of some of the cure/control and the timeline subscales (Moss-Morris et al., 2002). The outcome of a factor analysis led to the cure/control subscale being divided into two components: personal and treatment control. The importance of this amendment has been highlighted more recently given treatment beliefs' important role in predicting adherence to health promoting behaviour (Cooper, Weinman, Hankins, Jackson, & Horne, 2007). The original IPQ did not encompass emotional representations identified as important in the Parallel-Processing Model (Leventhal et al., 1984). This oversight was rectified by the

addition of an emotional subscale. Finally, another subscale developed to assess patients' comprehension of their illness was added to the questionnaire. Following these amendments, issues concerning the internal consistency of the domains were addressed: identity, consequences ( $\alpha = .84$ ); timeline acute/chronic ( $\alpha = .89$ ); timeline cyclical ( $\alpha = .79$ ); personal control ( $\alpha = .81$ ); treatment control ( $\alpha = .80$ ); illness coherence ( $\alpha = .87$ ) and emotional representations ( $\alpha = .88$ ).

Validation of the IPQ-R was conducted in eight different illness groups, including; Human Immuno-deficiency Virus, rheumatoid arthritis, diabetes, asthma, acute and chronic pain, multiple sclerosis and MI, confirming the improved reliability of the new subscales. The concept of identity has been successfully separated from the experience of symptoms and cognitive and emotional representations can be considered separately.

A meta-analysis examined the pattern of relationships between illness representation dimensions and those measures used to quantify them (i.e. the IPQ and IPQ-R). Significant positive  $r_c$  co-efficients for: identity-consequences ( $r_c=0.37$ ,  $p<0.05$ ); identity-timeline ( $r_c=0.16$ ,  $p<0.05$ ) and timeline-consequences ( $r_c=0.43$ ,  $p<0.05$ ) and negative relationships identified between the cure/control dimension and the other illness cognition dimensions: cure/control-consequences ( $r_c=0.18$ ,  $p<0.05$ ); identity-cure/control ( $r_c=0.11$ ,  $p<0.05$ ) and timeline-cure/control ( $r_c=0.34$ ,  $p<0.05$ ) support the construct validity of the illness cognition dimensions across a sample of studies. (Hagger & Orbell, 2003).

#### *3.4.1.3. The Brief Illness Perceptions Questionnaire (Broadbent, Petrie, Main, & Weinman, 2006)*

The IPQ-R is argued to lend itself to comprehensive investigation of the nine components of illness representations. However, with over 80 items, in some health care situations, where time constraints exist or patients are very unwell, it is not feasible to complete such a long questionnaire. A shorter version of the questionnaire was created to assess illness perceptions.

The Brief IPQ, with nine single items assessed on a continuous scale, was developed by forming one question that best summarises the items contained in each subscale of the IPQ-R. The brief version of the questionnaire was found to be valid and reliable when compared to the IPQ-R in various conditions (including; renal, asthma and diabetes) (Broadbent et al., 2006). All items except the causal question are rated using a zero to 10 response scale. Causal representations are assessed using an open-ended response item adapted from the IPQ-R.

#### 3.4.2. Illness perceptions in Chronic Obstructive Pulmonary Disease

The utility of examining illness perceptions in patients with COPD has been supported by a variety of studies, notably for patients with stable status of the condition. Illness perceptions have been associated with a number of health outcomes including quality of life and wellbeing, psychological symptoms, health-related behaviour and exercise capacity.

Symptom identification (the identity subscale) appears key in explaining patients' quality of life and general wellbeing (Braido et al., 2011; Scharloo et al., 1998). Two separate studies have identified inverse correlations between increased quality of life and, number of symptoms, severity of consequences and emotional affect, emphasising the impact of emotional representations on patients' health status and general wellbeing (Braido et al., 2011; Scharloo et al., 2007), and providing support for Leventhal's Parallel-Processing Model (Leventhal et al., 1997). Patients' perceptions of chronicity are also strongly associated with quality of life. Patients correctly believe their disease to be permanent underlining the challenges of maintaining quality of life in patients with chronic conditions. Surprisingly, personal control was not related to quality of life or wellbeing (Braido et al., 2011; Scharloo et al., 2007) this may be reflective of the difficulties in controlling a progressive disease. When combined with measures of coping illness perceptions were able to predict quality of life and healthcare utilisation one year later (Scharloo, Kaptein, Weinman, Willems, & Rooijmans, 2000).

The three studies by Scharloo et al (1998; 2000; 2007) contribute to a 16 paper systematic review of literature exploring illness perceptions in patients with COPD (Scharloo et al., 1998; Scharloo et al., 2000; Scharloo et al., 2007). The remaining 13



studies did not use the IPQ but instead utilised a variety of tools and interviewing techniques to explore illness perceptions and health beliefs (Kaptein et al., 2009). Illness perceptions which attribute many symptoms to the condition, perceive a low sense of control and strong emotional representations were associated with poorer health outcomes; increased disability, reduced quality of life and higher psychological morbidity.

Since the publication of this review illness perceptions have been demonstrated to predict presentation of panic in patients with COPD (Howard, Hallas, Wray, & Carby, 2009). Individuals who report experiencing panic attacks in the past year have stronger identity beliefs and increased chronicity, with representations regarding consequences being perhaps the most influential. Along with emotional representations, consequences helped to define panic severity and distinguish between recent and non-recent panickers. The authors suggest that some individuals may be predisposed to over-interpreting symptoms, such as breathlessness, reinforcing negative cognitions and creating a vicious circle of panic. Further support for the role of illness perceptions in predicting psychological morbidity stems from a recent study reporting an association between lower scores on the Brief IPQ, representing more positive illness representations, and lower levels of depression (Weldam, Lammers, Decates, & Schuurmans, 2013). The causal subscale of the IPQ-R has been afforded less attention than the other domains of the questionnaire, yet the factors patients associate with the cause of their COPD may be influential in predicting psychological symptoms. Patients who agree their disease may be caused by; emotional state, personality, family worries and mental attitude were found to have increased symptoms of anxiety and depression as well as reduced quality life (Hoth, Wamboldt, Bowler, Make, & Holm, 2011).

The role of illness perceptions in predicting quality of life and psychological morbidity is convincing and yet the impact of patients' illness perceptions on positive health-behaviour is less clear. The Brief IPQ could not explain engagement in daily activities (Weldam et al., 2013) and causal attributions were not associated with increased physical activity, treatment-seeking or smoking behaviour (Hoth et al., 2011). These results are surprising considering the influential role of illness perceptions in explaining variability in exercise capacity following a PR program (Zoeckler, Kenn, Kuehl,

Stenzel, & Rief, 2014). These results emphasise the complex nature of health-promoting behaviour in patients with COPD which may be attributable to a combination of factors.

#### 3.4.3. Illness perceptions and interventions

Illness perception research is often criticised for being cross-sectional, preventing the examination of causal pathways and mediating affects, however a small number of intervention-driven cohort studies in patients with COPD have been carried out utilising illness perceptions and one RCT. Unfortunately the RCT, claiming to examine the effect of PR on health perceptions, used a measure of health status (Theander, Jakobsson, Jorgensen, & Unosson, 2009), the St Georges Hospital Respiratory Questionnaire (SGRQ) (Jones et al., 1992). Questions on the SGRQ relate to symptoms, somatic sensations, activities which induce breathlessness, effectiveness of medication and functional limitations, and whilst these questions superficially resemble aspects of the identity, treatment control and consequences subscales of the IPQ-R it cannot be considered an in-depth investigation of illness perceptions. It describes itself as a tool to find out which aspects of illness cause patients problems and is not an investigation into patients' thoughts and feelings regarding their disease.

The IPQ-R has been utilised to assess patients' illness perceptions prior to and following a programme of PR. The majority of illness perception dimensions remained unchanged following the programme although, significant differences did exist in the personal control and the cyclical timeline subscales (Fischer et al., 2010). An increase in the personal control subscale following PR is not surprising, supporting literature which demonstrates the efficacy of PR at improving self-efficacy (Arnold & Ranchor et al., 2006). Perhaps more interesting is the increase in the cyclical timeline following PR. These changes may have occurred due to patients' increased symptom monitoring encouraged during PR or an increased awareness of acute exacerbations. In support of Fischer's work a recent study found the combined score of the IPQ-R (scores for illness coherence and the control domains were reversed) to be significantly reduced following PR, suggesting that completion of the program lead to more positive perceptions of disease (Zoeckler et al., 2014).

Despite the comprehensive exploration of the role of illness perceptions in patients with stable disease, no research has investigated patients' illness perceptions using the IPQ-R following an acute exacerbation. This is particularly surprising considering patients' illness perceptions following significant acute health - related events have been shown to affect disease management in other chronic conditions such as diabetes (Skinner et al., 2011) and following an MI (Alsen et al., 2010; French et al., 2006). Patients who exhibit a high sense of personal and treatment control but who also view their illness to be serious were the most likely to have positive health outcomes and adhere to health promoting behaviour. With these findings in mind perhaps illness perceptions may be valuable in identifying patients who are more or less likely to adhere to health promoting behaviour, such as PR.

A number of research studies have explored the value of illness perceptions in predicting the engagement of patients in rehabilitation programmes. Treatment control measured using the IPQ-R has been found to differ significantly between patients with stable COPD classified as adhering to a PR programme and those who displayed only low adherence (Fischer et al., 2009). These findings compliment previous literature conducted in patients attending a cardiac rehabilitation programme (Cooper, Weinman, Hankins, Jackson, & Horne, 2007; French, Cooper, & Weinman, 2006). A more recent study in COPD reported that patients who believed participation in PR to have contributed to the achievement of desired outcomes had greater perceived controllability of the illness and fewer perceived consequences (Fischer et al., 2010). The treatment control domain of the IPQ-R appears to be influential in predicting patients' perceived controllability of the disease as well as adherence to rehabilitation. The assessment of patients' illness perceptions whilst they consider attendance to PR, may best predict programme adherence.

# **Chapter 4**

## **4. NARRATIVE REVIEW: BEHAVIOURAL INTERVENTION PLANNING**

The benefits of Pulmonary Rehabilitation (PR) in a stable population are well recognised (Chapter 2) leading to its expansion for patients with more brittle disease. However, there are concerns regarding attendance, and adherence to PR particularly following an acute exacerbation of Chronic Obstructive Pulmonary Disease (COPD). This is perhaps unsurprising as PR programmes were originally developed for patients in whom COPD is stable and the additional needs of a post-exacerbation population have largely been ignored. In order to develop an intervention which is likely to enhance attendance to PR following an acute exacerbation the additional need of this vulnerable population ought to be considered. This chapter describes two frameworks which are argued to promote the tailoring of psychological treatment, to more individualised patient needs, through a phased approach. By considering the strengths and weaknesses of each framework a strategy to assess the specific needs of patients following an acute exacerbation of COPD is adopted informing the subsequent elements of this thesis.

### **4.1. Health promotion**

‘Health promotion’ is interested in helping people to make positive changes which will optimise their health and has been defined by Green and Kreuter (2005) as the “educational, political, regulatory and organisational supports for behavioural and environmental changes that are conducive to health” (Bartholomew, Parcel, Kok, Gottlieb, & Fernandez, 2011). Health promotion is applicable for all people but is particularly salient in the management of those with chronic conditions, becoming a standard component of health care professionals’ everyday practice, however often it appears to be taken for granted. By increasing understanding regarding the processes involved in encouraging behaviour change, health care professionals may be able to tailor the delivery of advice conducive to positive health behaviour (i.e. engaging in PR

and increased physical activity) (Needle et al., 2011) perhaps impacting upon the burden of the disease both for the individual and in terms of costs to the healthcare system.

#### **4.2. Individual versus group therapy**

To successfully provide support for health promotion it is important to attend to the specific needs of the population and the individual. Currently PR programmes are delivered in the same manner for all patients with COPD with little focus on the additional needs of those following an acute exacerbation. Group therapies are often cost-driven, although treatments which are delivered via a blanket approach and assume homogeneity have not always been found to promote positive health outcomes. Yet a recent review of the literature exploring psychologically-based interventions for patients with COPD, revealed that all interventions had been delivered within a group setting (Baraniak & Sheffield, 2011). These group interventions were found to be limited in their effectiveness at improving symptoms of anxiety and health related quality of life in patients with COPD. The individual delivery of therapies (i.e. Cognitive Behavioural Therapy (CBT)) has been found to be superior to group therapy in reducing social phobia and anxiety in an otherwise 'healthy population' and also produce more prompt reductions in symptoms of Obsessive Compulsive Disorder (Stangier, Heidenreich, Peitz, Lauterbach, & Clark, 2003; Fals-Stewart, Marks, & Schafer, 1993). It would appear that to maximise the effectiveness of behavioural strategies, designed to promote positive health behaviour for patients with COPD (i.e. engaging in PR and increased physical activity) the concept of tailoring ought to be endorsed by attending to patients' individual problems and beliefs.

There appears to be two main frameworks which promote the idea of tailoring treatment through a phased approach to intervention development: Medical Research Council (MRC) guidance and Intervention Mapping (IM).

#### **4.3. Medical Research Council: Developing and evaluating complex interventions**

Complex interventions are commonly applied in a health care setting and refer to interventions consisting of several interacting components. In 2000 The MRC produced

a framework for the development and evaluation of randomised controlled trials for complex interventions which was subsequently updated in 2006 (Campbell et al., 2000; Campbell et al., 2007). The process consists of five main elements and can be lengthy: 1. developing; 2. piloting and feasibility; 3. testing; 4. reporting; and 5. implementation. Spending time and focusing on the developmental stage of planning is more likely to facilitate the development of a successful intervention which can be easily implemented.

Prior to the developmental stage it is important to identify the relevant, existing evidence surrounding current interventions. To date, the most commonly applied psychological intervention for patients with COPD is CBT (Baraniak & Sheffield, 2011). Despite the limited effectiveness of group CBT, alternative options for psychological support have not been suggested. The issue remains that without a clear understanding of patients' needs following an acute exacerbation of COPD it is impossible to determine what type of intervention is likely to be of benefit. Therefore a thorough assessment of patients' needs following an acute exacerbation is required before the developmental stage of the MRC framework can be commenced.

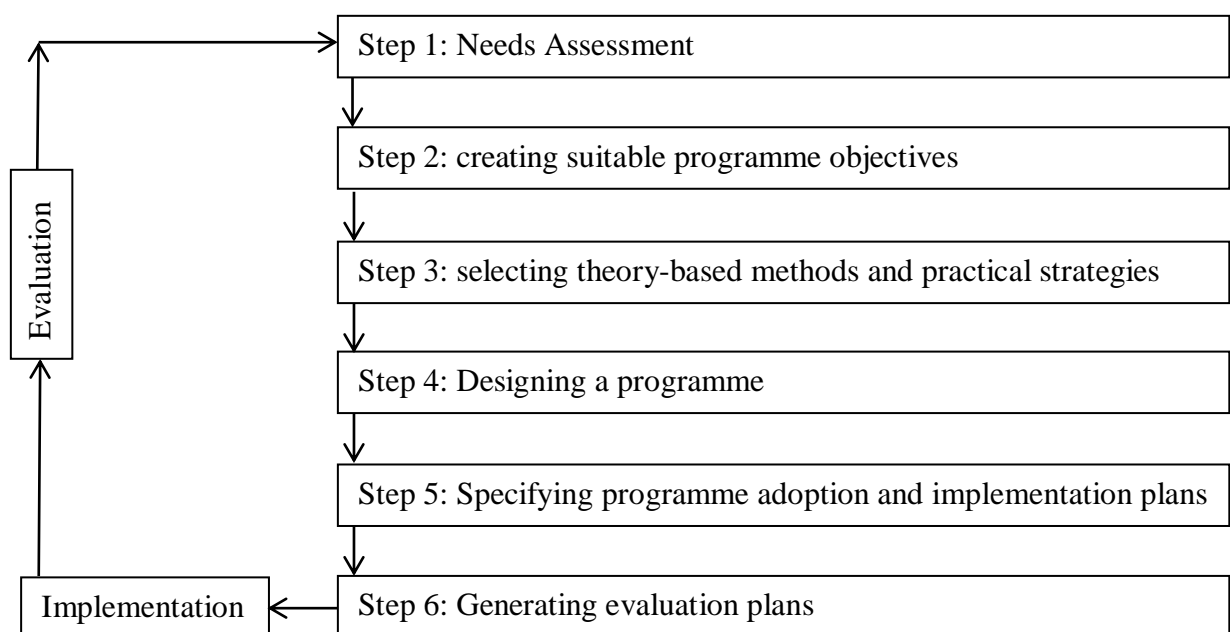
Another issue with the MRC framework is the assumption that an intervention is necessary when, in fact, tailoring the manner in which health care professionals deliver care may be adequate for some individuals. The MRC framework which focuses on development and testing of an intervention may not be appropriate; instead it may be more helpful to focus on the patient population in particular because exiting literature and knowledge surrounding patients following an acute exacerbation is limited.

#### **4.4. Intervention Mapping**

IM is an alternative framework which aids decision making in intervention planning, implementation and evaluation (Bartholomew, Parcel, & Kok, 1998). The focus on health promotion is greater than with the MRC framework and there is a greater emphasis on the developmental stage which is described in six steps: 1. Conduct a needs assessment. This involves reviewing the key determinants of behaviour such as, illness perceptions, discerning and distinguishing environmental and behavioural causes of behaviour (i.e. influence of health care professionals and avoidance of PR stemming

from fear of breathlessness) and identifying an at risk population (i.e. patient post-exacerbation with maladaptive illness perceptions who fail to engage in PR): 2. Create proximal programme objectives. This requires stating the expected changes in behaviour, specifying the determinants of behaviour, differentiating the target population and documenting learning and change objectives: 3. Select theory-based methods and practical strategies to change (determinants of) health behaviour. This process involves brainstorming and translating methods into practical, organised strategies: 4. Design a programme. The health care professionals responsible for implementing plans and the hospital environment where plans will be implemented require consideration. Documents are developed and a pilot test of the program is conducted with the target population: 5. Specify programme adoption and implementation plans. It is necessary to agree the objectives and the determinants of behaviour and write an implementation plan: 6. Generate evaluation plans. The researchers need to agree appropriate outcome measures and develop a protocol for evaluation (i.e. a randomised controlled trial). Although IM is described in a linear fashion, like the MRC framework, it ought to be conducted as an iterative process whereby researchers move back and forth between the steps. It is also cumulative, each step serves to inform the next. Figure 2 displays an overview of the IM model.

**Figure 2. Intervention Mapping Model**



The three core processes described for IM advocate the necessity of a thorough ‘needs assessment’ enabling the identification of causal links for health behaviour (including refusal of interventions conducive to health), which may be amenable to intervention: 1. the search for empirical findings from the existing literature; 2. accessing and using theory to inform strategies; and 3. collecting new data. A thorough ‘needs assessment’ through the adoption of these three processes is described in the subsequent sections of this thesis.

## **4.5. Tailoring psychological interventions**

### **4.5.1. Triage models**

Of all the behavioural interventions tested in patient populations, the most successful, and therefore the strongest recommended, adopt a triage model whereby patients are identified and prioritised for different stages of intervention.

An example of such an approach is embodied in The Improving Access to Psychological Therapies (IAPT) scheme funded by the Department of Health and implemented across the United Kingdom to improve the delivery of psychological services (Department of Health, 2008). It focuses on treating anxiety and depression through a stepped-care approach. Key to this is explicit assessment of severity and duration of presenting difficulties. By this means, treatment of proven efficacy is offered without burdening the patient with interventions which are unnecessarily intensive. Secondly, continued review allows detection of non-improvement enabling referral to more intensive treatments as well as discontinuation when intervention is no longer appropriate or necessary.

Although decisions regarding the most appropriate level of intervention is led by health care professionals the scheme advocates patient choice, allowing patients to have a say in the type of treatment they receive. The success of IAPT in reducing symptoms of anxiety and depression and improving employment rates (Clark et al., 2009) has led to its continued development. The four year action plan “Talking therapies” focuses on improving access to psychological therapies for older adults with chronic conditions



(Department of Health, 2011) although, the manner in which these therapies are delivered for patients with unstable conditions has not yet been given consideration.

Parallel developments in such individualised care have also been embraced within rehabilitation. The cardiac rehabilitation team at Guy's and St Thomas's foundation trust developed and assessed the effectiveness of a stepped-care approach to treating the specific psychological needs of cardiac patients who had suffered a recent cardiac event. The intervention steps included; education, a brief behavioural intervention and individual CBT. 460 patients attended the cardiac rehabilitation programme over a two year period and almost 50% of all the patients offered a referral to the psychological service, accepted. Following the programme symptoms of anxiety and depression were reduced overall by 19% and 13.5% respectively and only 23 out of the 125 patients referred had opted for the most intense intervention (individual CBT) (Child, Sanders, Sigel, & Hunter, 2010). It would appear that a stepped-care approach to treating specific psychological needs can successfully reduce psychological symptoms in patients with chronic disease following an acute event. Child et al (2010) also demonstrates the feasibility of delivering such a programme within a cardiac rehabilitation setting (Child et al., 2010).

# **Chapter 5**

## **5. “CONSUMED BY BREATHING” – A CRITICAL INTERPRETATIVE META-SYNTHESIS OF THE QUALITATIVE LITERATURE**

As described by the Intervention Mapping framework, the first stage of developing an intervention, likely to be successful in promoting behaviour change, constitutes a ‘needs assessment’ beginning with a review of the literature exploring the needs of the population. To this end, this chapter describes a meta-synthesis of the existing qualitative literature, a methodology commonly applied to explore the experience of patients and the manner in which they respond to, appraise and understand acute exacerbations of Chronic Obstructive Pulmonary Disease (COPD). The conclusions drawn from this synthesis reveal patients’ sense of overwhelming breathlessness experienced during an acute exacerbation, prompting feelings of distress and likely deterring engagement in interventions (Pulmonary Rehabilitation (PR)) which explicitly provoke increased breathlessness, questioning the suitability of PR, when delivered in its current form, for this vulnerable population. Knowledge gleaned from this chapter makes recommendations for the timing and context of delivering health messages and describes how psychological interventions which focus on patients’ fears and aim to shape appraisals may have a role in mitigating distress following an acute exacerbation.

### **5.1. Introduction**

The early stages of COPD often go unrecognised although long episodes of coughing and sputum production are common. As the disease progresses the later stages are characterised by acute exacerbations defined by a worsening of symptoms, predominantly breathlessness, and often resulting in an admission to hospital.

Patients who experience acute exacerbations of COPD have higher readmission rates to hospital than for any other disease process (Farr, 2010; Miravittles et al., 2000) and

despite medical care, approximately one third of patients will experience recurrent symptoms within 14 days (Emerman et al., 1991). The treatment of acute exacerbations is clearly challenging and their prevention a priority. Hospital readmissions following an acute exacerbation account for a large proportion of the direct costs of COPD, estimated at £800 million per year in the United Kingdom (UK) (Department of Health, 2005; Emerman et al., 1991; Fan et al., 2008).

The unpredictable nature of exacerbations and the disruption they cause to a person's daily life are associated with significant psychosocial co-morbidities including symptoms of anxiety and depression (Quint et al., 2008; Kessler et al., 2006). However, despite the treatment of acute exacerbations being prioritised in national guidelines (National Institute for Clinical Excellence, 2010), the emotional impact is not considered, nor is patients' psychological status routinely assessed following an acute exacerbation of COPD. Currently the only source of psychological support available is provided by The Improving Access to Psychological Therapies scheme (Department of Health, 2008). The four year action plan "Talking therapies" outlines the government's commitment to improving access to psychological therapies for older adults with chronic conditions (Department of Health, 2011). However, the manner in which these therapies are delivered for patients with unstable conditions has not been given consideration.

PR has shown promise in reducing readmission rates, as well as eliciting benefits in terms of patients' psychological status, functional capacity and health status following an acute exacerbation of COPD (Man et al., 2004; Seymour et al., 2010). Despite the documented benefits of PR, there are difficulties recruiting to, and poor attendance, at PR programmes even in a population of patients for whom COPD is stable (Fischer et al., 2009; Garrod et al., 2006; Hogg et al., 2012). Interestingly, notably higher levels of anxiety have been observed in those patients for whom the onset of an acute exacerbation lead to them dropping out of a PR programme (Hayton et al., 2012), yet, programmes have not been tailored to meet the additional needs of patients and the issue of poor acceptance in this vulnerable population is likely to be magnified. This concept is supported by the lengthy recruitment periods and small patient numbers in post-exacerbation research studies (Eaton et al., 2009; Seymour et al., 2010).

Despite researchers best attempts, understanding regarding the additional needs of patients following an acute exacerbation of COPD are still limited. A substantial body of research evidence derived from psychological theories such as the Common Sense Model (CSM) suggest that patients' perceptions of a challenge to health affect coping responses and behaviour (Leventhal et al., 1984; Leventhal et al., 1997). Therefore, the experience of an acute exacerbation may affect the manner in which a patient perceives their illness and in turn, illness perceptions may affect patients' engagement in disease management strategies i.e. adherence to PR (Leventhal et al., 1984).

Attendance and drop out from a PR programme appear, at least in part, to be predicted by patient beliefs relating to the effectiveness of treatment (Fischer et al., 2009; Fan et al., 2008). However, these studies were conducted on patients whose COPD is stable. Indeed PR programmes have largely been developed for patients for whom COPD is stable; therefore the more complex requirements of patients following an acute exacerbation have been given relatively little consideration. The paucity of information regarding patients' beliefs/appraisals following an acute exacerbation of COPD is surprising given that such appraisals following other acute significant health - related events have been found to affect disease management in other chronic conditions such as diabetes (Skinner et al., 2011) and following myocardial infarction (Alsen et al., 2010; French et al., 2006). Such research has shown that patients who exhibit a high sense of personal and treatment control but who also view their illness as serious seem the most likely to adhere to health promoting behaviour and have positive health outcomes.

Historically, rigorously conducted systematic reviews have directed health care professionals to best practice grounded in the best available evidence. The movement towards evidence-based practice led to the development of the Cochrane Collaboration; an international network devoted to the identification and synthesis of randomised controlled trials (RCT) in medicine. However, the Cochrane review represents only one approach within the broader context of systematic review methodology. The limitations of acknowledging evidence only emerging from RCT and only recognising the benefits of reviews including RCT are increasingly documented (Dixon-Woods & Fitzpatrick, 2001).

Qualitative research has been increasingly recognised as a legitimate way of gathering evidence which cannot be obtained using quantitative methodologies (Green & Britten, 1998) and is becoming increasingly valued in its contribution to the evidence for policy and practice (Sheldon, 2005). It has been found to be particularly useful in the identification of facilitators and barriers to assessing and complying with treatment (Noyes & Popay, 2007). However, some researchers are of the opinion that the differing philosophical assumptions underpinning qualitative studies make the synthesising of qualitative research inappropriate by promoting a 'positivist approach' (Barbour, 2001). The context of qualitative research is fundamental to the exploratory content and interpretation of data and yet previously, qualitative studies have been criticised for being contextually specific. In response to this criticism it has been suggested that by integrating results is a systematic way from numerous worldwide qualitative studies the generalisability of the findings can be improved and hypotheses more rigorously tested. Furthermore, conflicts in findings can be elicited and explored enabling the more rigorous testing of a hypothesis.

The current evidence base permits only speculation about why patients are reluctant to engage in PR following an acute exacerbation of COPD. However, a substantial body of research evidence derived from psychological theory suggests that patients' perceptions of a challenge to health (in this case an acute exacerbation) affect coping responses and behaviour (Leventhal et al., 1984; Leventhal et al., 1997). Informed by a theoretical base, this chapter describes a review which aimed to derive new conceptual understanding by interrogating existing qualitative studies reporting how patients respond to, appraise and understand acute exacerbations of COPD resulting in hospitalisation. This interpretative meta-synthesis of a body of evidence was hoped to provide a context in which to understand patients' health-management behaviour. In addition to providing new insights, findings may inform strategies to shape patients' appraisals about the acute exacerbation and inform ways to enhance engagement in PR following hospitalisation for an acute exacerbation of COPD.

## **5.2. Methods**

To inform both the approach to the review and meta-synthesis meta-ethnography, an established method for interpretative meta-synthesis (Noblit & Hare, 1988), was used

(Pound et al., 2005; Campbell et al., 2003; Britton, 2003). The methods applied consisted of a number of stages, incorporating the seven phases originally proposed by Noblit and Hare (1988) (Noblit & Hare, 1988): 1. the development of research questions and an appropriate search strategy to identify appropriate literature; 2. the identification of relevant studies according to an inclusion criteria; 3. determination of the quality of articles; 4. data extraction and the application of methods of Reciprocal Translational Analysis (RTA).

#### 5.2.1. Search strategy

The research questions and the search strategy was formulated using CHIP (Context, How, Issue of interest, Population) (Shaw, 2011). The CHIP tool was selected rather than SPICE (Setting, Perspective, Intervention, Comparison, Evaluation) given the aim of the review was not to explore the effectiveness of an intervention but rather to explore patients' experience within a specific context. Thus, the context of interest was within a hospital setting, the issue of interest was acute exacerbations and the population of interest was patients with COPD. Qualitative methodologies are often privileged in order to explore patients' experiences and formed the focus of this review. To refine search terms the library of Medical Subject Headings (MeSH) was used. The set of terms in the final strategy was as follows: *exacerbate\** OR *hospital\** AND "Chronic obstructive" OR *emphysema* OR *bronchitis*. To optimise identification of qualitative studies the following search terms were added: *interview\** OR *qualitative*: these simple terms have been assessed as successful additional filters for identifying qualitative research (Grant M, 2000).

An extensive search was conducted July 2011 and was updated in September 2012 of electronic sociological and psychological databases including: ISI web of knowledge, CINAHL, British Nursing Index, PsychINFO and Scopus.

The review was restricted to papers published in peer reviewed journals reporting qualitative research about patients' experiences of acute exacerbations of COPD from first onset of symptoms through to coping at home following discharge from hospital. Studies were excluded if they documented only the experiences of family/caregivers or health care professionals and if the primary concern was focused on the patients'

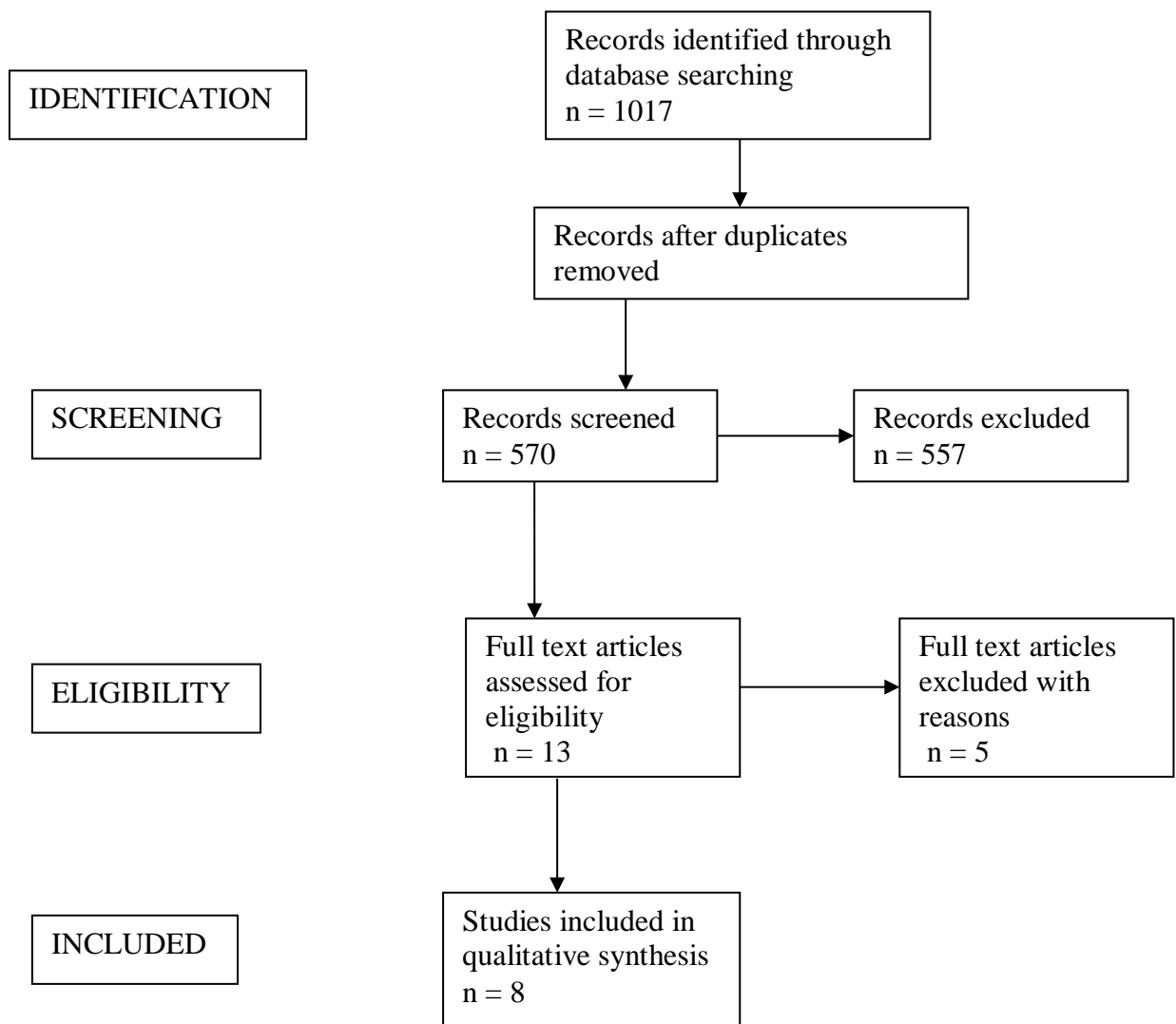
experiences of interventions or outcomes of an intervention including; PR, oxygen therapy, non-invasive ventilation and medications. The focus was on studies of patients clearly documenting an experience of an acute exacerbation of COPD. Papers had to report results of qualitative analysis based on qualitative methods of data collection. It was not felt necessary to exclude studies by date published as qualitative methodologies have only been utilised more recently in the respiratory field and it was expected that most papers included would have been published in the preceding 20 years. The meta-synthesis included all studies published in English. Editorials and reviews were excluded but multiple papers from studies were included if they offered new data and interpretation.

#### 5.2.2. Identification of papers

The initial database search produced 1017 titles and abstracts. 570 records were available after the removal of duplicates. All titles and abstracts were screened. The initial screening questions comprised the following: 1. Is the study about an exacerbation of COPD? 2. Does the study evaluate patients' responses, appraisal and understanding of an exacerbation of COPD? From the title and abstract 557 studies were excluded leaving 570 for future scrutiny. The full text was obtained for 13 papers which met the inclusion criteria or could not be excluded based on the title and abstract alone. No further relevant studies were identified from the reference lists of key papers, highlighting the quality and appropriateness of the final search terms and strategy.

The identification of papers is documented in a PRISMA flow chart (Figure 3).

**Figure 3. PRISMA flow chart.**



### 5.2.3. Determination of quality

The quality of the 13 papers was independently assessed by three reviewers using a formal appraisal checklist (The Critical Appraisal Skills Programme (CASP) (Milton Keynes Primary Care Trust, 2005). The CASP has been used in numerous previous syntheses of qualitative research it prompts judgements on the procedural aspects of the research and is a useful tool for researchers not experienced in qualitative research (Dixon-Woods et al., 2007; Campbell et al., 2003). However, un-prompted judgements inevitably shaped decisions regarding inclusion and were useful in promoting agreement between the researchers (Dixon-Woods et al., 2007).



Five studies were excluded following appraisal; two failed to meet the aims of the review because their primary concern was with the evaluation of a service (Schofield, Knussen, & Tolson, 2006; Costi, Brooks, & Goldstein, 2006), one failed to justify the exclusion of a large proportion of COPD patients (Nicolson & Anderson, 2000), one was excluded on grounds of qualitative methodological quality (Kessler et al., 2006) and one was deterministic in its design (Small & Graydon, 1993). Eight studies were thus included in the analysis. Two papers authored by Bailey used the same population of patients and therefore the results were combined to preclude giving the data unfair weighting in the meta-synthesis (Bailey, 2004; Bailey, 2001).

The profile of the eight studies included in the meta-synthesis is displayed in Table 2.

**Table 2. Profile of studies**

Study	Gruffrdd-Jones et al (2007), UK	Bailey		Adams et al (2006), Denmark, UK, Netherlands	Yu et al (2007), China	Russell et al (1998), USA	DeVito (1990), USA	Jeng et al (2002), Taiwan
		(2001), Canada	(2004), Canada					
<b>Research aims</b>	To identify patients' needs following discharge from hospital after an acute exacerbation of COPD.	To develop an understanding of patients', family caregivers' and nurses' experiences of an acute exacerbation of COPD necessitating hospitalisation.	To explore the affective component of dyspnoea and anxiety as described by the patients and carers who have experienced an acute exacerbation of COPD.	To explore the notion of COPD exacerbations from the viewpoint of patients who had recently suffered an exacerbation.	To investigate the phenomenon of recurrent hospital readmission from the perspective of older Chinese COPD patients.	To explore how persons recognise and respond to their heart failure and COPD exacerbations.	To investigate how the patient with COPD perceives the experience of dyspnoea and nursing actions while hospitalised.	To explore the experiences of daily activities during the first two weeks after hospital discharge.
<b>Theoretical framework</b>	Interpretative Phenomenology	Ethnography		Grounded theory	Thematic	Naturalistic inquiry	<i>Not reported.</i>	<i>Not reported</i>
<b>Sampling/ Population</b>	Purposive sampling. n=25.	Opportunistic sampling. 10 family-nurse units.		Convenience sampling across three countries. n=23.	Purposive sampling. n=5.	Opportunistic sampling. n=60 COPD, n=60 heart failure.	<i>Not reported.</i> n=96.	Purposive sampling. n=9.

**Table 2. Profile of studies** *continued*

	<b>Gruffrdd-Jones et al (2007), UK</b>	<b>Bailey</b> (2001), Canada (2004), Canada		<b>Adams et al (2006), Denmark, UK, Netherlands</b>	<b>Yu et al (2007), China</b>	<b>Russell et al (1998), USA</b>	<b>DeVito (1990), USA</b>	<b>Jeng et al (2002), Taiwan</b>
<b>Methodology</b>	Two focus groups (n=3). Data collection at two time points: seven days and three months post discharge.	In-depth interviews		Semi-structured in-depth interviews	Unstructured interviews	Semi-structured interviews	Semi-structured interviews	In-depth interviews
<b>Analysis</b>	Interpretative Phenomenological Analysis	Narrative analysis		Thematic analysis	Thematic content analysis	Three stage analysis process (Miles & Huberman, 1994)	Content analysis	Constant comparative method
<b>Ethical considerations</b>	None	Institutions		Locally in each country.	Local	Informed consent was obtained.	Patients were informed of the researcher's interest.	Informed consent was obtained.
<b>Reflexivity</b>	None	None		None	None	None	None	None

Across the eight studies sample size varied considerable ranging from five to 96 participants. Various theoretical frameworks informed the research studies resulting in different analysis techniques being utilised. Some consistency did exist in the data collection; semi-structured interviews followed by in-depth interviews were favoured.

#### 5.2.4. An interpretative meta-synthesis

Noblit and Hare (1988) propose that in meta-ethnography 'each account is an interpretation of an interpretation' (Noblit & Hare, 1988). These are presented by the authors of the papers and termed by Britten et al (2002) as 'second order constructs' (Britten et al., 2002). The focus of ethnography is to develop new insights: 'interpretations of interpretations of interpretations' these become 'third order constructs'.

Methods of RTA were applied (Noblit & Hare, 1988). RTA uses hermeneutic dimensions to synthesis permitting understanding of parts of a whole which, in turn, progress to global understanding that can be referred back to the individual. This approach has particular value in giving prominence to the interpretative qualities of the studies being analysed. Firstly, the key themes are identified from each of the included studies. An iterative process is incorporated whereby common themes are translated into each other. Judgements are made about the ability of themes identified from one study to accurately reflect the themes from another. The themes which appear to be best complement each other are chosen to be presented and may be taken to a deeper level of interpretation. Although the utility of RTA was originally advanced for synthesis of studies similar in methodology, more recent work has provided evidence for the application of RTA in studies varying in methodology (Campbell et al., 2003). As a technique its effectiveness is best when reviews comprise analysis of fewer than 50 papers (Dixon-Woods et al., 2006).

The use of a refutational or line-of-argument approach was debated. A refutational approach characterises contraindications between findings and line-of-argument, involving constant comparison, draws out the most powerful themes from the entire dataset. Although the importance of considering the quality of evidence and contraindications in the body of literature is acknowledged, in an area where the body of

evidence is small the application of this approach can limit the conclusions to be drawn. A line-of-argument approach focuses on comparing and contrasting individual findings. However, a broad over-view of patient experience may be required before a detailed interpretation of individual accounts is conducted. Furthermore, contraindications were limited within the dataset.

#### 5.2.5. Data extraction/ first order constructs

A data-extraction form was devised to assist in the identification of patient characteristics, methodology, analysis, major findings, conclusions and limitations. All data were extracted from the primary studies deemed relevant to addressing the aim of the review. The information provided in all studies was considered adequate and therefore no key researchers were contacted. Data extraction was conducted by three reviewers and included authors commentary and direct quotations from the papers (Appendix A).

#### 5.2.6. Second order constructs

Development of the second order themes involved an iterative process. With the eight original papers to hand additional ideas and interpretations were noted. These initial ideas were reflected in themes surrounding minimising and/or dismissing symptoms, emotional responses and being consumed by dyspnoea, promoting meaning of the disease, help-seeking behaviour and conscious body management (Table 3).

#### 5.2.7. Third order constructs

The accounts which emerged appeared consistent across the primary studies enabling the accounts to be translated into one another. Interpretations were developed from the second order constructs. Interpretations were not explicit in the primary data; rather they represented the reviewers' interpretation of the authors' interpretation of the patients' accounts. Throughout the development of interpretations the table of first and second order constructs was kept close to hand, along with the original eight papers to ensure the interpretations stemmed from the original data (Table 4).

Second order themes were grouped under headings/conceptual themes reflecting two stages of disease management and emphasised how exacerbations appeared implicit to the dynamic nature of COPD. The conceptual themes comprised of: 'Acute Effect' describing symptom onset and patients' need for rescue and 'Sustained Regulation' embodying the impact of an acute exacerbation of COPD on the individual as an iterative process. The themes are discussed under these two headings.

**Table 3. First and second order constructs**

Studies	Aims	Themes	Author's comments	Conclusions
<b>Gruffrdd-Jones et al (2007), UK</b>	To identify patients' needs following hospital discharge after an acute exacerbation of COPD.	<ul style="list-style-type: none"> <li>• <b>Reluctance to seek medical help for an exacerbation.</b> "not wanting to bother my doctor because I know how busy he is". "This generation – it was brought up not to whinge and whine".</li> <li>• <b>Fear associated with acute attacks of breathlessness.</b> Fear of breathlessness. Uncertainty about who to contact.</li> <li>• <b>Follow up after hospital.</b> "Reassurance that I'm still in touch with medical people". Almost half the patients had no medical or personal contact one week after admission.</li> <li>• <b>Educational needs.</b> How and when could oxygen be provided. "How ill do you have to be before you can get oxygen?"</li> </ul>	<ul style="list-style-type: none"> <li>• Avoidance of help-seeking - not wanting to bother doctors, fear of hospital admission and a perception that exacerbations would get better by themselves. Reluctance attributed to a more stoical attitude.</li> <li>• Uncertainty about what action to take linked with a lack of knowledge regarding use of oxygen. Patients believed and felt that oxygen helped with breathlessness and anxiety whilst in hospital.</li> <li>• Uncertainty regarding medical and social support on discharge induced feelings of isolation.</li> <li>• Patients felt they needed more help about what to do when symptoms deteriorated and were concerned about the provision of medication and use of home oxygen.</li> </ul>	<ul style="list-style-type: none"> <li>• Patients expressed high levels of anxiety, fear and uncertainty associated with breathlessness.</li> <li>• Patients delayed help-seeking behaviour.</li> <li>• Patients feel socially and medically isolated following discharge.</li> <li>• Patients require better education on the provision and use of oxygen.</li> </ul>

**Table 3. First and second order constructs** *continued*

Study	Aims	Themes	Author's comments	Conclusions
<b>Bailey (2001), /Bailey (2004), Canada</b>	To develop an understanding of patients', caregivers' and nurses' experiences of an acute exacerbation of COPD necessitating hospitalisation. /To explore the affective component of dyspnoea and anxiety as described by the patients and carers who have experienced an acute exacerbation of COPD.	<ul style="list-style-type: none"> <li>• <b>Intractable dyspnoea.</b> Circumstances of dyspnoea were described. Many patients cried. Emotions expressed when representing dyspnoea had a role in initiating acute exacerbations and the threat of increased dyspnoea exacerbated emotions. Emotional vulnerability reduced activity, increased dyspnoea and triggered further distress or help seeking behaviour.</li> <li>• <b>Help seeking.</b> If patients experienced dyspnoea at home they alerted a family member.</li> <li>• <b>The rescue.</b> Patients described care from paramedics, arriving at accident and emergency, receiving intervention/ medications. Many references to the necessity and timing of the rescue.</li> <li>• <b>Incomplete stories.</b> Partial recall of exacerbations. Patients reported being told about the events from doctors, family members.</li> <li>• <b>Meaning of death stories.</b> Patients spoke about respiratory failure requiring interventions to prevent death. Other stories reported less severe dyspnoea requiring hospitalisation or breathlessness managed by health care professionals.</li> </ul>	<ul style="list-style-type: none"> <li>• Patients repeated words or phrases to emphasise seriousness of breathlessness. 'Just' was used to diminish the episode. Strong sense of distress. Emotion and dyspnoea was reciprocal. By making dyspnoea visible patients legitimised help-seeking.</li> <li>• Acute exacerbations often took Patients and family members by surprise and prompted the establishment of clear strategies.</li> <li>• The rescue was characterised as miraculous or fortuitous. Patients implied the help received could not be delivered outside the hospital.</li> <li>• Patients used information from others to recall the events immediately preceding hospital, this resulted in patients emphasising details of the rescue.</li> <li>• Descriptions divide in to 'near-death stories' and 'shadow-of-death stories' respectively.</li> </ul>	<ul style="list-style-type: none"> <li>• Patients express uncertainty and a fear of death via narratives.</li> <li>• Anxiety is a symptom of long standing acute respiratory failure.</li> <li>• Patients who have experienced near death events now live in 'shadow'/fear of future events.</li> <li>• Emphasised need for nurses to attend to the meaning of illness for both patient and caregiver.</li> <li>• Watershed function of death stories significantly change understanding of acute exacerbations.</li> </ul>



**Table 3. First and second order constructs** *continued*

Study	Aims	Themes	Author's comments	Conclusions
<b>Adams et al (2006), Denmark, UK, Netherlands</b>	To explore COPD exacerbations from the viewpoint of patients.	<ul style="list-style-type: none"> <li>• <b>Prominence of exacerbations in life with COPD.</b> Patients described living with COPD as “a nightmare”/ “horrible”. Patients focused on the impact on daily living.</li> <li>• <b>Decision to consult.</b> Reluctance. “I don’t go easily to see the doctor”</li> <li>• <b>Exacerbations as ‘forgotten events’.</b> On visits to health care professionals patients did not remember exacerbations being referred to.</li> <li>• <b>Symptoms.</b> Patients saw health care professionals for their symptoms. “It’s up and down sometimes a bit better and then its worse”.</li> </ul>	<ul style="list-style-type: none"> <li>• Think about categories of exacerbations and how patients label them.</li> <li>• Reluctance to consult. Dictated by anxiety/distress in response to symptoms.</li> <li>• Exacerbations did not seem memorable, suggesting that they were not understood as significant.</li> </ul>	<ul style="list-style-type: none"> <li>• Need to check patient understanding of symptoms and consultation.</li> <li>• Stories of unsatisfactory consultations.</li> <li>• Empowering patients so they have a greater role in management.</li> </ul>
<b>Yu et al (2007), China</b>	To investigate recurrent hospital readmission from the perspective of older Chinese COPD patients.	<ul style="list-style-type: none"> <li>• <b>Perceived powerless to manage after discharge.</b> “I knew I was not ok. I consulted a private doctor immediately after hospital discharge and was readmitted to hospital”. Feelings of impending death associated with dyspnoea prompted patients to seek readmission.</li> <li>• <b>Lack of confidence in community-based health care services.</b> Frustration with the experience of using community-based services in managing exacerbation. ‘No method to cure them’.</li> <li>• <b>Tension relationships between caregiver and patient.</b> “My wife begged the doctors in the accident and emergency department to admit me to the hospital. I don’t want to”.</li> <li>• <b>Satisfaction with social atmosphere in hospital.</b> Explanation for recurrent admission ‘more happy in hospital than at home’.</li> </ul>	<ul style="list-style-type: none"> <li>• Patients lacked confidence in their ability to control dyspnoea post discharge. Seeking readmission was common in those who believed their condition was not ready for discharge.</li> <li>• Frustration with community services prompted readmission.</li> <li>• Family members didn’t feel they could cope with care-giving duties so requested hospital readmission.</li> </ul>	<ul style="list-style-type: none"> <li>• There appears to be unequal power in the doctor/patient relationship.</li> <li>• Dyspnoea induces feelings of impending death which prompts fear and failure to engage in self-management.</li> <li>• Caring dilemma - cultural obligation but wish to be relieved.</li> <li>• Hospital readmission is shaped by an individual’s cultural and socially determined illness experience.</li> </ul>

**Table 3. First and second order constructs** *continued*

Study	Aims	Themes	Author's comments	Conclusions
<b>Russell et al (1998), USA</b>	To explore how persons' recognise and respond to their heart failure and COPD exacerbations.	<ul style="list-style-type: none"> <li>• <b>Etiology.</b> "I couldn't breath", "waking up choking". Shortness of breath the primary symptom described.</li> <li>• <b>Cause.</b> Extrinsic factors: intake of food/fluids, exposure to noxious materials or pollution (controllable) and intrinsic factors: 'fluid build up' and outside controllers influence.</li> <li>• <b>Effect.</b> Patients reported not being able to do what they wanted/used to do. "Made me feel like my life was over". Symptoms and watchful protection of friends and family limited activities. Patients described the uncertainty caused by disease.</li> <li>• <b>Treatment-provider help.</b> Patients discussed health care professionals' actions they thought should have occurred. Professionals made suggestions but patients had not changed behaviour. "Doctors just tell me to take it easy". "Should have stayed on me about my smoking".</li> </ul>	<ul style="list-style-type: none"> <li>• Symptoms creating intense physical distress often triggered hospitalisations.</li> <li>• Patients with COPD identified more extrinsic causes of their disease.</li> <li>• Reports of a sense of overwhelming despair.</li> <li>• Patients expressed some personal responsibility for their admission. A desire for better communication with providers was expressed.</li> </ul>	<ul style="list-style-type: none"> <li>• The presence of symptoms effecting personal and social lives triggered hospitalisation.</li> <li>• Patients acknowledge their role in prevention.</li> <li>• Disparity between health care professionals recommendations and patient actions.</li> </ul>

**Table 3. First and second order constructs** *continued*

Study	Aims	Themes	Author's comments	Conclusions
<b>DeVito (1990), USA</b>	Investigate how patients with COPD perceive the experience of dyspnea and nursing actions while hospitalised.	<ul style="list-style-type: none"> <li>• <b>Fear.</b> "It's the worst feeling in the world....it's like smothering to death".</li> <li>• <b>Helplessness.</b> "I can't help it...my breathing is fast, but I can't slow it down". "Do they really think that we'd prolong this agony if we had the power to stop it?"</li> <li>• <b>Loss of vitality.</b> The power to live. "...my breathing trouble was killing me". "When you can't breathe of course you're dying".</li> <li>• <b>Preoccupation.</b> Taking up all the attention of the individual. "I could not take my mind off breathing for fear my life would end". 'Consumed by breathing'.</li> <li>• <b>Legitimacy (to conform to accepted standards).</b> "no one knows what it's like to be short of breath and gasping for air". Patients described others' misunderstanding to realise the direct significance of their episodes of breathlessness. Effort to convince others of their distress.</li> </ul>	<ul style="list-style-type: none"> <li>• Fear influenced subjective shortness of breath. Dyspnoea induces fear which induces dyspnoea.</li> <li>• Comments from nurses about controlling breathing were a source of frustration. Nurses should respect the seriousness of patients' situation and were thought to undermine by suggesting that stopping the dyspnoeic episode was within patients' power.</li> <li>• The process of respiration becomes conscious. A sense of urgency prevailed throughout patients' accounts of their dyspnoeic experiences with breathing vital to living. Preoccupation with breathing emerged. Patients reported attempts to control likelihood of an acute exacerbation by withdrawing from their surroundings.</li> <li>• Legitimacy was recognised as a problem by patients with dyspnoea.</li> </ul>	<ul style="list-style-type: none"> <li>• Fear - a universal response.</li> <li>• Want disease to be dealt with by competent staff modelling the desired response.</li> <li>• During acute exacerbations patients felt helpless.</li> <li>• Isolation and withdrawal are protective mechanisms to reduce the impact of emotions.</li> <li>• Emphasised more need to acknowledge the fear and transient state of helplessness.</li> <li>• Acknowledging the potential for patients' fear and validating its presence may be therapeutic in itself.</li> </ul>

**Table 3. First and second order constructs** *continued*

Study	Aims	Themes	Author's comments	Conclusions
<b>Jeng et al (2002), Taiwan</b>	Explore the experiences of daily activities during the first two weeks after hospital discharge.	<ul style="list-style-type: none"> <li>• <b>Changing expectations.</b> Becoming aged. "My spirit is willing but my flesh is weak".</li> <li>• <b>Fear of having another attack.</b> Patients/families fear another attack of heavy breathing which might be too late for additional medical treatment.</li> <li>• <b>Slowing and simplifying activities.</b> Adjusting by slowing down, simplifying activities and resting.</li> <li>• <b>Acting according to one's ability.</b> Doing whatever one is capable of without being forced to, "act according to ability".</li> <li>• <b>Protecting oneself.</b> Seeking help and selecting activities which fit oneself. Interviewees said they would ask for doctor's help when needed. They would fulfil medical advice by using the environment around them or setting up plans</li> <li>• <b>Striving for an independent life.</b> Standing firmly on one's own without relying on others or becoming a burden to one's family.</li> <li>• <b>Trying to continue living.</b> Moving while breathing so that life can last longer.</li> </ul>	<ul style="list-style-type: none"> <li>• Patients try to resume normal daily activities but are limited by recovery and aging.</li> <li>• Fear stems from suffering extensively for their actions. Patients considered causes of a possible attack when determining whether to continue daily activities.</li> <li>• Some elderly patients gradually strive for self-motivated adjustment to daily activities.</li> <li>• Selection of activities according to own physical condition.</li> <li>• Patients preferred control over all the daily activities, do not want to rely on others or become a burden. Most patients were confident of their own ability to continue activities of daily living.</li> <li>• Daily activities are good for recovery and continuing to live.</li> </ul>	<ul style="list-style-type: none"> <li>• Patients realised the difference between actual capabilities, changing expectations and seeking help.</li> <li>• Patients strive to maintain an independent life.</li> <li>• Daily activities are needed for physical/mental pleasure as a means for continued life.</li> </ul>

**Table 4. Third order constructs. Taxonomy of findings**

<p><b>Acute Effect</b></p> <p><u>Intense emotions</u></p> <ul style="list-style-type: none"> <li>• Overwhelming response to threat prompted by dyspnoea.</li> <li>• Catastrophising – dyspnoea means death.</li> <li>• Helplessness – unpredictability/uncontrollability of an acute exacerbation induces fear, reciprocal interaction of fear/anxiety and dyspnoea.</li> <li>• Acute distress caused by attributions which prompts help seeking.</li> </ul> <p><u>Body awareness</u></p> <ul style="list-style-type: none"> <li>• Respiration becomes conscious. Patients focus attention on breathing.</li> <li>• Breathing is vital, loss of breath equates to loss of life. Absolute seriousness/centrality of drawing breath emphasised.</li> <li>• Need to make (sensory) dyspnoea visible to get help (legitimacy).</li> <li>• Family passivity with COPD until acute exacerbation.</li> <li>• Watchful protection – limited activities.</li> </ul> <p><u>Need to be saved</u></p> <ul style="list-style-type: none"> <li>• Concerned about legitimacy of admission. Need to justify management beyond the home.</li> <li>• Characterised as miraculous or fortuitous.</li> <li>• Emphasised details of the rescue through accounts from others, bolsters legitimacy (others perceived need emphasises the threat).</li> </ul>
<p><b>Sustained Regulation</b></p> <p><u>Interruption</u></p> <ul style="list-style-type: none"> <li>• Preoccupied with breathing and fear of dying.</li> <li>• Normal life can never be spontaneous always planned.</li> </ul> <p><u>Understanding, believing and behaving</u></p> <ul style="list-style-type: none"> <li>• Acknowledging own role in prevention but uncertain what to do in an acute exacerbation and post-hospital discharge.</li> <li>• Need to better understand oxygen use.</li> <li>• Confidence in controlling dyspnoea. Empowering patients to take control.</li> </ul> <p><u>Conscious self-management</u></p> <ul style="list-style-type: none"> <li>• Readjustment of expectations to manage distress.</li> <li>• Deliberate isolation to reduce exposure to stimuli and to avoid burden of self on others.</li> </ul> <p><u>Help-seeking</u></p> <ul style="list-style-type: none"> <li>• Avoidance, stoicism, uncertainty about what actions to take.</li> <li>• Prompted by increased breathlessness and fear of dying.</li> <li>• Limited by age/aging/scope for recovery.</li> </ul>

### 5.3. Findings

All quotes are from authors' commentary or are direct patient quotation, sourced from the primary data.

#### 5.3.1. Acute effect

##### *5.3.1.1. Intense emotions*

Patients described overwhelming threat in the context of an acute exacerbation prompted by the experience of dyspnoea. *"It's the worst feeling in the world...the worst way to die...it's like smothering to death"* (DeVito, 1990:188) (DeVito, 1990). *"When [patients] are anxious they realise this emotion is an indicator that they are breathless"* (Bailey, 2004: 775) (Bailey, 2004). The cyclical and reciprocal nature of anxiety and dyspnoea pervaded all narratives, consistent with the concept of breathlessness as a key feature of an acute exacerbation being induced by, and exacerbating anxiety (Bailey, 2004). The inter-relationship of fear and breathlessness has been consistently articulated in literature describing patients with stable COPD (Janssen et al., 2010).

Patients appeared unable to remain emotionally neutral whilst struggling for breath, understandably construing breathlessness as a threat of dying, voicing catastrophic cognitions. *"It's scary when you can't breathe"* (Bailey, 2004: 768). *"I couldn't breathe. Afraid I was choking to death and I was"* (Russell et al, 1998: 172) (Russell, Geraci, Hooper, Shull, & Gregory, 1998). Anxiety as reported by patients in this review appeared to distort cognitions and alert patients to future threats *"If I am close to home I can be hurried to hospital or taken back home when an emergency occurs"* (Jeng et al 2002: 171) (Jeng, Tsao, Ho, & Chang, 2002).

Patients' acute distress, elicited by the attributions they made about symptoms, initiated help-seeking behaviour. *"Patients attempted to seek help to deal with what they believed was unmanageable breathlessness"* (Bailey, 2001: 326) (Bailey, 2001).

#### 5.3.1.2. Body awareness

During an exacerbation patients emphasised the essential nature of breathing and respiration was reported as becoming conscious, laboured and deliberate. Narratives revealed patients' need to explicitly communicate the seriousness of the situation by making their breathlessness visible to others. *"No-one knows what it is like to be short of breath"* (DeVito, 1990: 189).

Patients expressed frustration with other passivity in response to COPD until they witnessed an acute exacerbation where breathlessness was increased. Health care professionals and loved ones appear unable to appreciate the seriousness of their situation, *"they want nurses to understand their fear"* (Bailey, 2001: 335). Patients felt they needed to emphasise the seriousness of their condition via the use of strong language. *"Do they think we would prolong this agony if we had the power to stop it"* (DeVito, 1990: 188). Respondents emphasised symptom severity to justify their help-seeking behaviour. However, patients described being faced with a dilemma: despite experiencing difficulties in portraying the seriousness of their condition they did not welcome the watchful protection of family members. Instead they considered it a barrier to physical activity and independence *"Now my wife doesn't want me to get out, I may fall"* (Russell et al, 1998: 176).

#### 5.3.1.3. Need to be saved

Feelings of fear and incompetence seemed to stem from concerns regarding the adequacy of medical and social support received at home *"One man indicated to his provider that he should get him a home health nurse"* (Russell et al, 1998: 178). Respondents felt that in order for their needs to be met a hospital admission was essential and expressed concern about the inadequacy of community services having *"no method to cure them"* (Yu et al, 2007: 1759) (Yu, Lee, & Woo, 2007). Furthermore, to address intensely distressing symptoms, patients emphasised the uniqueness of provision within the hospital settings by stressing treatments that could not be offered elsewhere (such as scans and x-rays). Their description of these active interventions also emphasised a sense of powerlessness in the face of symptoms where

something “*miraculous or fortuitous*” (Bailey, 2001: 327) was required to save them. Such powerlessness may reflect fear and a realistic appraisal of need for expertise in the face of an overwhelming acute exacerbation.

Respondents presented themselves as debilitated and vulnerable both through their accounts of the exacerbation and reports derived from others who witness the exacerbation such as, family members and health care professionals. “*They saved her life four times*” (Bailey, 2001: 327). In reporting such indirect accounts of the acute event as described by others, patients reinforced their passivity, the necessity of the hospital admission and attempted to diminish any sense of illegitimacy.

A lack of patients’ efficacy and powerlessness also seemed to persist in narratives disclosing unreadiness for discharge and need for readmission, “*I knew I was not ok for discharge. I consulted a private doctor immediately after hospital discharge and was readmitted*” (Yu et al, 2007: 1759). Yet, in spite of significant apprehension patients did describe successfully identifying actions to take upon discharge including the pacing of activities “*when I had just come back from the hospital, I gradually resumed my morning activities. I divided them into sections to allow myself to recover*” (Jeng et al, 2002: 171).

### 5.3.2. Sustained regulation

#### *5.3.2.1. Interruption*

Statements from patients appeared to reflect a constant state of arousal and hypervigilance to symptoms and body changes arising from the unpredictability and perceived uncontrollability of acute exacerbations. Patients described their breathlessness as being all consuming “*I could not take my mind off breathing for fear my life would end*” (DeVito, 1990: 189) and this preoccupation interfered with and dictated daily activities “*they could no-longer do what they wanted to do or what they used to do*” (Russell et al, 1998: 176).



The overt need for self-regulation described by patients compromised their spontaneous enjoyment of life. Constant consideration of oxygen, medication and environmental triggers, and an intense fear of the latter's potential to provoke an exacerbation was constraining. *"I also feel like I might have another attack when the air is polluted"* (Jeng et al, 2002: 170). Patients' statements reflected the need for everything in life to be carefully contemplated and planned in order to avoid a distressing and potentially life threatening situation, adversely affecting feelings of independence and autonomy, *"made me feel like my life was over"* (Russell et al, 1998: 177).

#### 5.3.2.2. *Understanding, believing and behaving*

Respondents described how they adopted a regulatory role in their own disease management driven by their motivation to prevent another attack *"The disease has something to do with the weather....I will postpone the time when I go outdoor"* (Jeng et al, 2002: 171). Yet, many patients disclosed feeling factually ill-equipped to successfully manage their condition *"How ill have you got to be before you can get oxygen?"* (Gruffydd-Jones et al, 2007: 366) (Gruffydd-Jones et al., 2007).

#### 5.3.2.3. *Conscious self- management*

Patients socially isolated themselves in an attempt to self-manage: *"Patients reported attempts to insulate themselves by withdrawing from their surroundings"* (DeVito, 1990: 189). Historically, patients have found that symptom management is eased when external stimuli are reduced (Dudley, Verhey, Masuda, Martin, & Holmes, 1969), yet, patients broadened this strategic social isolation to mitigate the burden of themselves on others. *"She was too tired to take care of me (wife) I am her burden"* (Yu et al, 2007: 1759). This appears to create a dilemma if, as noted earlier, there is a perceived need to communicate the seriousness of exacerbations to others.

#### 5.3.2.4. *Help-seeking*

Patients articulated ambivalent attitudes to help-seeking, *"This generation it was brought up not to whinge and whine"* (Gruffydd-Jones et al, 2007: 367). *"I don't go*

*easily to see the doctor*” (Adams et al, 2006: 106) (Adams, Chavannes, Jones, Ostergaard, & Price, 2006), yet, when experiencing intense breathlessness help seeking is urgent, prompted by a fear of dying. COPD tends to present more frequently in older adults so issues around stoicism and doubts about legitimacy of help-seeking were unsurprising. Patients appeared to be insightful about the effects of aging regarding the management of their condition, and seemed to be hopeful about their limitations, often expressing difficulties in separating disease and aging effects, and attributing symptoms as an inevitable consequence of disease. *“My body does not allow me to. Now I am old, and lack strength. My spirit is willing but my flesh is weak”* (Jeng et al, 2002: 170).

## **5.4. Discussion**

This review of eight papers provides a comprehensive meta-synthesis of patients’ narratives around their responses, appraisals and understanding of acute exacerbations of COPD. Patients describe intense fear and heightened arousal prompted by acute breathlessness and reinforced by the intensity of others responses to the acute event. A constant state of hypervigilance is reflected, arising from living with an unpredictable and uncontrollable disease. Patients feel powerless in response to overwhelming symptoms, expressing a struggle to maintain autonomy.

### **5.4.1. The intensity of breathlessness**

Following an acute exacerbation, patients’ expressed narratives emphasise intense breathlessness. Patients’ appraisals of their dyspnoea elicit acute distress and are associated with feelings of powerlessness, pervasive anxiety and catastrophic cognitions. Many patients understandably construe breathlessness as preceding death, a finding echoing catastrophic cognition identified explicitly in patients with COPD (Porzelius, Vest, & Nochomovitz, 1992).

Despite the frequent and profound emotional impact of an acute exacerbation a patients’ psychological status is not routinely assessed in its aftermath. Psychological morbidity is an acknowledged accompaniment to COPD, with Post Traumatic Stress Disorder being diagnosed in approximately eight percent of patients whose disease is stable and

are undertaking PR (Jones, Harding, Chung, & Campbell, 2009). This prevalence figure may well be inflated after an acute exacerbation both because of symptom intensity and patients' perceived impotence regarding both breathing control and in communicating their fears to others. Routine assessment of extreme anxiety states and trauma may be warranted and appropriate management strategies offered if identified. The importance of conducting research to support the development of psychological strategies and their delivery to target populations of patients is supported by national guidelines for COPD (2010) (National Institute for Clinical Excellence, 2010; Department of Health, 2010b).

Patients' distress appears to persist as they struggle to explicitly communicate the seriousness of their condition to health care professionals. The powerful need to be heard seems to overcome stoicism. At a time when breathlessness is all consuming, patients feel symptoms are dismissed by those with the expertise to save them, exacerbating frustration and heightening arousal. The diminished ability of health care professionals to fully empathise with patients has previously been attributed to their experience working in a health care setting and the pressures to treat high numbers of patients (Belcher, Fried, Agostini, & Tinetti, 2006). Professionals may need to more openly acknowledge and empathise with patients' symptoms and associated fear, to foster more collaborative care rather than alienate.

In managing acute exacerbations of COPD effectively, the timing and context of delivering health-messages needs to be carefully considered by health care professionals. PR, with its emphasis on encouraging exercise, will explicitly provoke shortness of breath. At a time when patients are fearful of breathlessness, raising such a remedial intervention may not only increase patients' sense of threat (MacLeod & Rutherford, 1992), but also be interpreted as a failure to give adequate validity to symptoms which patients understandably feel are life-threatening. Furthermore, during an acute exacerbation patients' attention is likely to be focused on the imminent threat of dying and information about sustained management of the disease may not be attended to (Chajut & Algom, 2003). Reported arousal, could prompt the diversion of attention in a similar way to that expressed by patients who experience chronic pain and it may be that dyspnoea, fear of increased breathlessness (an exacerbation) and the threat to life serves to distract patients with COPD as pain-related fear and the

sensation of pain interrupts patients with chronic pain (Crombez, Eccleston, Baeyens, van Houdenhove & van den Broeck, 1999). Currently there is an absence of guidance regarding the optimum time for delivering PR to patients following an acute exacerbation of COPD but perhaps it would be advantageous to broach the topic of disease management and PR once patients have recovered equilibrium with their breathing and exacerbation-related anxiety has diminished.

#### 5.4.2. The acute versus the chronic model of Chronic Obstructive Pulmonary Disease

Patients are aware of family members' passivity in response to their disease until they are witness to an acute exacerbation where breathlessness is increased and symptoms become visible. These experiences are aligned with those of patients living with chronic pain who are also sensitive to the invisibility of pain arousing others' scepticism regarding the reality of symptoms and the lack of a diagnostic label heightens this issue (Holloway, Sofaer-Bennett, & Walker, 2007).

Despite patients' strong desire to communicate the seriousness of their disease, the watchful protection of family members does not seem welcome; instead patients consider it a barrier to maintaining independence and autonomy. This is a frequent dilemma in managing chronic progressive conditions which are punctuated by acute episodes.

To successfully maintain a level of autonomy and control patients and their carers need to understand the progressive and punctuated nature of the disease. This knowledge ought to be coupled with support for the appraisal and re-appraisal of their activities within the reference of their "*current circumstances*" which inevitably fluctuate (Mars, Proot, Janssen, van Eijk, & Kempen, 2007). Furthermore, the involvement of carers in patients' disease management may enable more effective collaborative strategies to be developed with awareness of family systems.

#### 5.4.3. An unpredictable and uncontrollable disease

The unpredictable and uncontrollable nature of acute exacerbations creates a constant state of hypervigilance to body changes and symptoms. Vigilance is also likely to be heightened by PR and self-management programmes which encourage self-monitoring of increased breathlessness, considered by patients to be a threatening sign for an acute exacerbation and death (Fan et al., 2012). Interestingly, patients with COPD showed improved functional exercise performance whilst listening to auditory stimuli (Singh et al., 2001; Bauldoff, Hoffman, Zullo, & Sciruba, 2002). Such findings suggest the role of interruptive cognitions in COPD and the mitigation of symptoms with functional benefits when attention is diverted. The use of distractive auditory stimuli during exercise programmes may have value in encouraging exercise behaviour which induces breathlessness, without provoking a fear response.

As well as feeling powerless in response to overwhelming symptoms at the time of an acute exacerbation. Patients disclose feeling factually ill-equipped with knowledge on discharge from hospital, prompting feelings of uncertainty. It has been suggested that there may be a pattern of cognitive dysfunction specific to COPD and furthermore, the ability of older adults to deliberate information is compromised due to the effect of aging (Peters, Hess, Vastfjall, & Auman, 2007; Dodd, Getov, & Jones, 2010). Health care professionals need to assist patients in asserting control over their disease by involving them further in partnership working. Furthermore, care needs to be continuous to reduce any inconsistency in health messages being delivered to patients. Steps towards adopting a consistent and 'lean' approach to patient care have been taken by the incorporation of the 'discharge care bundle' in some UK secondary care centers (Hopkinson et al., 2012). Constancy of health messages and multiple modes of delivery (verbal and written) may help to embed knowledge, overriding feelings of incompetence which pervade narratives discussing hospital discharge, supporting the role of collaborative working beyond acute interventions.

#### 5.4.4. Strengths and limitations

The search strategy employed ensured that articles relevant to the aims of the synthesis were identified from substantive databases. It is acknowledged that the synthesis may be limited by including only published papers and excluding 'grey literature'. The systematic identification and the critical appraisal of papers by three independent reviewers enhanced rigor. Although the process of synthesising is dependant upon the authors' interpretations, the involvement of two reviewers in verifying the second order constructs arguably improved robustness.

#### 5.4.5. Conclusions

Patients who have experienced an acute exacerbation of COPD report negative appraisals of symptoms which appear to adversely affect emotional arousal and vigilance. Patients express a strong desire to maintain autonomy yet struggle with a sense of powerlessness provoked by the unpredictability of the disease and overwhelming breathlessness and difficulties communicating the severity of symptoms. Ongoing interventions which are more attuned to psychological processes and morbidity, and are collaborative in acknowledging and addressing patients' fear and shaping appraisals, may mitigate distress, enhancing the impact of health messages. The prominence of distress reported by patients should also inform the timing and context of health messages to facilitate engagement in PR.

# **Chapter 6**

## **6. EXPLORING THE INTERACTION BETWEEN PSYCHOLOGICAL SYMPTOMS AND PULMONARY REHABILITATION**

The Hospital Anxiety and Depression Scale (HADS) is the most commonly applied tool to assess psychological morbidity in patients with Chronic Obstructive Pulmonary Disease (COPD). The original purpose of the study described in this chapter was to explore the effectiveness of Pulmonary Rehabilitation (PR), delivered in its current form, in reducing symptoms of anxiety and depression in patients with COPD and to assess the utility of the HADS in identifying patients able to successfully complete PR and those who are unable. Whilst it was not initially the intention of this chapter to question the HADS, the results prompted reflection on its utility, thus the content and structure of the questionnaire is considered. The findings from this chapter, the meta-synthesis (Chapter 5) and the literature presented in the narrative review (Chapter 3) contributed to the selection of the Illness Perceptions Questionnaire-Revised as a measure of psychological status in patients following an acute exacerbation of COPD.

### **6.1. Introduction**

COPD is a multi-organ disease, causing not only breathlessness but also a reduction in physical activity, limiting everyday tasks (Donaldson et al., 2005; Pitta et al., 2006a). Given its pervasive physical effects it is not surprising that the consequent reduction in quality of life experienced by patients can lead to associated psychological co-morbidities including symptoms of anxiety and depression (Cully et al., 2006).

A number of studies have reported that patients with COPD have an elevated prevalence of symptoms of anxiety and depression compared to that of normal populations (Karajgi, Rifkin, Doddi, & Kolli, 1990; van Ede, Yzermans, & Brouwer, 1999). A critical review of the literature conducted over a 15 year period estimates the prevalence

of anxiety and depression in patients with COPD as 36% and 40% respectively although these figures are wide ranging (7% to 46% for depression and up to 49% for anxiety) due to the variety in screening tools and classification (Yohannes et al., 2000).

In both research and clinical practice one of the most frequently used tools to assess psychological morbidity in patients with physical health problems is the HADS (Yohannes et al., 2010). Anxiety scores  $\geq 10$  points were identified in 32% of patients and depression scores  $\geq 10$  points were present in 27% (Janssen et al., 2010). A score of  $\geq 10$  points was thus considered by Janssen and colleagues (2010) as indicative of psychological symptoms. These percentages can be compared to the normative values produced for the HADS in a United Kingdom population: only 12.6% scored  $\geq 10$  on the anxiety subscale and 3.6% scored  $\geq 10$  on the depression subscale (Crawford, Henry, Crombie, & Taylor, 2001).

Importantly, increased symptoms of anxiety and depression have been associated with a number of adverse health outcomes in patients with COPD including; physical and functional impairment, increased symptom reporting, an increased risk of mortality, a reduction in quality of life, an increased risk of exacerbation of symptoms and an increase in health care utilisation (Brenes, 2003; Egede, 2007; Kim et al., 2000; Xu et al., 2008; Yohannes, Roomi, Waters, & Connolly, 1998; Yohannes, Roomi, & Connolly, 1998; Yohannes, Baldwin, & Connolly, 2005).

PR is central to the management of patients with COPD and the efficacy of the intervention in this patient group is widely recognised (Nici et al., 2006; National Institute for Clinical Excellence, 2010; Bolton et al., 2013; Griffiths et al., 2000; Lacasse et al., 2002). It has been recommended that part of the specific role of PR is to provide psychosocial support (Nici et al., 2006; Bolton et al., 2013). To date, the multi-factorial nature of a PR programme makes it difficult to explore which components of the programme may be most effective in reducing symptoms of anxiety and depression and improving quality of life. It is possible to theorise that in addition to the benefits of exercise on reducing physical impairment, the educational component increases coping skills and social support may also play an important role. One study examining the effect of a psychosocial intervention in the absence of an exercise programme found no



improvements were gained in psychosocial measures (Rose et al., 2002), suggesting that perhaps the most effective way of influencing psychosocial issues is to use a combination of strategies involving both exercise and education in addition to psychosocial support. The content of PR programmes provides a useful setting for implementing a psychosocial intervention.

Although meta-analysis has examined the effects of PR on symptoms of anxiety and depression in COPD the mean scores for anxiety and depression were either within the normal range or patients had mild symptoms (Coventry & Hind, 2007). Overall these findings are unsurprising; to be motivated to attend a programme of rehabilitation the majority of patients would be expected to be of stable mood. As a result it is only possible to interpret that PR is effective in reducing levels of anxiety and depression in those patients with mild symptoms. The efficacy of PR in treating more severe symptoms of anxiety and depression remains unproven (Coventry & Hind, 2007).

Despite the documented benefits of PR, 20-40% of patients do not complete the programme (Fischer et al., 2009; Garrod et al., 2006; Hogg et al., 2012; Hayton et al., 2012) leading to an inefficient use of valuable health resources and reducing opportunity to affect meaningful clinical change. Sociodemographic data and clinical variables have not been successful in predicting patient drop out in PR and psychosocial measures may have a greater predictive value (Garrod et al., 2006; Fischer et al., 2009; Selzler et al., 2012). It has previously been suggested that depression as assessed using the Brief Assessment Schedule for Depression Cards (BASDEC) and the SF36 has an impact on patients dropping out of a PR programme (Fan et al., 2008; Garrod et al., 2006) yet, no studies have used the HADS to identify psychological symptoms and linked these to outcomes of PR, including drop out. Given the variance in prevalence of psychological symptoms reported by various tools it appears sensible to examine the predictive value of the HADS as it is the most frequently applied tool to assess psychological status in patients with COPD and serves as an outcome measure in PR programmes (Yohannes et al., 2010).

In addition to concerns about drop out there is evidence that approximately 30% of patients achieve little or no clinical benefit in terms of health status or exercise

performance (Garrod et al., 2004). A variety of variables including self-efficacy and depression, have shown no predictive status in improving exercise performance or health status following a PR programme (Garrod et al., 2006). However, to date the impact of anxiety on the achievement of a clinical benefit has not been explored. Recently anxiety has been found to be related to poorer health outcomes including sub-maximal exercise tolerance in patients with COPD (von Leupoldt et al., 2011; Eisner et al., 2010). However, these results were derived from observational data and were not analysed in response to a PR programme. It remains unclear how symptoms of anxiety specifically, relate to a patients' ability to achieve a clinically meaningful improvement in exercise performance following PR.

This chapter reports a study exploring the effectiveness of PR in reducing symptoms of anxiety and depression across a spectrum of psychological severities. A secondary objective was to examine the utility of the HADS in identifying patients able to successfully complete PR and those who are unable.

## **6.2. Methods**

### **6.2.1. Study design**

The study used principles of comparative effectiveness research (CER). CER aims to improve the quality, effectiveness and efficiency of health care by helping to inform clinical strategies. This appeared to be an appropriate analysis to undertake given the study aim of examining the efficacy of an intervention on an outcome which is relevant across multiple conditions (Tinetti & Studenski, 2011). Despite the consideration of CER principles, the study is of a retrospective observational study design. Data was collected on patients who attended an initial assessment for an outpatient PR programme at a single centre within an acute trust in the East Midlands between January 1999 and January 2010. Patients gave consent for data to be recorded on a PR database. This data comprised of demographic and anthropometric variables, lung function results, walking test results and self-reported measures of self-efficacy, anxiety and depression and health status. The walking tests and self-reported measures were repeated on completion of the PR programme and all data were stored on one database.

### 6.2.2. Ethics approval

This study was assessed as being a service evaluation by the chair of the appropriate ethics committee and therefore was not required to have ethical approval under the National Health Service research governance arrangements.

### 6.2.3. Study population

A total of 518 patients were identified from the database using the following inclusion criteria: a physician confirmed diagnosis of COPD, obstructive spirometry (Global Initiative for Chronic Obstructive Lung Disease (GOLD) stage  $\geq 2$ ) and a recorded HADS score.

### 6.2.4. Measures

#### *6.2.4.1. The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) (Appendix B)*

The HADS comprises of 14 statements relating to either general anxiety or depression and was developed to assess psychological morbidity in hospital outpatients. The questionnaire is a valid measure, commonly used in the self-reported assessment of patients with COPD being quick to complete. Questions are scored on a four point likert scale ranging from zero to three and are divided into two subscales: (anxiety ( $\alpha = .68$ ) and depression ( $\alpha = .91$ )) which are scored between zero and 21 (Zigmond & Snaith, 1983). Each subscale was analysed separately and divided into three predefined and validated groups; scores of zero to seven were considered to be in the normal range, a score of eight to 10 suggested a probable presence of anxious or depressed state and scores higher than 11 were indicative of a presence of psychological 'caseness'. The minimal clinically important difference (MCID) for a change in each subscale has been established in patients with COPD and quoted as -1.5 (Puhan, Frey, Buchi, & Schunemann, 2008).

#### 6.2.4.2. *Chronic Respiratory Questionnaire – Self Reported (Williams et al., 2001)* (Appendix C)

The Chronic Respiratory Questionnaire (CRQ) is an established measure of health status which was originally interviewer led making it time consuming to administer. The basic structure, content and scoring of the Chronic Respiratory Questionnaire – Self Reported (CRQ-SR) is exactly the same as the CRQ but patients are required to tick an appropriate answer on a questionnaire rather than responding to the interviewer, reducing completion time to approximately 10 minutes. The CRQ-SR measure has been found to be a valid and reliable measure of health status in patients with COPD and has been used extensively both clinically and for research purposes (Williams, Singh, Sewell, & Morgan, 2003). The CRQ-SR is divided into four dimensions: dyspnoea ( $\alpha = .51$ ), fatigue ( $\alpha = .78$ ), emotion ( $\alpha = .81$ ) and mastery ( $\alpha = .83$ ) (Wijkstra et al., 1994). Mean score is calculated per dimension providing a range between one and seven, a higher score indicates better health status (Williams et al., 2001). The MCID for a change in each domain has previously been described as 0.5 (Jaeschke, Singer, & Guyatt, 1989).

#### 6.2.4.3. *The Incremental Shuttle Walking Test (Singh et al., 1992)*

The Incremental Shuttle Walking Test (ISWT) is an objective test of maximum exercise capacity and requires subjects to walk up and down a 10 metre course which is marked out by two cones placed nine metres apart. The walking speed is externally paced and dictated by a pre-recorded audio signal (a ‘bleep’). The test is terminated due to symptoms, failure to maintain walking speed or completion. The maximum distance achievable is 1020m. The test is repeated after a 30 minute rest on the same day (Singh et al., 1992) and peak distance achieved from the two tests is recorded (m).

#### 6.2.5. The Pulmonary Rehabilitation programme

The content of PR programmes in accordance with national and international guidelines is discussed in Chapter 2 (Bolton, 2013; Nici et al., 2006). A detailed description of the PR programme run at the acute trust within the East Midlands follows: The outpatient

PR programme was delivered by a multidisciplinary team. Patients were required to attend twice a week for seven weeks. Sessions lasted two hours; the first hour consisted of an exercise programme and the second hour involved patient education. The exercise programme involved endurance training in the form of walking and stationary cycling. Strength exercises were carried out once a week. The education sessions covered; dietary advice, disease education, relaxation techniques, exercise advice, avoiding exacerbations, energy conservation, chest clearance, breathing control and medication management. The sessions were run by the appropriate health care professional. Following the seven week programme patients were required to attend a discharge appointment where the outcome measures were re-assessed.

#### 6.2.6. Data collection

Data was recorded at the time of the patient's initial assessment for a PR programme and again at their discharge appointment (seven weeks later) following completion of the PR programme.

Patients were divided into 'completers' of PR' and 'drop outs' from PR. 'Completers' will have attended 14 sessions of PR before completing their discharge assessment. A very strict criterion was applied and the latter was defined as those who did not attend their discharge assessment following PR. Patients who completed the PR programme were then further subdivided into 'responders' and 'non-responders'. 'Responders' were defined as improving by at least the MCID of the ISWT following PR, previously defined as 48m (Singh, Jones, Evans, & Morgan, 2008). 'Non-responders' did not achieve the MCID of the ISWT following PR.

#### 6.2.7. Statistical analysis

The data was checked by two researchers and incorrect data was removed. Analyses were carried out using SPSS 18.0 for Windows (SPSS Inc, Chicago, USA). A paired t-test was conducted on those who completed the PR programme to analyse the effect of PR on anxious and depressed symptoms as measured by the HADS. To analyse the effectiveness of PR in reducing anxiety and depression in patients with various

severities of symptoms ('none', 'probable', 'presence') an Analysis of Variance with a Bonferroni post-hoc analysis was applied to look at the differences in change in HADS scores between groups. Due to multiple comparisons post-hoc significance levels were set at  $p < 0.017$ .

Characteristics between PR completers and drop outs were compared using independent t-tests for continuous data and chi squared for categorical data. Correlations between baseline characteristics and completion or drop out and baseline characteristics and responders or non-responders were identified using Pearson's Correlation coefficients.

### **6.3. Results**

#### **6.3.1. Patient population**

This comprised 518 patients (310 male) with a mean (SD) age of 69.2 years ( $\pm 8.8$  years) (Table 5). Divided into the three categories ('none', 'probable' and 'presence'), the prevalence for anxious symptoms was 48.5%, 24.3% and 27.2% and for symptoms of depression was 60.9%, 21.7% and 17.4% respectively.

**Table 5. Baseline variables for the total population and each sub-group**

	<b>Total group (n=518)</b>	<b>None</b>		<b>Probable</b>		<b>Presence</b>	
<b>Mean (SD)</b>		<b>Anxiety</b>	<b>Depression</b>	<b>Anxiety</b>	<b>Depression</b>	<b>Anxiety</b>	<b>Depression</b>
<b>HADS</b>		4.28 (2.18)	4.49 (1.86)	9.00 (0.81)	8.90 (0.79)	13.31 (2.23)	12.83 (2.02)
<b>Gender (% male)</b>	57.49%	58.58%	58.28%	61.90%	56.36%	60.28%	69.32%
<b>Age</b>	69.23 (8.80)	69.57 (8.63)	69.30 (8.50)	69.12 (9.50)	69.77 (8.96)	68.70 (8.49)	68.28 (9.60)
<b>FEV<sub>1</sub> % predicted</b>	39.89 (15.10)	39.68 (15.21)	39.50 (14.55)	40.24 (16.42)	41.46 (16.32)	39.94 (13.73)	39.06 (15.42)
<b>MRC</b>	4 IQR 3-4	4 IQR 3-5	3 IQR 3-4	3 IQR 3-4	3 IQR 3-4	4 IQR 3-5	4 IQR 3-5
<b>BMI</b>	26.24 (5.69)	26.20 (5.99)	26.00 (5.96)	25.88 (5.36)	25.92 (5.16)	26.64 (5.43)	27.12 (5.48)
<b>Pack years</b>	41.67 (24.64)	43.55 (25.01)	42.85 (23.79)	42.66 (23.71)	39.44 (26.73)	42.66 (23.71)	42.21 (24.15)
<b>Social status (% living alone)</b>	27.66%	27.54%	29.02%	28.85%	26.19%	26.79%	24.66%
<b>ISWT (m)</b>	208.32 (130.95)	200.91 (137.42)	206.15 (132.90)	209.09 (115.12)	210.09 (120.72)	220.43 (132.23)	211.49 (138.61)
<b>CRQ-SR Dyspnoea</b>	2.35 (0.93)	2.30 (0.95)	2.28 (0.94)	2.42 (0.87)	2.48 (0.94)	2.37 (0.96)	2.45 (0.95)
<b>CRQ-SR Fatigue</b>	3.29 (1.29)	3.22 (1.32)	3.23 (1.29)	3.40 (1.30)	3.40 (1.26)	3.33 (1.24)	2.45 (0.95)
<b>CRQ-SR Emotion</b>	4.19 (1.25)	4.10 (1.23)	4.12 (1.28)	4.18 (1.26)	4.20 (1.28)	4.40 (1.26)	4.34 (1.22)
<b>CRQ-SR Mastery</b>	4.21 (1.35)	4.11 (1.33)	4.13 (1.35)	4.28 (1.40)	4.31 (1.37)	4.34 (1.32)	4.29 (1.30)

SD = Standard deviation; HADS = Hospital Anxiety and Depression Scale, categories ‘none’ 0-7, ‘probable’ 8-10, ‘presence’ 11-21; FEV<sub>1</sub> = Forced Expiratory Volume in One Second; MRC = Medical Research Council; BMI = Body Mass Index; IQR = Inter Quartile Range. ISWT = Incremental Shuttle Walk Test; CRQ-SR = Chronic Respiratory Questionnaire-Self Reported.

### 6.3.2. The effect of Pulmonary Rehabilitation on anxiety and depression

Before PR the mean (standard deviation (SD)) score for patients who completed the programme was 7.99 (4.10) for anxiety and 6.80 (3.56) for depression. These scores reduced following PR to 6.72 (3.72) and 5.74 (3.45) respectively (both  $p < 0.001$ ). Although significant, the reduction in HADS score for both subscales did not reach the MCID.

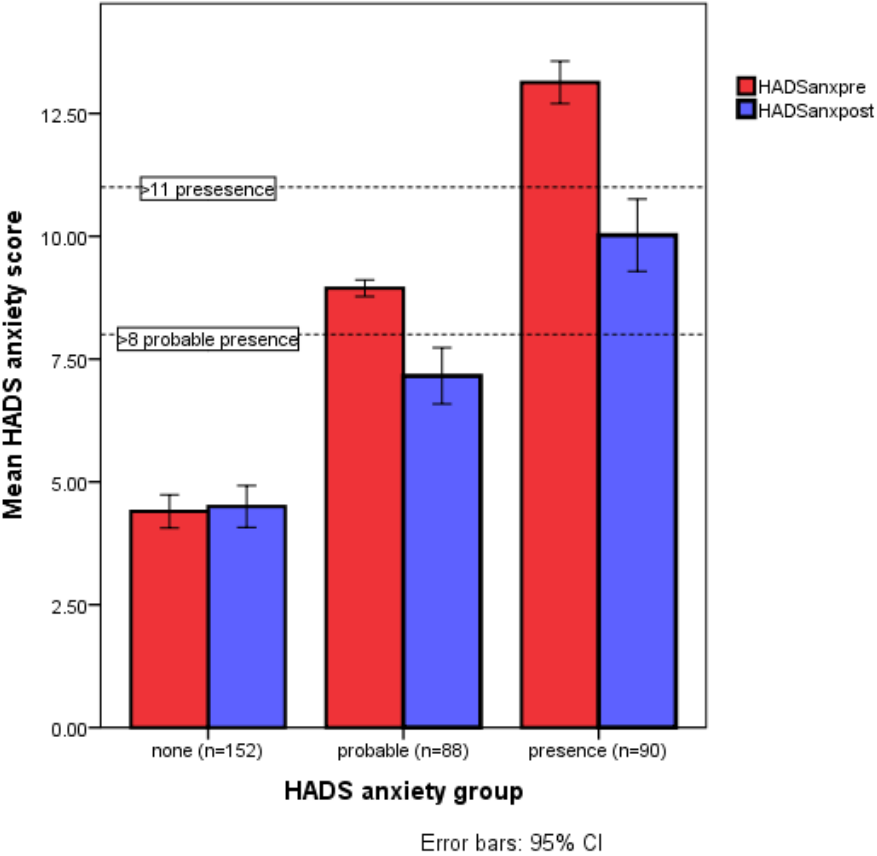
Figures 2 and 3 display the effectiveness of PR in reducing anxiety and depression in patients with various severity of symptoms.

There was no significant difference in changes in anxiety or depression following PR in patients with no evidence of anxiety or depression (none: anxiety mean (standard error) 0.99 (0.19), depression -0.25 (0.14),  $p > 0.05$ ). Patients with a probable or definite presence of psychological symptoms had significantly reduced levels of anxiety and depression following PR (probable: anxiety -1.78 (0.27), depression -1.71 (0.34), presence: anxiety -3.11 (0.35) depression -3.19 (0.47),  $p < 0.001$ ). This reduction is greater than the MCID of  $> -1.5$  for both anxiety and depression.

There was a significant difference between groups in change for both anxiety and depression ( $p < 0.001$ ). Post-hoc analysis demonstrated significant differences between all subgroups for both anxiety and depression (all  $p < 0.004$ ) with patients scoring highest having the greatest reductions.

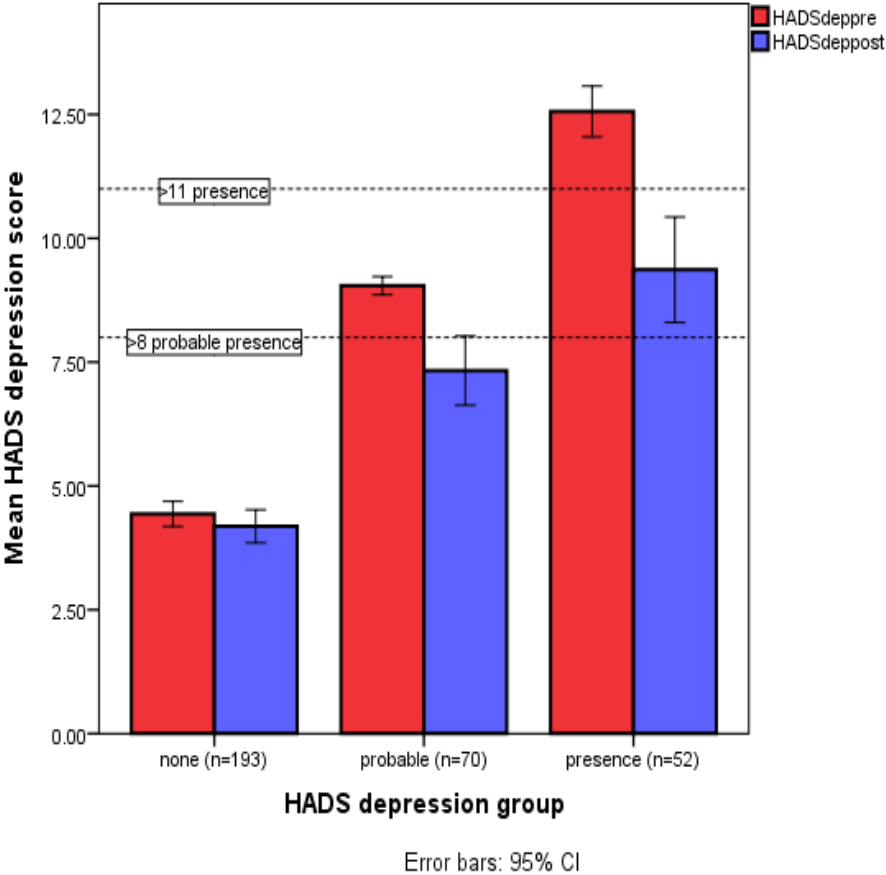


**Figure 4. Anxiety pre and post Pulmonary Rehabilitation**



Hospital Anxiety and Depression Scale (HADS) anxiety score pre and post Pulmonary Rehabilitation in three groups categorised according to baseline HADS anxiety score: 'none' 0-7, 'probable' 8-10, presence '11-21'.

**Figure 5. Depression pre and post Pulmonary Rehabilitation**



Hospital Anxiety and Depression Scale (HADS) depression score pre and post Pulmonary Rehabilitation in three groups categorised according to baseline HADS depression score: 'none' 0-7, 'probable' 8-10, presence '11-21'.

Another way of looking at this data is to examine how many patients remain in the same category ('none', 'probable', 'presence') for anxiety and depression despite completing PR. Although the majority of patients either stayed in the same category or had reduced symptoms, it is interesting to note that a proportion of patients develop symptoms of anxiety and depression, over the course of a PR programme (Table 6).

**Table 6. Patients' movement between the Hospital Anxiety and Depression Scale categories before and after Pulmonary Rehabilitation**

Category of anxiety/depression	Anxiety		Depression	
	N	%	N	%
<b>None-None</b>	131	86	176	91
<b>None-Probable</b>	19	13	15	8
<b>None-Presence</b>	2	1	2	2
<b>Probable – None</b>	47	53	33	47
<b>Probable – Probable</b>	32	36	30	43
<b>Probable – Presence</b>	9	10	7	10
<b>Presence – None</b>	24	27	16	31
<b>Presence – Probable</b>	24	27	15	29
<b>Presence – Presence</b>	42	47	21	40

Hospital Anxiety and Depression Scale score categorised according to severity of symptoms ('none' 0-7, 'probable' 8-10, 'presence' 11- 21.). The number and % of patients moving between each sub-group.

There were no significant differences between any baseline variables or change in ISWT distance or CRQ-SR scores following PR between any of the three groups for anxiety or depression (Table 7).

**Table 7. Changes in outcome measures between the three groups for anxiety and depression**

<b>Groups (HADS score)</b>		<b>None</b>		<b>Probable</b>		<b>Presence</b>		<b>P value</b>	
<b>Sub-groups</b>		<b>Anxiety</b>	<b>Depression</b>	<b>Anxiety</b>	<b>Depression</b>	<b>Anxiety</b>	<b>Depression</b>	<b>Anxiety</b>	<b>Depression</b>
<b>Outcome measures (mean change (SD))</b>	ISWT distance (m)	64.38 (71.97)	57.76 (67.72)	65.44 (59.29)	66.30 (72.26)	59.47 (71.88)	69.15 (65.01)	0.817	0.434
	CRQ-SR dyspnoea	0.94 (1.10)	0.87 (1.04)	0.74 (1.01)	0.78 (1.08)	0.86 (1.03)	0.98 (1.10)	0.496	0.648
	CRQ-SR fatigue	0.75 (1.28)	0.86 (1.24)	0.77 (1.08)	0.61 (1.17)	0.82 (1.29)	0.77 (1.30)	0.912	0.395
	CRQ-SR emotion	0.79 (1.15)	0.80 (1.15)	0.85 (0.97)	0.66 (1.06)	0.48 (1.13)	0.57 (1.14)	0.690	0.360
	CRQ-SR mastery	0.77 (1.21)	0.77 (1.31)	0.77 (1.26)	0.57 (0.95)	0.59 (1.16)	0.74 (1.25)	0.511	0.517

SD = Standard Deviation; ISWT = Incremental Shuttle Walking Test; CRQ-SR = Chronic Respiratory Questionnaire-Self-Reported; HADS = Hospital Anxiety and Depression Scale, categories 'none' 0-7, 'probable' 8-10, 'presence' 11-21.

### 6.3.3. The influence of symptoms of anxiety and depression on drop out

Of the 518 patients who attended their initial assessment for PR 184 dropped out (35.5%). Completers and drop outs did not differ significantly in any of the baseline variables except pre ISWT distance ( $p=0.003$ ). Patients who went on to complete the programme achieved greater distances on the ISWT at baseline (mean (SD) 220m (136.14)) than those who subsequently dropped out (185m (117.07)).

There was no correlation between either HADS anxiety score ( $p>0.05$ ) or HADS depression score ( $p>0.05$ ) and completion of PR. The HADS subscales correlated highly with each other ( $r=0.59$ ,  $p<0.001$ ). A weak correlation was found between completion and pre ISWT distance ( $r=0.13$ ,  $p<0.05$ ) and CRQ-SR fatigue ( $r=0.26$ ,  $p<0.05$ ).

### 6.3.4. The influence of symptoms of anxiety and depression on exercise performance

Three hundred and thirty four patients completed the PR programme. One hundred and ninety seven (59%) achieved an improvement of  $>48$ m (MCID) on the ISWT. There was a significant difference between responders and non-responders in age (responders 68.42 years (SD 8.56), non-responders 70.92 years (7.71),  $p=0.007$ ). There was no difference in any other baseline measures, including HADS score.

## **6.4. Discussion**

This is the first study to examine the effect of PR on severe symptoms of anxiety and depression. Results show that following PR HADS scores are significantly reduced in those patients who present with symptoms of anxiety and/or depression at baseline.

Symptoms of anxiety and depression are high in COPD patients and the extent of psychological morbidity in the current study population is similar to previously found (Coventry & Hind, 2007). Although a previous study conducted in a PR cohort has divided HADS scores according to severity of symptoms the outcomes of PR were not considered (Janssen et al., 2010).

Previous research summarised by a meta-analysis has described the effects of PR on symptoms of anxiety and depression in COPD. However, the mean scores were either within the normal range or patients had only mild symptoms (Coventry & Hind, 2007). As a result it was only possible to interpret the effects of PR on reducing levels of anxiety and depression in those patients with mild symptoms. The efficacy of PR in treating more severe symptoms of anxiety and depression remained unproven. These results suggest that the biggest reduction in HADS scores following PR occurred in the group of patients displaying the most severe symptoms of anxiety and depression.

Furthermore, patients whose baseline HADS score indicated no symptoms of anxiety and depression unsurprisingly did not have a significant change in HADS score following PR. These results indicate that previous studies examining the effect of PR on symptoms of anxiety and depression in all patients with COPD, including those with no symptoms, may have underestimated the effectiveness of the PR programme.

Whilst this study showed that PR significantly reduced symptoms of anxiety and depression in those with a HADS score of  $\geq 11$ , a percentage of patients still had HADS scores  $\geq 8$  following PR. This is displayed in Figures 2 and 3. Table 6 displays the movement of patients between categories before and following PR. Forty seven percent and 40% of patients who had a 'presence' of anxious and depressed symptoms respectively before PR still had a 'presence' of symptoms despite the completion of the programme. This suggests that some patients may require additional interventions to reduce their symptoms of anxiety and depression to within the normal range. Interestingly although the majority of patients remained in the same category before and after PR a small percentage of patients had an increase in mood disorder. This effect may be a result of patients' increased recognition of breathlessness following PR which encourages the monitoring of breathless symptoms perhaps promoting hypervigilance. It is likely that knowledge gained through the education programme concerning end of life issues increases awareness of the disease process. This awareness may also be promoted by seeing patients in a much more advanced stage of the disease. Downward assimilation has been recognised in a PR population and found to enhance social comparisons and anxious mood (Petersen, Taube, Lehmann, van den Bergh, & von Leupoldt, 2012). An additional intervention may have a role in alleviating these concerns by shaping the association patients make with additional knowledge.

In keeping with previous data (Fischer et al., 2009; Garrod et al., 2006), results showed a high percentage of patients did not complete PR (35.5%) with such attrition it is likely that the health benefits patients obtained from PR were compromised. Whilst in this study, drop out rate is slightly higher than some previously reported (Garrod et al., 2006) variability may be explained by variation in the way a 'completer' is defined. Like Fisher et al, this study applied strict criteria; patients were required to attend their follow up appointment to be classified as a 'completer', yet still drop out rate is higher than what they reported (23%) (Fischer et al., 2009). Discrepancy may well be ascribed to our exclusion of inpatients.

Results did not show symptoms of depression to be a predictor of drop out, differing from Garrod et al's work who reported the risk of drop out to be higher in depressed patients (Garrod et al., 2006). However, they classified patients using the BASDEC rather than the HADS. The wide range of tools used to screen for symptoms of anxiety and depression makes it difficult to reach a consensus regarding the characteristics of patients with symptoms (Yohannes et al., 2010). The HADS has been reported to be the most frequently-used tool in patients with COPD (Yohannes et al., 2010). Arguably it is still a very crude measurement tool. In a recent systematic review the greatest number of studies indicated a two-factor structure: anxiety and depression (Cosco, Doyle, Ward, & McGee, 2012), however there have been many proponents of a three-factor structure with the anxiety component consisting of negative affectivity and autonomic arousal (Martin, 2005; Friedman, Samuelian, Lancrenon, Even, & Chiarelli, 2001; Dunbar, Ford, Hunt, & Der, 2000). Certainly, it is difficult to avoid the automatic arousal of the anxiety subscale which could be potentially acting as a confounding variable. There is conflicting opinions regarding whether the use of the HADS should be abandoned all together but the variability of psychometrics applied to analyse data sets makes it difficult to draw definitive conclusions (Coyne & van Sonderen, 2012; Straat, van der Ark, & Sijtsma, 2013).

In particular, the appropriateness of the HADS in specific patient groups has been questioned (Johnston, Pollard, & Hennessey, 2000). There are certainly issues with its application in patients with respiratory disease. One question asks patients to indicate how often 'they feel slowed down'. The majority of patients will answer 'nearly all the time' scoring the maximum number of points on the four point scale (0-3). Patients with

COPD often feel slowed down as a result of their disease leading clinicians to question its usefulness as an indicator of mood state in this population.

The HADS collected in patients for whom COPD is stable (Chapter 6) was compared with patients, with an acute exacerbation of COPD, who completed the HADS immediately following hospital discharge. We might imagine that psychological morbidity would be higher in a population of patients who have recently suffered from severe symptoms of breathlessness and are reluctant to engage in PR. However, no significant differences were found between the two groups for either anxiety or depression. These results are surprising and are in contrast to literature supporting heightened symptoms of anxiety and depression in patients after an acute exacerbation of COPD (Dowson et al., 2001; Gudmundsson et al., 2005). Furthermore, a recent systematic review, consisting of 20 studies, found that increased symptoms of anxiety and depression lead to a greater risk of patients being hospitalized with an acute exacerbation. One of the limitations of this review is the heterogeneity of the included studies, particularly in relation to outcome measures, although the HADS was the most frequently applied. The lack of significant differences detected between the two patient populations may be associated with a number of factors. Firstly, all patients (stable and post-exacerbation) had received intervention from a specialised respiratory hospital. There was a large variation in sample size (stable  $n=500$  versus post-exacerbation  $n=86$ ) although equal variances were assumed. The time the data were collected also varies considerably with a proportion of the data collected over a decade ago on patients whose COPD is stable. We would hope that over this period of time health care professionals have become better at detecting and attending to patients' psychological requirements. Finally, these results may be a further indication that the HADS is not the best measures to detect the sophisticated psychological disturbances prevalent in patients with COPD, particularly following an acute exacerbation.

No correlation was revealed between either anxiety or depression and completion of PR. Unsurprisingly the two HADS subscales correlated highly with each other, the commonality of clinical symptoms of anxiety and depression has long since been established (Stavrakaki & Vargo, 1986). Previously one study has reported the St Georges Respiratory Questionnaire (SGRQ) to predict drop out ( $p=0.02$ ). This study included a much smaller sample size (Garrod et al., 2006). The SGRQ is a disease-

specific tool unlike the HADS. Perhaps when attempting to predict drop out it is important to use a tool which is specific to the patient population. However, the only correlation found using the CRQ-SR (a disease specific measure) was between the dimension of fatigue and completion of PR and this correlation was very weak.

Exercise performance was assessed using the ISWT. Forty one percent of patients did not achieve a change in ISWT distance that related to a MCID of 48m. This percentage can be compared to Garrod et al's (2006) group of patients where only 23% did not improve following PR, although exercise performance was measured by six minute walk distance (6MWD) rather than the ISWT.

Although anxiety has been found to be related to poorer health outcomes including sub-maximal exercise tolerance in patients with COPD (Eisner et al., 2010; von Leupoldt et al., 2011) no influence of anxious or depressive symptoms was found regarding improvement in exercise performance following PR. Similar findings were reported by Garrod et al (2006) (Garrod et al., 2006). Baseline ISWT distance and age appeared to be the only factors that differed between responders and non-responders. Cilione et al (2002) also found that lower initial walking distance was predictive of a greater change in walking distance after rehabilitation (Cilione et al., 2002). Younger people were perhaps more likely to improve in exercise performance because they had greater incentives for improvement, i.e. get back to work or look after a young family, whereas older people could attribute a reduction in exercise performance, in part, to the natural aging process.

The findings from this study indicate that symptoms of anxiety and depression do not influence the outcomes of PR. With this in mind it would appear that the delivery of psychological support designed to reduce symptoms of anxiety and depression is not necessary before PR but instead could run alongside or afterwards. The concept of a stepped-care approach to patient care could be adopted where psychological strategies are implemented with those patients screened at the outset as having a presence of anxiety and/or depression. Integrating psychological support in PR is likely to reduce any possible stigma and encourage patients to take up such support. Targeting treatment to patients' needs is a cost effective patient-centred approach to delivering patient care



and is a notion supported by the national guidelines for COPD (Department of Health, 2010b; National Institute for Clinical Excellence, 2010).

The apparent ineffectiveness of the HADS in identifying clinical outcomes of PR for patients with COPD raises questions regarding the appropriateness of the scale. Perhaps a more sensitive tool is required to screen for patients likely not to complete a programme. It is important to understand how patients who are unable to complete a programme differ from those who are successful. This information can inform the content of interventions designed to promote adherence to disease management strategies.

A systematic review conducted in patients with COPD found illness perceptions which attributed many symptoms, perceiving a low sense of control and strong emotional representations were found to be associated with poorer health outcomes. Specifically, increased disability, reduced quality of life and higher anxiety and depression (Kaptein et al., 2008). Since this review studies conducted in other chronic conditions including: diabetes and post myocardial infarction (MI) found that patients who exhibited a high sense of personal and treatment control but who also viewed their illness to be serious were the most likely to have positive health outcome and adhere to health promoting behaviour (Alsen et al., 2010; Skinner et al., 2011). These findings would suggest that patients' illness perceptions may have a role in their successful completion of PR and as a result should be routinely assessed.

A study conducted on patients post MI found approximately 20% more patients attended cardiac rehabilitation if they had completed an intervention designed to shape illness perceptions (Petrie, Cameron, Ellis, Buick, & Weinman, 2002). There is increasing support for the development of tailored interventions designed to shape patients' illness perceptions, yet, to date, no such interventions have been applied to patients with COPD.

#### 6.4.1. Strengths and limitations

This study is not without limitations. Larger changes were seen in groups with higher HADS scores. This could be an effect of regression to the mean, but this effect is

clinically understandable. No inferences regarding the long term effects of PR on symptoms of anxiety and depression measured using the HADS can be made. Interestingly, other data shows that although PR was effective in reducing symptoms of anxiety and depression in the short term, these improvements were not maintained over a 12 month period following PR (Griffiths et al., 2000). A more tailored, psychologically-focused intervention may have a role in mitigating symptoms of anxiety and depression over a more sustained period.

#### 6.4.2. Conclusions

PR appears to be effective in reducing symptoms of anxiety and depression. By including patients with no symptoms previous studies may have underestimated the effectiveness of the PR programme in reducing anxiety and depression. However, following PR severe symptoms were not reduced to a level which represents no presence of anxiety or depression. This indicates that symptoms of anxiety and depression may not be adequately addressed before patients are discharged from PR. Although, no relationship between baseline HADS scores and outcomes of PR was established, an intervention designed to reduce symptoms of anxiety and depression is unlikely to improve outcomes of PR. It ought to be considered that the HADS may not be the best tool to explore psychological symptoms and predict success of PR in patients with COPD. Evidence would suggest a more sophisticated tool may provide more useful information regarding attendance to PR and inform the content of tailored interventions designed to promote health behaviour.

# **Chapter 7**

## **7. CONCEPTUALISATION OF A MIXED-METHODS RESEARCH DESIGN**

As argued in previous chapters a comprehensive assessment of patients amenability to Pulmonary Rehabilitation (PR) may be benefited by greater understanding of patients' appraisals and interpretations of symptoms, rather than cruder reliance on biomedical indices and generically deployed tools such as the Hospital Anxiety and Depression Scale (HADS). With this in mind, methodology is required to be able to successfully explore patients' 'meaning making' process following an acute exacerbation, and its potential impact on intervention development for those with Chronic Obstructive Pulmonary Disease (COPD) is considered. Beginning with a description of conceptualisation of the research design, this chapter describes and justifies the approaches which were adopted in the subsequent studies. The critical synthesis, described in Chapter 5, served to inform and verify the concepts for investigation. Following an acute exacerbation where shortness of breath is increased, patients' appraisals appear to reflect intense fear, increased arousal and hypervigilance as well as feelings of powerlessness, seeming to question the simple and uniform application of post-exacerbation PR. A general review of various psychological theories suggests that the manner in which patients perceive acute exacerbations can impact on subsequent health behaviour (Chapter 3). Such theories resonate with research conducted in patients whose COPD is stable (Chapter 3). It was therefore necessary to design a research study which was firstly able to explore experience and secondly was able to assess patients' illness perceptions in a large population.

### **7.1. Research design**

An observational mixed-methods design was considered appropriate for addressing the research aims.

Currently the field of mixed-methods is poorly defined. Following examination of the existing literature Johnson et al (2007) put forward the following definition:

*“Mixed-methods is an intellectual and practical synthesis based on qualitative and quantitative research. It recognises the importance of traditional quantitative and qualitative research but also offers a powerful third paradigm choice that often will provide the most informative, complete, balanced and useful research results. Furthermore, the mixed-methods research paradigm offers an important approach for generating important research questions and providing warranted answers to those questions”* (Johnson, Onwuegbuzie, & Turner, 2007).

Mixed-methods research is becoming increasingly popular, it capitalises on the various strengths and minimises the weaknesses of qualitative and quantitative research by synthesising ideas from both methodological techniques. ‘Purists’ would argue that quantitative and qualitative research paradigms cannot and should not be mixed and attempts to do so undermine the assumptions of the underlying research methods. However, mixed-method researchers advocate that research methods are autonomous and the use of mixed-methods increases confidence in findings, thickens and enriches data and uncovers contradictions (Jick, 1979).

Mixed-methods research has been successful in formulating hypothesis and informing the development of health interventions (e.g. for persons with Human Immunodeficiency Virus) (Nicca, Fierz, Happ, Moody, & Spirig, 2012; Petros, 2012). Given that the overall aim of this thesis is to inform how a PR intervention may be facilitated and enhanced, a mixed-methods approach seemed appropriate.

Triangulation (the use of multiple methods) is the most common approach to this research strategy, put forward by Webb (1966) and formed around Campbell and Fiske’s (1959) idea of ‘multi-operationalism’ (Campbell & Frisk, 1959; Webb, Campbell, Schwartz, & Sechrest, 1999). They argue that more than one technique should be used in the validation process to ensure that any variance is the result of an underlying phenomenon or trait. Morse (1991) proposed two types of methodological triangulation: simultaneous and sequential (Morse, 1991). Simultaneous triangulation refers to the complementary use of qualitative and quantitative methodologies to assist

with the interpretation of findings. Sequential triangulation is applied to inform planning for the next method. The construction of a mixed-method design depends on whether one wants to operate largely within a dominant paradigm (i.e. focus on qualitative or quantitative methodologies) or not (equal status) and whether one wants to conduct the phases simultaneously or sequentially. As the purpose of this thesis is to explore and increase understanding, qualitative research and quantitative research were conducted simultaneously (QUAL - QUAN) and both techniques given equal status.

Greene et al (1989) put forward a further four purposes for applying a mixed-methods approach in addition to triangulation. These include: a complementarily purpose, seeking elaboration and enhancement of the results from one method with the results from another; a developmental purpose, using the results from one method to inform another; the purpose of initiation, which involves discovering contradictions that lead to reframing of the research question; and finally, the purpose of expansion, seeking to expand the breath and range of enquiry (Greene, Caracelli, & Graham, 1989). For the subsequent studies triangulation and an expansion approach were assumed with the aim of the qualitative research being to obtain in-depth information and the aim of the quantitative data being to expand the range of enquiry.

## **7.2. Approval of the research protocol**

Although the research concepts are well informed, being based on; an overview of the literature, findings from a critical synthesis and a retrospective observation using a current tool to assess psychological morbidity, approval for the proposed research was sought from two sources: Patient Public Involvement (PPI) group members and the appropriate ethical committees.

### **7.2.1. Patient and Public Involvement group**

The use of PPI groups has become an important component in all research activity since the formation of a support group: “Consumers in National Health Service Research” (1996) who in 2003 became INVOLVE. The aim is to ‘involve’ patients in the production of research; improving the way it is prioritised, undertaken and disseminated

(Blackburn, Hanley, & Staley, 2010). Basing research on the feedback from PPI members can also enrich ethical dimensions (Staley & Minogue, 2006).

A PPI group consisting of four healthy volunteers and seven patients was included throughout the study process (Appendix D). Prior to seeking ethical approval the PPI group were gathered at a meeting where the study protocol was presented and feedback regarding the usefulness of the research was provided (Appendix E). All members expressed the view that the research was important and appropriate and that they would be happy to be involved throughout the study period.

Furthermore, prior to beginning the recruitment of patients, members of the PPI group were asked to review the patient information sheets for issues regarding the clarity of information supplied. Alterations were made in light of the feedback provided (Appendix F).

#### 7.2.2. Ethical approval

Before data collection could commence all procedures for the experimental methods had to be approved by the research ethics committee (approval no. 11/EM/0089) (Appendix G.i) and the Comprehensive Local Research Network (approval no. 71766) (Appendix G.ii). Approval was received in July 2011

Ethical approval for a substantial amendment to allow for the recruitment of patients who had completed PR in the previous 12 months was submitted in December 2011 and approval was confirmed by both ethics committees February 2012. Theory suggests that the experience of an acute exacerbation of COPD influences the manner in which patients appraise their illness. Therefore, the experience of completing PR prior to an acute exacerbation is expected to have no bearing on patients' illness appraisals following the acute event. Furthermore, literature and an audit of our own service suggests that PR has only a modest effect in altering the way in which patients appraise their disease (Fischer et al., 2010; Harrison, Robertson, Williams, Steiner, & Singh, 2012).

### **7.3. Qualitative methodology**

The following section will describe and justify the decisions made regarding the conduction of the qualitative study.

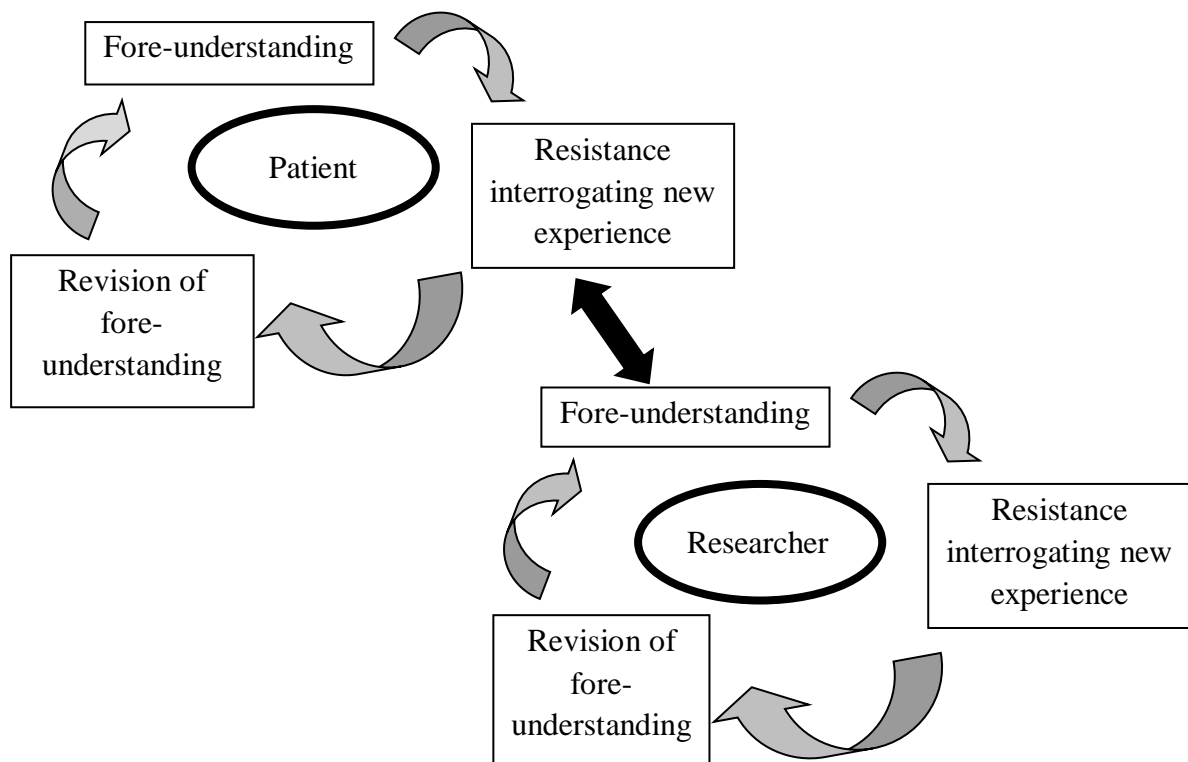
#### **7.3.1. Theoretical grounding**

The theoretical grounding of qualitative research shapes the way in which the study is conducted, from how patients are sampled to how the data is analysed. Phenomenology is the philosophical approach to examining experience through reflection and therefore is useful for this study which seeks to understand how patients ascribe meaning to experiences.

The philosopher Husserl emphasises that as researchers we can only examine what is experienced consciously by the individual. By contrast Heidegger believes that we cannot disengage with our surroundings but instead we are engaged with our world and this is reflected in the way we perceive our experiences. In this way, researchers' prior experiences and perceptions inevitably shape their interpretations. These are labelled as fore-structure. Rather than fore-structure being a barrier to interpretation it can be useful in making sense of accounts, endorsing the concept of hermeneutics which is the theory of interpretation. Accordingly, researchers' prior experiences of delivering PR may encourage the drawing of enriched and better informed interpretations from patients' accounts.

However, engaging in the process of hermeneutics is iterative by increasing researchers' awareness of their fore-structures and shaping prior perceptions. This concept is depicted by the hermeneutic cycle which is concerned with the dynamic relationship between part and whole understanding. In fact, the concept is better described by a double hermeneutic cycle which encompasses both patients' and researchers' understanding (Figure 6).

**Figure 6. Double hermeneutic cycle**



### 7.3.2. Interpretative Phenomenological Analysis

Qualitative approaches are incredibly diverse and complex. Whilst some approaches aim to produce theories (Grounded Theory approach) or derive meaning (Thematic Analysis) the application of Interpretative Phenomenological Analysis (IPA) lies within the exploration of how people make sense of major life experiences. By engaging in double hermeneutics the researcher is able to interpret the participants' interpretations of the experience, described as second order interpretations (Smith, Flowers, & Larkin, 2009).

#### *7.3.2.1. Sampling*

To ensure patients were able to provide a perspective on the experience under investigation (an acute exacerbation) patient selection occurred prospectively. Sampling targeted those patients who had been hospitalised with an acute exacerbation of COPD



and had refused a referral to PR. By carefully selecting a purposive sample the concept of idiography was endorsed. Idiography is concerned with the particular, referring to the depth of analysis and the understanding of a particular event, experienced by an individual in a specific context. Interviewing patients who had all refused a referral to PR following an acute exacerbation of COPD allowed for different interpretations of a shared experience and enabled the comparison of interpretations.

In keeping with the theoretical assumptions of IPA rich data is generated from a small, homogenous sample of patients. To elicit open discussion interviews were chosen over focus groups which would also have required patients to travel during a period when they were acutely unwell. Patients were interviewed individually in their own homes. It was hoped that by interviewing patients in their own environment it would encourage them to discuss freely their experience with the service provided at the hospital and their interactions with members of staff. To prompt honest and frank responses I introduced myself as ‘a researcher’ and wore smart attire to reduce patients construing me in my role as providing clinical care. Patients may associate the job role (physiotherapist) with exercise and activity, perhaps altering their account.

#### *7.3.2.2. Development of the interview schedule*

An informal interview schedule consisting of open-ended questions was developed (Appendix H) by considering findings from the critical synthesis exploring patients’ experiences of an acute exacerbation of COPD (Chapter 5). The findings from the review were presented to six members of the PPI group. As previously described the group were familiar with the protocol for the overall study and they had been educated with regards to the theoretical grounding for the qualitative component. The group members expressed ideas surrounding the content of the interview schedule and the phrasing of the questions (Appendix I). Following this feedback and advice from my supervisor and a health psychologist experienced in qualitative methodologies, the first draft of the interview schedule was composed. This was sent around to the members of the PPI group for approval.

At the time of data collection the interview schedule was revised. Specifically the first interview was transcribed and reviewed before the following interviews were

conducted. This was to ensure the questions both stimulated narratives focusing on acute exacerbations and also permitted other topics, salient to the patient, to emerge. Reflection on interviewing strategies was aided by the completion of a reflective diary documenting initial responses following each interview, the patients' story was also summarised. During the more detailed stage of analysis notes were made regarding key themes and important areas of interest to ensure bias was minimised and that themes remained grounded in the data set (Smith, 2007).

A detailed description of the study including the process of analysis is provided in Chapter 9.

#### **7.4. Quantitative methodology**

Although qualitative methodologies provide rich and detailed data regarding patients' appraisals of an experience they do not allow for generalisations to be made. Illness perceptions can also be assessed quantitatively using the Illness Perceptions Questionnaire-Revised (IPQ-R). The collection of IPQ-R data in patients following an acute exacerbation of COPD will be described, in detail, in Chapter 10. Data retrieved via questionnaires allows for the collection of data on a large sample size enabling the exploration of subgroups within a population. This type of information can facilitate the development of interventions designed to meet the specific needs of patients.

The complexities of predicting engagement in PR have been revealed in a general review of the literature (Chapter 3) and a retrospective study exploring the utility of the HADS in explaining adherence to PR (Chapter 6). Although patients' illness perceptions appear to have some predictive value it may be that a combination of illness perceptions can better account for the variance in health-promoting behaviour between individuals with COPD. Accordingly, a methodology was applied which considers the association between patients' illness perceptions.

##### **7.4.1. Cluster analysis**

Cluster analysis is a descriptive statistical technique used to identify similar people. When applied in analysing illness perceptions it takes into account a patient's entire

illness schema and can identify patients with similar illness schemata. A number of different methods of cluster analysis exist but the two most commonly applied in health behaviour research are: hierarchical methods i.e. average linkage, complete linkage, Wards method and partitioning methods i.e. K-means.

#### *7.4.1.1. Hierarchical methods of clustering*

During hierarchical clustering, data points which are “nearest” to each other are combined to form a pair. The most commonly applied metric for measuring distance between individual data points is the Euclidean distance; this relates to the sum of squared distances between data points. Pairs of clusters which are closest to each other are merged until one cluster is formed. This matrix consisting of the pair-wise distance between the data points can be displayed on a dendrogram. For the two most similar clusters to be merged, the distance between clusters pairs needs to be calculated, the method applied is referred to as linkage. Various methods of linkage exist including average linkage and complete linkage; these consider the average distance between all pairs and the complete distance between all pairs respectively. Wards method provides an alternative way of calculating the distance between pairs by considering how much the sum of squares will increase when pairs are merged. With all these methods the aim is to keep the value as small as possible.

#### *7.4.1.2. K-means clustering*

In the term K-means clustering, ‘K’ represents the number of clusters which is usually unknown and pre-determined by the researcher. Each cluster has a centroid (centre or representative of the cluster) which is usually computed as the mean of the variables in the cluster. The researcher pre-specifies the initial ‘K’ values for the centroids at the beginning of the cluster process, as cluster centroids cannot be directly calculated until clusters are formed. Cluster membership for each data point is decided based on the cluster-centroid nearest that point. Euclidean distance is applied and instead of referring to the sum of squared distances between two data points the distances between a data point and its closest centroid is calculated. The K-means clustering procedure moves data points between clusters in order to minimise the sum of squared distances.

#### *7.4.1.3. Two-step approach to cluster analysis*

A two-step approach to cluster analysis involves a combination of hierarchical clustering followed by a K-means. The use of this procedure allows for the identification of clusters and cluster centroids to arise from the hierarchical method rather than being chosen at random by the researcher. When compared to hierarchical clustering alone K-means cluster analysis using the number of clusters and cluster centroids determined by Wards method was found to be the most successful in correctly classifying the greatest percentage of cases using artificial datasets, even in sample sizes as small as  $n=42$  (Clatworthy, Hankins, Buick, Weinman, & Horne, 2007). Furthermore, Wards method and K-means have been found to most accurately reflect true clusters during a cross-validation approach consisting of two aspects of replication; consistency and symmetry conducted on ten cluster algorithms (Breckenridge, 2000).

Considering the ability of a two-step approach to cluster analysis in identifying clusters and cluster centroids without subjection to researcher interpretation, and given its proven accuracy, this type of approach was chosen and applied to IPQ-R data gathered following an acute exacerbation of COPD. Despite the success of the above mentioned approach in sample sizes as small as  $n=42$  a consideration of other studies conducting cluster analysis in different disease populations led to setting a recruitment target of  $n=128$  (Hobro, Weinman, & Hankins, 2004). An investigation into the illness perceptions of patients following an acute exacerbation of COPD and the applied cluster analysis is described fully in Chapter 10.

# **Chapter 8**

## **8. ACCEPTANCE, UPTAKE AND ADHERENCE TO PULMONARY REHABILITATION FOLLOWING AN ACUTE EXACERBATION OF CHRONIC OBSTRUCTIVE PULMONARY DISEASE**

Despite the proven benefits of Pulmonary Rehabilitation (PR) drop-out rates are high, even in a population of patients for whom Chronic Obstructive Pulmonary Disease (COPD) is stable (Chapter 6). Adherence to PR following an acute exacerbation might be considered to be even more challenging given the immediacy of intense fear and distress experienced by patients initiated by and accompanying shortness of breath (Chapter 5). To date, patients' uptake of PR has not been explored following an acute exacerbation. This chapter describes a prospective observational study demonstrating the important clinical issue of non-adherence to PR following an acute exacerbation of COPD and justifying subsequent research designed to inform strategies to facilitate attendance to post-exacerbation PR.

### **8.1. Introduction**

The debilitating nature of COPD means that the physical activity levels of patients are already low and are restricted further following an acute exacerbation (Pitta et al., 2006b; Pitta et al., 2006a; Pitta et al., 2009). Patients with lower levels of physical activity have been found to be at a greater risk of being readmitted to hospital (Garcia-Aymerich et al., 2001) and therefore interventions which target physical activity following an exacerbation are likely to impact positively on hospital readmission rates.

One intervention which has shown promise in improving the physical activity levels of patients with COPD, as well as reducing hospital readmission rates and eliciting benefits in terms of patients psychological status, functional capacity and health status is PR (Man et al., 2004; Pitta et al., 2006a; Seymour et al., 2010). The content of PR

programmes delivered within the United Kingdom is discussed in Chapter 2. The primary goal of PR is to optimise independent function through increasing patients' knowledge about disease management and subsequently encouraging patients to develop and utilise disease management strategies. PR is recommended for all patients with airflow limitation as it has been shown to be successful in improving exercise capacity, health status and reducing health care utilisation in patients whose COPD is stable (Griffiths et al., 2000; Lacasse et al., 2002).

The benefits of PR for patients whose disease is stable has led to its expansion for patients with more advanced and brittle disease. However, programmes have not been tailored to meet the individual needs of patients following an acute exacerbation and there are difficulties recruiting to, and poor attendance at PR programmes in this vulnerable population. This issue is demonstrated not only in attrition from referral to attendance at programmes, but is also revealed by lengthy recruitment periods and small patient numbers in post-exacerbation research studies (Eaton et al., 2009; Seymour et al., 2010).

To date, a prospective observation of acceptance, uptake, adherence and completion of post-exacerbation PR has not been conducted. This type of information is useful in determining the efficacy of the intervention for patients following an acute exacerbation of COPD.

The aim of this chapter is to provide a prospective observation of a PR service delivered to patients following an acute exacerbation of COPD and reasons for not accepting or attending the programme are described.

## **8.2. Methods**

### **8.2.1. Patient recruitment**

Between July 2011 and May 2012 patients admitted to a secondary care centre within the East Midlands with a coded diagnosis of an acute exacerbation of COPD were

recruited from acute respiratory wards. The following inclusion/exclusion criteria were applied:

#### 8.2.2. Inclusion criteria

- Patients who were 10 days (+/- three days) post discharge from hospital following an admission with a diagnosis of an acute exacerbation of COPD (Man et al, 2004).

#### 8.2.3. Exclusion criteria

- Patients who had completed PR in the previous 12 months including inpatient PR (prior to approval of the substantial amendment, February 2012).
- Patients without the capacity to give informed consent; if they were confused or impaired by pain.
- Patients who were not appropriate for PR due to physical and psychosocial co-morbidities.

The Respiratory Early Discharge Scheme (REDS) team comprised of five nurses whose role involved providing support upon discharge for patients admitted to hospital with an acute exacerbation of COPD. Given their role, the members of the REDS team were ideally placed to assist with patient recruitment offering patient information sheets (PIS) to individuals who met the inclusion criteria and had been discharged from hospital following an acute exacerbation of COPD.

Interested patients completed a reply slip giving permission for me to contact them. Patients were given a minimum of 24 hours to read the PIS (in-line with the requirements of the appropriate ethics committees) interested patients were then contacted by telephone and if they were happy to take part in the study a visit was arranged. Patients were offered the choice to attend hospital to complete the study visit or for the visit to take place in their home. During this visit informed consent was gained (Appendix J).

The role of the REDS team was altered in March 2012 following the launch of the ‘care bundle’ (Hopkinson et al., 2012) with more patients to assess in hospital and fewer home visits forcing revision of recruitment strategies. It was decided that rather than offering information to patients once they had been discharged from hospital, the team would alert me to patients admitted onto the acute medical units. Instead of contacting patients by telephone, patients were approached in hospital to discuss the content of the study. Patients were still requested to read the PIS and complete the reply slip if they were interested in participating. Permission was given for me to check their details on the hospital database and to contact them once they had been discharged home to arrange a study visit.

Once patients consented to participate, I wrote to the patients’ general practitioner (GP) (Appendix K) regarding their involvement in the research study, a copy of the PIS was also enclosed. Patients’ medical records were obtained to store the appropriate paper work including; the consent form, the PIS and the letter to the GP.

The sample size (n=128) was informed by considering the future conduction of a cluster analysis (Chapter 7 and Chapter 10). Using information from the screening log of a large randomised controlled trial; ‘Can REhabilitation delivered immediately on hospitalisation for an Acute exacerbation of Chronic respiratory disease improve long term Health outcomes?’ it was anticipated that up to 10 patients would be available to recruit per week. A recruitment target of three patients per week was set as this was considered manageable. As recruitment and data completion occurred simultaneously it was not deemed necessary to consider refusal rates, drop-out rates or mortality rates when setting recruitment targets. Patient recruitment was completed within a 12 month period (Table 8).



**Table 8. Recruitment targets and progress**

<b>Milestones</b>	<b>Recruitment target (Date)</b>	<b>Recruitment target achieved (Date)</b>
<b>25% recruitment complete. n=32</b>	10/10/11	10/10/11
<b>50% recruitment complete. n=64</b>	26/12/11	17/01/12
<b>75% recruitment complete. n=96</b>	12/03/12	20/03/12
<b>100% recruitment complete. n=128</b>	28/05/12	18/05/12

#### 8.2.4. Data collection

Comprehensive patient data was collected during a study visit which for the majority of patients (n=126) took place in their own homes. Subjective information was sought regarding: patient demographics (age, height, weight, body mass index (BMI)), period of time since diagnosis, previous exercise behaviour including previous attendance to a PR programme, length of hospital stay and number of hospitalisations in the previous 12 months. Information regarding inpatient hospitalisations was verified via the hospital trust database. Patients were classified according to the Medical Research Council dyspnoea grade and all subjects completed spirometry testing in accordance with national guidance (National Institute for Clinical Excellence, 2010). Spirometry is an accurate method for measuring airflow obstruction and is used by clinicians as a diagnostic tool.

A referral to PR was offered at the time of admission by clinical staff (i.e. ward nurses, physiotherapists, physicians) or shortly after discharge from hospital by the REDS nurses or me. If patients refused a referral to PR the reason supplied was recorded.

#### 8.2.5. Measures

##### *8.2.5.1. Physical activity: Energy expenditure and step count*

Data relating to physical activity was measured via a multi-sensor activity monitor (SenseWear PRO<sup>2</sup>, BodyMedia, Pittsburg, US) (SWM). The SWM contains two

accelerometers which measure motion through skin responses. Galvanic skin responses measure the electrical conductivity of the skin which changes in response to exertion as does skin temperature and the amount of heat radiating from the body. The SWM measures and quantifies the levels and duration of metabolic physical activity in terms of energy expenditure (Kcal) metabolic equivalents (METS) and number of steps. It also divides activity levels into sedentary (<3 METS), moderate ( $\geq 3$  METS), vigorous ( $\geq 6$  METS) and very vigorous ( $\geq 9$  METS).

Patients were instructed to wear the monitor on the back of the right arm, half way between the elbow and the shoulder. In order to ensure the collection of at least three days' worth of data patients were asked to wear the monitor for six days. The monitors were worn during the waking hours only (Appendix L). It was considered that as the purpose of the monitors was to record physical activity it was only necessary to wear the monitor whilst active. Furthermore, previous experience of asking patients to wear the monitor has shown that it is not to be well tolerated overnight. Patients' reluctance to sleep wearing their monitor is unsurprising as many patients with COPD experience difficulties with sleep as a result of their increased shortness of breath, particularly when lying supine or in a reclined position. A full justification for the measurement of physical activity using the SWM is described in Chapter 2.

#### 8.2.6. Six month follow up

##### *8.2.6.1. Pulmonary Rehabilitation*

Data regarding the uptake and completion of a PR programme was documented six months following hospital discharge. This data was gathered prospectively from the PR database at the two secondary care centres responsible for delivering PR within a city in the East Midlands. PR is also delivered in the local communities. The team responsible for this service were contacted to confirm patients' attendance and completion.

If patients attended a PR programme the following outcomes were recorded before and after PR: Incremental Shuttle Walking Test (ISWT) distance, Endurance Shuttle Walk Test (ESWT), Illness Perceptions Questionnaire-Revised (IPQ-R), Chronic Respiratory Questionnaire – Self-Reported, the Hospital Anxiety and Depression Scale and

Pulmonary Rehabilitation Adapted Index of Self-Efficacy. These outcome measures, with the exception of the IPQ-R, are all commonly applied in the assessment of patients attending PR programmes (Chapter 2). If patients completed the PR programme, they were asked to wear the SWM for six consecutive days following their discharge assessment from PR. A convenient time was arranged with the patient to collect the monitor from their homes.

Patients who had not attended PR following their referral or had dropped out of PR were contacted by telephone and their primary reason for not attending/completing was recorded.

#### *8.2.6.2. Hospital information*

All information concerning patients' hospital visits is stored on the hospital trust database. All cause, respiratory and non-respiratory hospital admissions were recorded from this database in the six month period following hospital discharge. If at six months patients had died hospital information was still recorded and their death documented.

#### *8.2.6.3. Confidentiality*

All patient information collected during the course of the research was documented on assessment forms (Appendices M and N) and kept strictly confidential, following the National Health Service code of confidentiality at all times. Patients were not identified in any data records, for example, numbers were used to refer to patients' names. All electronic data was password protected and all hard data was stored in a locked filing cabinet.

### 8.2.7. Statistical analysis

#### *8.2.7.1. Physical activity*

An Analysis of Variance and Scheffe post hoc test were conducted for energy expenditure and step count to look at differences between levels of physical activity on different days of the week. Basal Metabolic Rates (BMR) were calculated and translated

into a Physical Activity Level (PAL) defined by the World Health Organisation (Watz et al., 2008) (see formulas below).

$$\text{Women: BMR} = 655 + (4.35 \times \text{weight in pounds}) + (4.7 \times \text{height in inches}) - (4.7 \times \text{age in years})$$

$$\text{Men: BMR} = 66 + (6.23 \times \text{weight in pounds}) + (12.7 \times \text{height in inches}) - (6.8 \times \text{age in year})$$

$$\text{PAL} = \frac{\text{total EE}}{\text{BMR}}$$

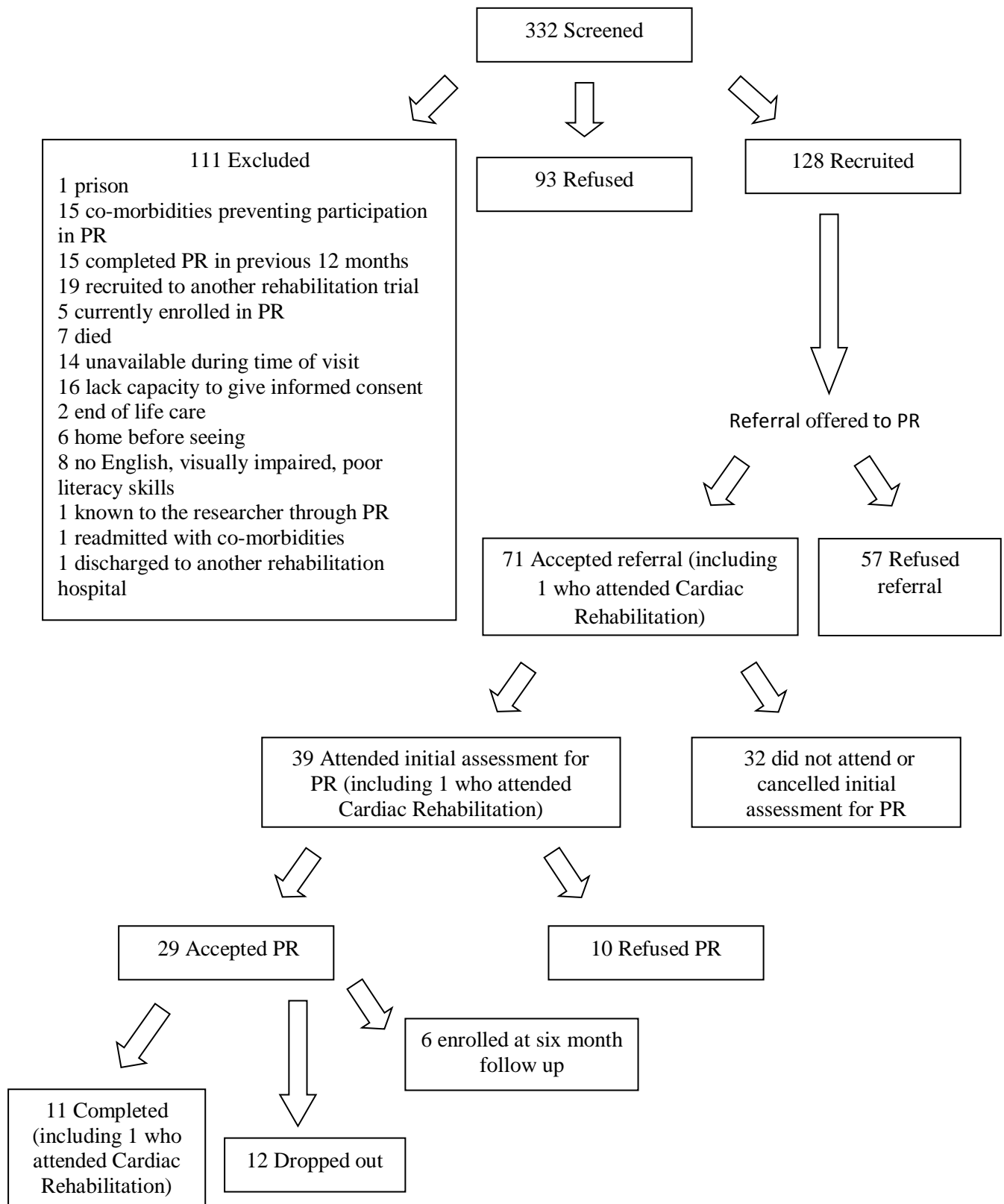
### **8.3. Results**

#### **8.3.1. Sample**

Three hundred and thirty two patients were identified as having been admitted to hospital with a coded diagnosis of an acute exacerbation of COPD. One hundred and eleven patients were excluded with reasons documented in Figure 7. Ninety three patients refused to take part and 128 were successfully recruited (Figure 7).

The demographics of the whole group (n=128), including previous PR and previous hospital information, are presented in Table 9. Although all patients had been admitted to hospital with a coded diagnosis of an acute exacerbation of COPD, 12 patients had a Forced Expiratory Volume in One Second/Forced Vital Capacity ratio greater than 70% (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2013). Despite their lung function being within the normal ‘healthy’ range, all patients recruited believed that an acute exacerbation of COPD was the cause of their admission.

**Figure 7. Recruitment flow diagram**



**Table 9. Whole group demographics (n=128)**

<b>Variable</b>	<b>Mean (SD)</b>
Age (years)	70.84 (8.87)
Gender	75 male. 53 female
Height (cm)	164.25 (9.59)
Weight (kg)	72.52 (19.64)
BMI	26.51 (6.70)
Ethnic origin	126 white British. 1 Irish, 1 Caribbean.
Age left education (years)	14.97 (0.85)
Accommodation	22 house. 35 bungalow. 21 flat.
Lives with	44 alone. 53 spouse. 23 family. 8 other.
Social status	17 divorced. 69 married. 7 single. 30 widowed. 4 partner. 1 separated.
Length of diagnosis (years)	5.87 (5.44)
Number of co-morbidities	3.04 (1.92)
Number of acute medications	3.03 (0.89)
Number of normal medications	8.76 (4.37)
Acute respiratory support (Non-invasive ventilation and/or oxygen)	89 support. 39 no support.
Chronic respiratory support (oxygen at home).	31 yes. 97 no.
Smoking status	43 current smokers. 78 ex smokers. 7 never smoked.
Pack years (years)	48.77 (29.90)
FEV <sub>1</sub> (l)	1.10 (0.49)
FVC (l)	2.20 (0.77)
FEV <sub>1</sub> /FVC (%)	50.70 (13.24)
MRC scale dyspnoea grade	2 grade 1. 18 grade 2. 31 grade 3. 41 grade 4. 36 grade 5.
Previous lung volume reduction surgery	4 yes. 124 no.
Length of current hospital stay (days)	5.30 (5.78)
Support on hospital discharge	91 yes. 37 no.
Number of hospital admissions in the previous 12 months (count)	
All cause admissions	327
Respiratory admissions	266
Non-respiratory admissions	61
Previous PR %	
Referred	39
Completed (% of those referred)	48

BMI = Body Mass Index; FEV<sub>1</sub>= Forced Expiratory Volume in One Second; FVC = Forced Vital Capacity  
 FEV<sub>1</sub>/FVC = Forced Expiratory Volume in One Second/Forced Vital Capacity; l = Litres;  
 MRC =Medical Research Council; PR = Pulmonary Rehabilitation.

### 8.3.2. Physical activity

Forty nine patients did not have three days of valid activity monitor data leaving 79 patients for whom data was available. Ten patients had three days, 12 patients had four days, 20 patients had five days and 37 patients had six days. There are large discrepancies in the literature regarding the days of the week physical activity should be recorded for. This has been discussed in Chapter 2. No significant differences were identified between physical activity levels on each day of the week ( $p>0.05$ ) and therefore physical activity recorded on all days of the week was included. The average values for physical activity were calculated across all the included days. For the group as a whole ( $n=79$ ) the medium (Inter Quartile Range (IQR)) value for total daily energy expenditure was 1092.50 kcal (934.40–1323.33) (sedentary - 690.50 kcal (658.67-710.00), moderate – 28.83 kcal (9.8–6.00), vigorous – 0.00 kcal (0.00-1.00), very vigorous – 0.00 kcal (0.00–0.00) and for daily step count 1830.50 (746.25–3525.83).

According to the PAL classification system, 76 of the 79 patients were classified as extremely inactive, one was sedentary and two were vigorously active (Table 10). *Report of a Joint FAO/WHO/UNU Expert Consultation (2005).*

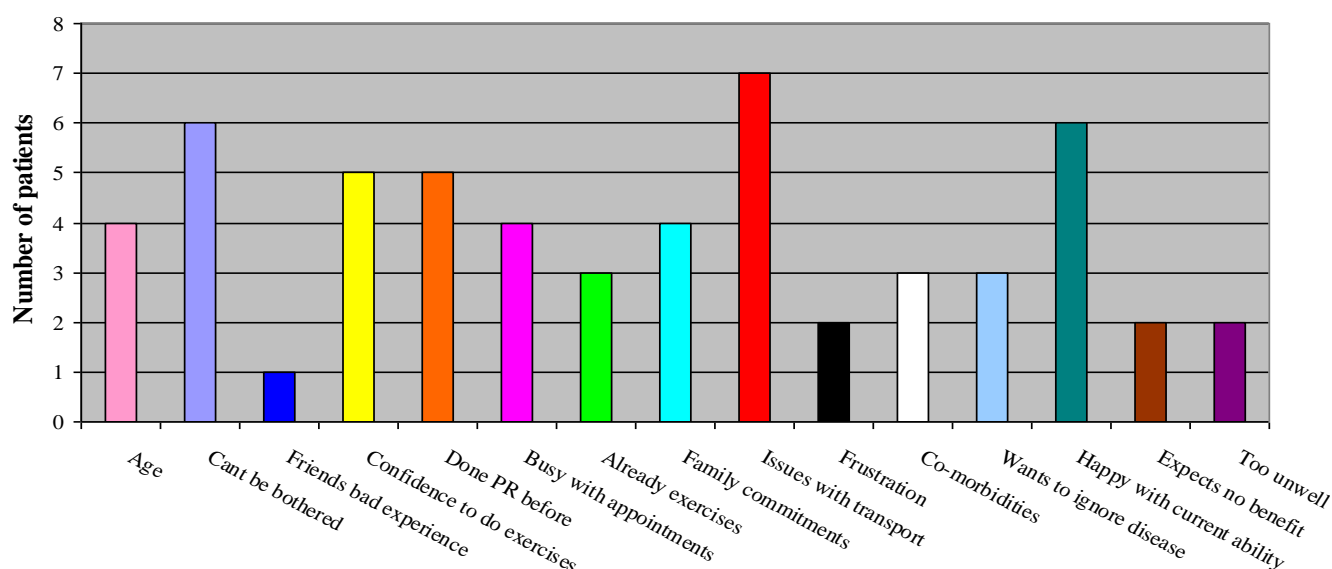
**Table 10. Physical Activity Level classification system**

<b>Lifestyle</b>	<b>Example</b>	<b>PAL</b>
<b>Extremely inactive</b>	Cerebral Palsy patient	<1.40
<b>Sedentary</b>	Office worker getting little or no exercise	1.40 – 1.69
<b>Moderately active</b>	Construction worker or person running for one hour daily	1.70 – 1.99
<b>Vigorously active</b>	Agricultural worker or person swimming 2 hours daily	2.00 – 2.40
<b>Extremely active</b>	Competitive cyclist	>2.40

### 8.3.3. Pulmonary Rehabilitation

Of the 128 patients recruited 70 accepted a referral to PR and one patient accepted a referral to Cardiac Rehabilitation (55%). Primary reasons for refusing a referral to PR were varied but the most commonly cited were: transport issues (12%); expressed satisfaction with functional ability (11%); indifference (11%); previous attendance at PR (9%); busy attending other appointments (7%); family commitments (7%); and feeling too old to exercise (7%) (Figure 8).

**Figure 8. Primary reasons for not accepting a referral to Pulmonary Rehabilitation (n=57)**



A further 10 patients attended their initial assessment but did not enrol in the PR classes. Of these four patients refused PR once they had received more information about the content of the program, one patient worked during the day, two were re-admitted to hospital with an acute exacerbation, one was happy with their ability, one was offered a self-management program and one patient died.

### 8.3.4. Six month follow up: Pulmonary Rehabilitation

At six months 39 (30%) attended their initial assessment, 29 (23%) had enrolled in the PR classes and 11 (9%) had completed the programme (Figure 7). The main primary reason cited for not attending the initial assessment or dropping out of the programme

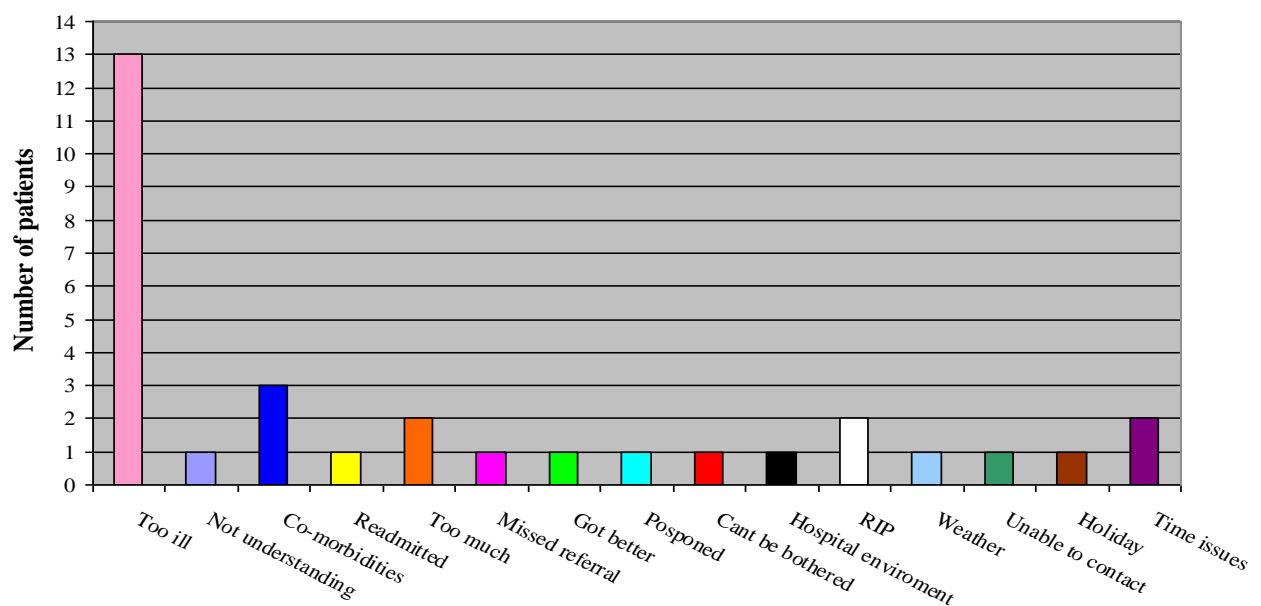


was feeling too ill and/or breathless (41%), other reasons included: not believing in benefits via increased functional capacity; physical co-morbidities; fear of the hospital environment; and feeling depressed. Primary reasons for non-attendance are displayed in Figure 9.

For the 29 patients who enrolled in the PR classes 58 days elapsed, on average, between the date of hospital discharge and attendance at PR.

Outcomes were recorded for those patients who completed PR but because this data was available for only 11 patients (9%), the values are not reported in detail. Following PR, for the group as a whole, the ISWT distance improved by 170m and walking time calculated using the ESWT increased beyond five minutes.

**Figure 9. Primary reasons for not attending an initial assessment for Pulmonary Rehabilitation (n=32)**



Of those patients who did attend the PR program 12 dropped out. Of these, two patients were re-admitted to hospital with an acute exacerbation, two cited personal reasons/family commitments, one patient reported back pain and stated that their general practitioner had advised them not to exercise, one was happy with what he could do and was given a wheelchair, one had been wrongly diagnosed with COPD, one reported feeling unwell, one was recuperating from surgery and in three instances the

reason for program drop out was not record by the attending health care professional and was absent from documentation.

#### 8.3.5. Six month follow up: Hospital information

At six month follow up there were 158 all cause hospital admissions for the group as a whole. One hundred and fourteen of these admissions were assigned to respiratory causes and 44 were non-respiratory admissions. These figures are also displayed in Chapter 10, Table 14.

Six months following discharge from hospital 12 (9%) patients had died.

### **8.4. Discussion**

The present study has prospectively identified uptake and adherence to PR post-exacerbation as being poor emphasising the importance of considering ways to revise and potentially tailor PR to meet the needs of patients following an acute exacerbation of COPD.

The low completion rate of PR in this study reiterates the probable sample bias which exists in current post-exacerbation PR research studies (Puhan et al., 2009). Certainly PR was very beneficial for the small percentage of patients who completed the programme, improvement on the ISWT substantially exceeded the minimal clinical important difference (47.5m) and also the distance at which patients are able to distinguish benefit (78.7m) (Singh et al., 2008). Yet, these findings emphasise issues of feasibility of post-exacerbation PR and emphasise the necessity of developing additional interventions to facilitate and enhance PR following an acute exacerbation, given the benefits which attendance affords.

Considering the low acceptance and uptake of PR it is perhaps not surprising to note that physical activity is also low in this vulnerable group of patients, highlighting the level of disability evoked by an acute exacerbation. This is the largest collection of activity monitor information provided for patients following an acute exacerbation of COPD, previous studies have consisted of significantly fewer patients (n=17) (Pitta et

al., 2006a). Furthermore, it is the first time energy expenditure, step count and PAL have been reported in this population. By displaying the physical activity data in PAL it allows associations to be made with four-year mortality (Waschki et al., 2011), with 96.2% of patients being classified as 'extremely inactive'. If patients PAL remains consistent after an acute exacerbation the absolute risk of mortality is 31% at four years. This information emphasises the importance of engaging patients in interventions which aim to increase physical activity following an acute exacerbation.

PR delivered within its current form does not appear to be optimised as a therapy following an acute exacerbation of COPD. Currently understanding regarding the additional needs of these vulnerable patients is limited, as patients who refuse interventions are also likely to refuse involvement in research. Yet, greater insight into this difficult to access population is necessary to inform strategies to facilitate and enhance post-exacerbation PR.

# **Chapter 9**

## **9. ‘WE ARE NOT WORTHY’ – UNDERSTANDING WHY PATIENTS DECLINE PULMONARY REHABILITATION FOLLOWING AN ACUTE EXACERBATION OF CHRONIC OBSTRUCTIVE PULMONARY DISEASE**

The previous chapter confirmed notions derived from indirect evidence that uptake and attendance to Pulmonary Rehabilitation (PR) is indeed poor following an acute exacerbation of Chronic Obstructive Pulmonary Disease (COPD). However, in depth understanding of those who refuse to engage in PR is limited not least because patients’ motivation to participate in research studies is also likely to be low, making this population difficult to access. Informed by a critical synthesis (Chapter 5) this chapter seeks to improve understanding regarding patients’ decision to decline PR following an acute exacerbation. Coupled with findings from the subsequent quantitative investigation such information may be helpful in better tailoring strategies to facilitate engagement in PR following hospitalisation with an acute exacerbation of COPD.

### **9.1. Introduction**

Patients who experience acute exacerbations of COPD have higher readmission rates to hospital than for any other disease (Farr, 2010). However, despite showing promise in enhancing functional capacity and health status of those with COPD and reducing readmission rates following an acute exacerbation (Man et al., 2004; Seymour et al., 2010; Puhan et al., 2009), PR programmes remain insufficiently tailored to the specific needs of those following an acute exacerbation. This is evidenced in difficulties recruiting to, and poor attendance at programmes in this vulnerable population (Chapter 8) as well as inferred from, lengthy recruitment periods and small patient numbers in post-exacerbation research studies (Eaton et al., 2009; Seymour et al., 2010; Puhan et al., 2011). Patients’ reluctance to attend PR programmes remains poorly understood and whilst socio-demographic data with measures of health status have had some success at

predicting attendance these have been unable to distinguished how those who undertake PR differ from patients who neither attend nor complete programmes (Chapter 6) (Fischer et al., 2009; Garrod et al., 2006; Selzler et al., 2012).

Existing research in this area is predominately quantitative but qualitative methodology and analysis, with its contribution to the exploratory content and interpretation of data, is increasingly utilised, informing clinical practice (Green & Britten, 1998; Sheldon, 2005), notably in describing potential barriers to PR attendance in patients whose COPD is stable (Fischer et al., 2007). Such analysis has suggested patients' perceived disabilities, fear of breathlessness and exercise, perceived treatment benefits, the influence of the referring practitioner, practical barriers and confidence may all be related to programme adherence (Arnold, Bruton, & Ellis-Hill, 2006; Bulley et al., 2009; Keating, Lee, & Holland, 2011a; Moore, Hogg, & White, 2012; Harris, Hayter, & Allender, 2008).

It is understandable that during an acute exacerbation of COPD when symptoms of breathlessness may be construed as preceding death, patients are reluctant to engage in an intervention which will explicitly provoke shortness of breath. Perceptions of symptoms as life threatening seem associated with fears regarding exercise which may deter some patients from accepting PR (Bulley et al., 2009). Such qualitative findings resonate with broader psychological conceptualisations of adherence, described by the Common Sense Model, suggesting that the experience of an acute exacerbation may affect coping responses and behaviour (Leventhal et al., 1984; Leventhal et al., 1997), namely uptake of PR.

Although researchers have made attempts to explore the beliefs of patients who refuse a referral, very few patients have been recruited, just two patients in one study and one patient in another, and where research has been conducted it has been reported on patients who at least attend PR programmes (Arnold et al., 2006; Harris et al., 2008). Unfortunately, those who decline active interventions are likely to be less motivated to participate in research studies, and are difficult to access. Prospective, purposive sampling of patients as they consider, yet refuse a referral to PR may enable researchers and clinicians to gain richer understanding of why these individual elect not to participate in PR, permitting development of strategies to enhance attendance.

Thus, informed by a theoretical base and the body of literature existing in patients whose disease is stable, the main aim of this research is to explore how patients appraise acute exacerbations of COPD particularly as they consider, yet decline PR. Such information may be helpful in better tailoring strategies to facilitate engagement in PR following hospitalisation with an acute exacerbation of COPD.

## **9.2. Methods**

Patients were recruited as part of a mixed-methods study design and all took part in a large observational study described in a subsequent chapter (Chapter 10). Patient recruitment and data collection is described fully in Chapter 8.

### **9.2.1. In-depth interviews**

An informal interview schedule consisting of open-ended questions was developed and used to facilitate in-depth interviews (Appendix H). A detailed description of the development of the interview schedule is described in Chapter 7. Patients were encouraged to tell their own story regarding their experience of being admitted to hospital with an acute exacerbation of COPD. Interviews were conducted individually in patients' own homes and lasted between 45 minutes and 75 minutes. Field notes were taken during the interviews to elicit future interpretations during data analysis.

Six patients, all of whom had been admitted to hospital with an acute exacerbation of COPD, agreed to participate in the in-depth interviews, conducted one month (+/- one week) following hospital discharge. None of the patients had previously completed PR, although two had started a programme more than 12 months prior and dropped out.

Demographic information was recorded and is displayed in Table 11. Information including Body Mass Index, time since diagnosis (years), Medical Research Council dyspnoea grade, length of hospital stay, support offered on hospital discharge and the number of respiratory admissions in the previous 12 months was also collected but is not presented here in order to maintain patient anonymity.

**Table 11. Patient demographics**

<b>Variables</b>	<b>Patient ID. 094</b>	<b>Patient ID. 110</b>	<b>Patient ID. 125</b>	<b>Patient ID. 126</b>	<b>Patient ID. 127</b>	<b>Patient ID. 128</b>
<b>Gender</b>	Female	Male	Female	Female	Male	Female
<b>Age (years)</b>	84	83	72	67	70	79
<b>Lives with</b>	Spouse	Alone	Spouse	Spouse	Spouse	Alone
<b>Co-morbidities</b>	1	5	8	4	6	4
<b>Smoking status</b>	Ex	Yes	Ex	Ex	Ex	Ex
<b>Pack years</b>	0	44	37	38	45	49
<b>FEV<sub>1</sub> (l)</b>	0.67	1.70	1.03	0.86	1.27	1.05
<b>FEV<sub>1</sub>/FVC (%)</b>	58.26	55.73	47.00	42.36	41.63	49.29
<b>Exercise behaviour</b>	Exercised previously	Exercised previously	Currently exercises	Never exercised	Never exercised	Never exercised

FEV<sub>1</sub> = Forced Expiratory Volume in One Second; FEV<sub>1</sub>/FVC = Forced Expiratory Volume in One Second/Forced Vital Capacity; l = Litres.

### 9.2.2. Data analysis

All interviews were recorded and transcribed verbatim with the participant's written consent. The data was stored and organised using a computer software programme (QSR NVivo version 9; QSR International, Doncaster, Australia) and analysed using Interpretative Phenomenological Analysis (IPA).

A close line by line analysis was conducted on each original transcript to explore the claims and understandings of the patients (Larkin, Watts, & Clifton, 2006). Emergent themes were identified rather than constructs being prepared in advance. Commonalties and conflicts were reflected within each of the single cases. The original transcripts were then reviewed by a health psychologist involved in the development of the interview schedule and regular meetings between me and my colleague permitted discussion of emergent findings.

Two members of the Patient Public Involvement (PPI) group were chosen to assist with the development and initial interpretation of emerging themes. Both members had COPD; one had experienced being hospitalised with an acute exacerbation and the other had not. The members were invited to attend a meeting which ran over two hours and was held at the hospital. My colleague and I presented our initial ideas regarding the formation and interpretation of emerging themes along with examples from the original transcripts. Given their disease experience the PPI members were able to consider further what the experience might mean to the patients. The themes were discussed and refined (Larkin et al., 2006). During the meeting minutes were taken by an independent administrator, these reflected the emerging themes and initial interpretations (Appendix O). Following the meeting the minutes were sent to all those present for approval.

Once the emerging themes were agreed, my colleague and I met to transfer them across the entire data set. After this stage themes were referred to as 'master themes' (Eatough & Smith, 2008).

The agreed master themes were presented to members of a 'collaborative workshop', comprising of: inpatient and outpatient PR specialists, Respiratory Early Discharge Scheme nurses, team managers, occupational therapists, specialist respiratory



consultants, a respiratory physiotherapist, a ward manager, a registrar and academics (Appendix P). The two PPI members were also present at the meeting acting as lay advisors. Feedback was provided and minutes were recorded by an independent administrator (Appendix Q). Although the interpretative approach of IPA focuses on the particular involving patients and health care providers in the analytic process can enhance the robustness of the findings by reinforcing and contextualising interpretative assumptions.

The final master themes were agreed and taken to a deeper level of interpretation. This final stage was conducted by me and my colleague who had been involved throughout each stage of the research process and also by my supervisor, an experienced clinical psychologist with extensive knowledge of chronic conditions including COPD and also expertise in qualitative data analysis. The findings were translated into a narrative account and verbatim extracts are included to provide a means of validation, ensuring the findings are derived from the patients' original reports (Osborn & Smith, 1998).

### **9.3. Findings**

Narratives reflecting a heightened level of anxiety and preoccupation with breathing were prominent throughout all the transcripts and directly ascribed to acute exacerbations in four transcripts. The emotional intensity of acute exacerbations is well documented with such impact emerging in the meta-synthesis of the qualitative evidence (Chapter 5). These findings were largely bracketed but informed and contextualised novel interpretations. Analytic process was undertaken with the study question in mind, and three inter-related conceptual themes emerged comprising: 'Construction of the self' reflecting the impact of the acute exacerbation on personal sense of identity, 'Relinquishing control' describing patients' struggle to maintain agency following an acute event; and 'Engagement with others' embodying patients' sensitivity and responsiveness to interactions with others. Although interwoven themes are described under these three descriptor headings and illustrated using direct quotations in order to validate interpretations. Patient identification numbers are used to preserve anonymity.

### 9.3.1. Construction of the self

#### *9.3.1.1. Guilt*

In the context of an acute exacerbation all patients articulated a sense of guilt relating to a perceived personal culpability for their disease *“I get cross with myself, because I think well it’s my own fault, if I’d never have smoked”* (patient ID 125), *“My family’s a big factor..... I feel as if I’m actually putting on them”* (patient ID 127).

Patient narratives articulated the sustained burden of COPD and the manner in which it influenced mood *“that is frustrating because you want to do it, you want to go to different places and yeah that does make you miserable”* (patient ID 126). There appeared a bi-directional relationship between lowered mood and disease constraints, with negative interpretations of behaviour and choices leading up to current state of health and accompanied by guilt which, in turn, seemed to magnify symptoms of depression. Guilt was not just self-focused but had external reference points, notably the perceived burden placed upon family members *“I do feel a bit guilty, because [name of family member removed to maintain anonymity] has all the pressure of it”* (patient ID 125) and society, *“I feel very guilty about it, and I think what it’s costing, you know national insurance”* (patient ID 125).

In an apparent effort to minimise feelings of culpability, negative self-evaluations and associated emotional responses, patients attempted to reframe and contextualise smoking behaviour both as a function of a different time, *“I worked in an office where we all smoked. And in them days you could smoke at work”* (patient ID 125), and within the family *“You see my mother suffered with her breathing you know...I mean she was 94 when she died”* (patient ID 128).

#### *9.3.1.2. Fear of others’ censure*

Within these appraisals of personal culpability, participants appeared particularly concerned about others’ evaluation of their behaviour and all patients strove to maintain a desirable self-image.

All patients appeared particularly sensitive to how others (notably, peers and health care professionals) viewed them. This was revealed not only in how verbal interactions with others were construed but also by more subtle, non-verbal cues. *“he [Doctor] was abit brash, forward”* (patient ID 127), *“I think sometimes the doctors can be very abrupt with you, as they were this time when I went in... I don’t know whether it’s my imagination or, I mean doctors are there to treat whoever, you know, and whatever your problem is, I do understand that, but perhaps my guilt thinking oh perhaps they haven’t got much patience with me because it’s self-inflicted, I don’t know”* (patient ID 125).

Fear of others’ condemnation seemed to encourage a defensive position in which patients emphasised their independence and legitimacy as contributors to society *“I’ve never been a person to lie about, I’ve always worked in heavy and hard jobs all my life”* (patient ID 127). Fear of others’ negative evaluations also appeared to foster isolation. Activities were declined or avoided to minimise others’ scrutiny and potential humiliation *“I don’t want to walk to suddenly go down on the floor, I don’t want a load of people hanging around you, I think how embarrassed that would be”* (patient ID 110), *“I know I wouldn’t be able to do it, I just know, so about making myself ill and look stupid”* (patient ID 126).

Patients expressed concern about unpalatable, overt physical symptoms when discussing how they might appear to others. Disgust in relation to symptoms presented during an exacerbation was prominent in the majority of transcripts, *“I was coughing, I was fetching up phlegm up, oh it was horrible”* (patient ID 094), *“Well, my phlegm was very, very dirty”* (patient ID 127).

#### 9.3.1.3. Self-worth

Narratives of five patients served to question their legitimacy as worthy of care, being unwilling to assert ‘self’ and engage in health interventions, *“you just have to sit on the chair. But what else can they do when they’re short staffed, they’ve got no beds”* (patient ID 094). In contrast, one patient appeared disinhibited in their desire to seek help, articulating an unwillingness to accept responsibility for their own disease management, *“I rang them yeah, but you see he wouldn’t let me go back in that time, he*

*said everything's all right with your heart. So I said well why can't I go in hospital, he said no need to you see. And no, they didn't let me go"* (patient ID 128).

Reluctance to engage in health interventions may stem from patients' ambivalence regarding their current functional abilities, *"It's not stopping me doing things because I still do the polishing"* (patient ID 094). Self-limiting statements coupled with low mood, conveyed no expectations or desire for improvement *"Oh I've never got no worries. I've got to the stage where if I go I go and that's the bloody end of it, that's how I feel, got no problems"* (patient ID 110).

Patients' beliefs regarding their own personal worth could be challenged by downward social comparisons and a fear of how they may be perceived by others, particularly during a time of vulnerability *"I think well I shouldn't be here because look at these people, bottles on and things up their noses and all sort like and I'm sitting here, I'm breathing, feeling normal sort of thing like, so I shouldn't be here"* (patient ID 127). By contrast, despite an unwillingness to assert themselves, patients contextualised themselves as independent and willing to take responsibility for their own disease management by emphasising others passivity *"she's 20 years younger than me and she sat about and sat about, her legs getting thinner, the muscle's gone. Smoking, she's smoking all the time"* (patient ID 094). This seemed to question the legitimacy of care for those failing to help themselves, *"I just can't believe one of my neighbours [who continues to smoke] it's a wonder the doctor goes and visits her so much"* (patient ID 126).

### 9.3.2. Relinquishing control

#### *9.3.2.1. Intermittent nature of Chronic Obstructive Pulmonary Disease*

Patients appeared keen to diminish the impact of the disease even in the face of overwhelming symptoms. This attempt to maintain 'normal' functioning and a desire to return to 'everyday life' post-exacerbation appeared to pose a barrier for prompt help-seeking, further delayed by multiple burdens challenging the prioritisation of COPD management.

The unpredictability of acute exacerbations was magnified in narratives in which patients strove for stability. In an attempt to maintain emotional equilibrium, patients adopted a process of normalising and minimising their condition even as symptoms became difficult, *“breathing wasn’t as good as, well worse than normal, I got more breathless going up stairs, more breathless when I moved about and I just thought well this is it, this is how it is”* (patient ID 125), *“your chest feels tight and you think oh am I going to have a cold”* (patient ID 126) presenting a barrier for intervention uptake, *“What energy I’ve got I like to put into doing my own things, you know what I mean”* (patient ID 094).

Patients also attributed their functional limitations to impairments other than those conferred by COPD, in an attempt to minimise the disease, *“I was coming out of the hospital I couldn’t walk because of my knees”* (patient ID 127), *“I’ve got arthritis in my spine and that affects your legs as well, so that affects you walking”* (patient ID 125). Physical burdens and social burdens arising from family issues and adoption of a caring role seemed interlinked, *“it was my brother in December, November when he died, my granddaughter was pregnant...oh it was an awful pregnancy”* (patient ID 126), *“she couldn’t move really, you know, completely out of it. She finally dies of dementia....Yeah, her carer, three year”* (patient ID 110). Such numerous challenges deplete emotional resources *“made me feel quite depressed”, I got quite worried”* (patient ID 125) and diminish COPD within an apparent hierarchy of stressors.

#### 9.3.2.2. Resistance to help-seeking

Patients’ apparent expressed resistance to help-seeking seemed further supported by their self-descriptions. These conveyed both stoicism as well as constructions of the hospital environment as a threat to control and integrity *“I didn’t have much choice [about going to hospital]”* (patient ID 110).

Patients emphasised their independence and attempted control of their disease. Positive personal attributions were emphasised by others *“one of my neighbours has got it, but she don’t do anything to help herself”* (patient ID 126) leading to the refusal of external

applications *“I don’t really want a wheelchair, I said I want to get about as much as I can”* (patient ID 125).

One individual offered an opposing perspective, *“Can I have a wheelchair?”* (patient ID 128) apparently absorbed in their condition, appearing oblivious to the psychological impact of the disease and describing socialisation to hospital *“Oh yeah, so I’ve been to all the hospitals now”* (patient ID 128).

The majority of patients described the hospital environment as contaminated and dirty, a place to be avoided until symptoms can no longer be ignored *“it was absolutely packed out with people coughing. And I felt, I really did feel ill”* (patient ID 094), *“Talk about feeling dirty and that when you have to go to the hospital”* (patient ID 126). Negative emotions were also reinforced by associations between the hospital environment and the death of loved ones, *“I don’t like being in hospital, I don’t even like visiting but sometimes you have to.... It was my brother in December, November when he died”* (patient ID 126).

### 9.3.3. Engagement with others

#### *9.3.3.1. Dismissal*

The sub-theme of dismissal seemed to apply to both the self and those undertaking a caring role. Notably all patients described themselves indirectly, talking in the past tense, and conveying a sense of passivity and distance, as though discussing another *“you know, there’s nothing really you can do like. You’ve just got to cope the best you can”* (patient ID 127). Self-dismissing statements appeared interwoven with self-worth, often linked to aging and with it the inevitability of disease-induced decline, *“it will get worse, because your lungs are getting more older and worn out, along with everything else”* (patient ID 125).

Patients described themselves as marginalised and invalidated in interactions with key staff, in particular clinicians responsible for delivering care *“the doctors told me I wasn’t trying hard enough and it’d be best if I went home, because I would have to do things and look after myself, the next day I was admitted with a PE”* (patient ID 125).

However, this was not solely construed as insulting but was also mitigated by exculpating staff behaviour as reflecting a cost cutting culture “*what else can they do when they’re short staffed, they’ve got no beds*” (patient ID 094), “*they want the beds for other people, but that’s the way things are nowadays*” (patient ID 125).

#### 9.3.3.2. Efficacy of Pulmonary Rehabilitation

Patients were explicitly asked about exercise and activity without specific mention of PR. All patients articulated conservative views regarding the perceived value of PR, within the context of their individual circumstances or family experience (i.e. a husband who had undertaken a rehabilitation programme and found it demanding), treatment expectations in general and previous experience of health care professionals, most often physiotherapists.

Having refused PR, patients described their own attempts to disease manage, refusing National Health Service provision and emphasising their own programme of manageable activities “*I do arm exercises and try to walk quick when I can*” (patient ID 125) “*being active is not a problem at my own pace*” (patient ID 127). In an effort to justify declining PR they argued for the adequacy of what they are do “*everybody who knows me says you can’t do more than what you’re doing, and I don’t think I could*” (patient ID 094), “*I felt as if I was doing enough at home*” (patient ID 127).

Patients expressed relative satisfaction in their current circumstances. PR was described as encroaching on domestic normality “*I would feel that the time I’m going there [PR] I could be doing things I want to do in the home, and I’m happy doing things at home*” (patient ID 094). Limited aspirations for improvement were coupled with conservative expectations of PR “*I don’t do it [exercise], can’t do a lot anyway*” (patient ID 110).

### 9.4. Discussion

This prospective qualitative study provides a rich account of how patients appraise an acute exacerbation of COPD resulting in hospitalisation whilst they decline participation in PR. Patients conveyed a diminished sense of self-worth associated with self-conscious cognitions notably, concerns about how they are viewed by others and

guilt about a self-inflicted disease rendering them unworthy of dedicated care. Additionally, patients expressed a desire to avoid hospital and return to a normal existence following an acute exacerbation. In the face of an unpredictable disease, patients appeared reluctant to relinquish control by accepting external support which was also described as threatening.

#### 9.4.1. Not 'worthy' of Pulmonary Rehabilitation

Following an acute exacerbation resulting in hospitalisation patients revealed; self-conscious cognitions including; shame, guilt, self-blame, embarrassment and fear of negative evaluation from others. As with experiences of patients with stable COPD (Arne, Emtner, Janson, & Wilde-Larsson, 2007; Clancy, Hallet, & Caress, 2009; Earnest, 2002) such self-conscious cognitions may cause those considering PR to decline intervention for fear that their shameful behaviour in causing their condition will be exposed.

There may be further effects from internalising responsibility for disease, notably social isolation, which has been observed in those with chronic conditions when making similar judgements about themselves (McPherson, Wilson, & Murray, 2007). Following an acute exacerbation, patients in this study described isolating themselves as a means of mitigating the burden imposed on others. This may also serve to alleviate feelings of guilt and reduce exposure to scrutiny but increases self-imposed limitations and the likelihood of rumination known to affect mood adversely (Martin & Dahlen, 2005).

If those who decline PR experience sensitivity to shaming then this may be exacerbated by unsympathetic interactions with others, including health care professionals (Berger, Kapella, & Larson, 2011). A substantial proportion of doctors believe patients with COPD are to blame for their disease and this may well be communicated to patients (Winstanley, 2008). In order to protect patients' sense of worth and promote therapeutic alliance, health care professionals should be particularly aware of the manner in which they address patients, who during a period of vulnerability attend closely to non-verbal cues and are increasingly sensitive of perceived dismissive behaviour. Dismissive behaviour is likely to increase a sense of threat, already heightened by the disease as experienced, and reduce potential for supported engagement in rehabilitation.



The importance of expressing empathy and reassurance by engaging with patients' concerns, even in the face of a demanding and pressurised health care setting seems paramount (Belcher et al., 2006). An approach of this kind may be useful in promoting a successful doctor-patient relationship which is acknowledged both by patients and health care professionals as an essential component in enhancing engagement in recommended health behaviour (Arnold et al., 2006; Bulley et al., 2009; Keating, Lee, & Holland, 2011b; Harris et al., 2008). By endorsing interventions founded on compassion patients may learn to be kind to themselves with consequent benefits to distress alleviation and wellbeing.

For those patients whose appraisals of limited self-worth and shame are prominent, interactions utilising compassion focused approaches may offer benefits. Interventions founded on compassion, with emphasis on reducing self-blame and self-critical thinking have been found to reduce self-conscious cognitions, including; feeling shamed, disgraced and embarrassed, shown to lead to reduced help-seeking and poor adherence to oxygen therapy in patients with stable COPD (Clancy et al., 2009; Earnest, 2002). Patients may be helped to explore how threatening experiences (i.e. an acute exacerbation of COPD) may relate to ongoing fears and safety strategies (i.e. submissive behaviour leading to helplessness) influencing motivation. (Gilbert, 2009). Compassion focused therapies may have a role in promoting active disease management strategies such as PR, in those individuals presenting with high levels of guilt and self-criticism following an acute exacerbation of COPD.

#### 9.4.2. Maintaining normality

Patients appeared to maintain emotional equilibrium by normalising their symptoms and diminishing their need for further intervention. PR, with its potential to reveal the realities of likely disease trajectory and others whose disease may be more severe, seems threatening and is avoided. These patients' descriptions of normalisation as coping resonate with narratives of patients living with stable COPD and asthma (Small & Lamb, 1999). Yet such avoidant coping is associated with increased distress and feelings of panic. This may reflect dominant strategies of those with trait anxiety yet may also undermine active coping strategies such as acceptance or challenge unhelpful,

catastrophising cognitions in the face of decline (Hallas, Howard, Theadom, & Wray, 2012).

Normalisation and symptom minimisation also served to justify avoidance of PR and mitigate any dissonant feelings if PR was thought to offer benefits. Patients felt that attending PR would not only interfere with their current lifestyle with which they were satisfied with but would also serve to remind them of the potency of the disease. It is however worth considering that by the nature of patient selection (patients were interviewed because they dismissed PR) it is unsurprising the group are 'dismissive' both of symptoms and intervention.

#### 9.4.3. Maintaining control and independence

Patients in this study sought to avoid subsequent admissions associating hospital with contamination, dirt and dying. This selective attention may reflect a more generalised sense of threat but may be problematic if avoidance until overwhelming breathlessness undermines timely interventions (DeVito, 1990). Following hospital discharge, once stability is regained, patients are again reluctant to relinquish control by handing management of their disease over to others agency (health care professionals). This appeared to be particularly the case when patients believed they were sufficiently active via activities of daily living such as; dog walking or household chores. Such emphasis on normal activity may reflect resilience, but may equally reflect denial and health professionals must negotiate appropriate help whilst being mindful of this paradox.

By actively involving patients in their treatment control can be retained (Dowell & Hudson, 1997). Solution focused approaches may have a role in encouraging patients to become active participants in their own disease management, including PR. These tailored goal-orientated therapies help patients to identify and utilise resources enabling more effective problem-solving. Additionally, clear collaboration to focus meaningful, individual goals can help health care professionals build successful therapeutic alliances and involve patients in PR from the earliest opportunity (e.g. at the point of referral). Nurses may be in the best position to engage in this way given patients better rapport with nurses than doctors in the event of an exacerbation (Oliver, 2001).

#### 9.4.4. Strengths and limitations

A major strength of this study is its assessment of a difficult to reach patient population. It offers initial yet rich insights about why patients with COPD decline PR following an acute exacerbation. As self-selected these patient views are not meant to be generalisable to other patient populations, although many themes expressed resonate with findings in patients whose condition is stable. Furthermore, the inclusion of PPI members and a collaborative workshop in addition to the three researchers supports the credibility of the interpretations which are linked to direct quotations to illustrate the constructs identified.

The selection of a small homogenous sample and analysis of a small data set is consistent with the theoretical underpinning of a phenomenological approach. However with its reliance on patients' ability to articulate thoughts and feelings through language data may be constrained. To address this we ensured that we attended and utilised paralinguistic data in our interpretation. As a method IPA in essence focuses on individual experiences and cognitions, which may limit the exploration of systemic issues. Further study utilising iterative approaches informed by Grounded Theory may permit greater exploration of interpersonal and organisational issues which may also impinge on patients refusing PR.

#### 9.4.5. Conclusions

Patients who refuse PR following an acute exacerbation of COPD report self-conscious cognitions associated with lowered self-worth and circumscribed with reduced help-seeking and isolation. Perceived personal culpability for COPD appears to sensitise patients towards their interactions with health care professionals which are construed as critical and judgemental and are likely to increase avoidant behaviours, of which a refusal to PR may be the most overt. Health care professions ought to be mindful of patients' sensitivities to being shamed and should aim to provide a safe and confiding opportunity for PR to be encouraged. Compassion focused interventions which encourage trust and safety may promote active partnership working and serve to facilitate engagement in PR.

# **Chapter 10**

## **10. USING CLUSTER ANALYSIS TO FOCUS THERAPEUTIC INTERVENTIONS FOLLOWING AN ACUTE EXACERBATION OF CHRONIC OBSTRUCTIVE PULMONARY DISEASE**

Chapter 9 offers rich insights into why patients decline Pulmonary Rehabilitation (PR) following an acute exacerbation of Chronic Obstructive Pulmonary Disease (COPD) enabling suggestions to be made for how health care professionals can tailor approaches to facilitate engagement in PR. However, this data was collected on a small, homogenous sample of patients. The use of a quantitative research methodology allows for the collection of data on a larger sample size expanding the breadth and range of enquiry into the needs of patients following an acute exacerbation of COPD. The Illness Perceptions Questionnaire-Revised (IPQ-R) was adopted as a tool to explore patients' appraisals possibly linked to health behaviour (uptake and attendance to PR). This decision was informed by a narrative review exploring associations between the IPQ-R and health behaviour in patients for whom COPD is stable (Chapter 3) and an investigation into the utility of a commonly applied measure in identifying patients who can successfully complete PR and those who are unable (Chapter 6). A cluster-analysis is described and findings are hoped to assist with the development of targeted psychologically-informed interventions which are tailored to shape maladaptive illness perceptions found to be associated with poor adherence to disease management strategies.

### **10.1. Introduction**

Currently, there does not appear to be a clear understanding about the additional needs of patients following an acute exacerbation of COPD and health care professionals remain unsure why patients are reluctant to attend PR. Despite the use of sociodemographic data and a range of clinical and psychological variables (including

anxiety and depression (Chapter 6), researchers have had little success in understanding how patients who complete PR programmes differ from those who are unable (Garrod et al., 2006). Yet, this information is important in determining how to best support the delivery of care following an acute exacerbation of COPD.

Psychological theories suggest that the experience of an acute exacerbation may affect the manner in which a patient perceives their illness. Illness perceptions may, in turn affect patients' engagement in disease management strategies i.e. adherence to PR (Leventhal et al., 1984; Leventhal et al., 1997). However, to date, patients' illness perceptions have not been assessed following an acute exacerbation of COPD.

One method used to identify associations between a variable and health outcome is linear association. However, the information gleaned from linear associations is only one-dimensional. It does not consider how a variable may be influenced by other factors, nor does it allow inferences to be made regarding cause and effect. Often, in explaining health behavior, illness perceptions are considered individually (Fischer et al., 2009). The Common Sense Model would advocate that illness perceptions are not held in isolation but instead interact with each other forming an illness schema. Therefore it may be appropriate to apply a methodology which considers the association between patients' illness perceptions.

Cluster analysis is an increasingly popular technique that has been applied in other disease populations to define meaningful profiles of patients based on their illness perceptions (Charlier et al., 2012; Hobro et al., 2004; Skinner et al., 2011; Medley, Powell, Worthington, Chohan, & Jones, 2010; Graham, Rose, Hankins, Chalder, & Weinman, 2012; Heijmans, 1999). Cluster analysis of psychological data has not been applied previously in COPD. A technique of this kind may be helpful in potentially identifying patients likely to benefit from an intervention designed to shape maladaptive illness perceptions found to be associated with poor adherence to disease management strategies.

The aim of this chapter is therefore to identify possible cluster groups according to patients' illness perceptions following hospitalisation for an acute exacerbation of COPD.

## 10.2. Methods

In Chapter 8 patient recruitment and data collection is described fully.

One hundred and twenty eight patients with a documented diagnosis of an acute exacerbation of COPD were recruited from acute respiratory wards. A referral to PR was offered at the time of hospital admission or shortly after discharge. Comprehensive patient data was collected during a home visit which took place 10 days (+/- three days) post-discharge from hospital.

### 10.2.1. Measures

During the home visit the following self-reported measures were completed by patients:

#### *10.2.1.1. Illness Perceptions Questionnaire-Revised (Moss-Morris et al., 2002)* (Appendix R)

The IPQ-R is a self-reported measure of patients' illness perceptions consisting of nine domains and has been shown to be valid in various disease populations (Moss-Morris et al., 2002). The decision to assess patients' illness appraisals was informed by preliminary work (Chapter 3, Chapter 5 and Chapter 6).

The *identity* component relates to patients' ideas concerning the label given to their disease and the number of symptoms attributed to their disease. The *consequences* domain (Cronbach's alpha ( $\alpha$ ) = .84) is indicative of patients' beliefs about illness severity and how it impacts on physical, social and psychological functioning. The *timeline acute/chronic* ( $\alpha$  = .89) and *timeline cyclical* ( $\alpha$  = .79) domains indicate patients' perceptions regarding the duration of the disease and whether symptoms are stable or fluctuating. *Personal control* ( $\alpha$  = .81) and *treatment control* ( $\alpha$  = .80) assess the extent to which patients feel their own actions or treatment can control their disease. *Illness coherence* ( $\alpha$  = .87) reflects patients' understanding of their disease and the extent to which it "makes sense" to them. Finally *emotional representations* ( $\alpha$  = .88) assess patients' affective response to disease.

The identity domain is scored by adding together the yes-rated items in column two (“this symptom is related to my illness”). The sum of items is used to calculate the other domains when, strongly disagree = 1; disagree = 2; neither agree or disagree = 3; agree = 4; strongly agree = 5 and considering reverse scoring. High scores on the identity, timeline, consequences, and cyclical dimensions represent strongly held beliefs about the number of symptoms attributed to the illness, the chronicity of the condition, the negative consequences of the illness, and the cyclical nature of the condition. High scores on the personal control, treatment control and coherence dimensions represent positive beliefs about the controllability of the illness and a personal understanding of the condition.

The English version of the questionnaire was used and the word ‘illness’ was replaced with ‘lung disease’ to make it specific to the population (Howard et al., 2009). In line with Fischer’s suggestion, weight gain was included in the symptoms/identity subscale (Fischer et al., 2010). PR was discussed before asking patients to complete the IPQ-R to encourage the consideration of PR as a treatment component in addition to medications. This was believed to be important because patients’ beliefs regarding the effectiveness of their treatment have been shown to predict attendance to cardiac rehabilitation programmes (Cooper et al., 2007).

#### *10.2.1.2. The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) (Appendix B)*

A detailed description of the Hospital Anxiety and Depression Scale (HADS) is provided in Chapter 6.

#### *10.2.1.3. The Chronic Respiratory Questionnaire-Self Reported (Williams et al., 2001) (Appendix C)*

A detailed description of the Chronic Respiratory Questionnaire-Self-Reported (CRQ-SR) is provided in Chapter 6.

#### *10.2.1.4. The Pulmonary Rehabilitation Adapted Index of Self-Efficacy (Vincent et al., 2011) (Appendix S)*

The Pulmonary Rehabilitation Adapted Index of Self-Efficacy (PRAISE) ( $\alpha = .95$ ), is an adapted version of the General Self-Efficacy Scale (Schwarzer & Jerusalem, 1995) for PR patients which has been fully validated in a PR population. The self-reported tool consists of 15 items scored from one to four; four being the highest level of perceived self-efficacy.

#### *10.2.1.5. Physical activity: Energy expenditure and step count*

The measurement of physical activity using the SenseWear PRO<sup>2</sup> Armband (SWM) is described in Chapter 8.

#### 10.2.2. Six month follow up

Data regarding the uptake and completion of a PR programme and all cause, respiratory and non-respiratory hospital admissions were documented six months following hospital discharge. In-depth information regarding collection of data at the six month follow up period is documented in Chapter 8.

#### 10.2.3. Statistical Analysis

Data were analysed using SPSS 18.0 for Windows (SPSS Inc, Chicago, USA).

##### *10.2.3.1. Preliminary data analysis*

A Shapiro-Wilk test for normality was performed on each variable of the IPQ-R and the appropriate statistical tests applied. A proportion of patients did not complete all the questionnaires so a missing data analysis was conducted including all variables. A Mann Whitney U was also used to compare patients who completed all the questionnaires versus those for whom no data was available.

#### 10.2.4. Cluster Analysis

Cluster analysis was used to classify cases to groups generated by patients' illness perceptions measured using the IPQ-R. Eight domains of the IPQ-R were included in



the cluster analysis. Data yielded from the causal domain of the IPQ-R was not considered because it provides a binary variable which cannot be dealt with using the method of cluster analysis applied. Furthermore, it does not support the development of a psychological intervention, one of the future aims arising from this thesis. Before running the analysis all eight domains of the IPQ-R were standardised into z-scores. A two-step approach to the cluster analysis was then applied. In the first step hierarchical cluster analysis using Ward's method (with squared Euclidian distance similarity measure) was used to identify the number of clusters and cluster centroids. Possible cluster divisions were decided by inconsistent jumps between stages in an agglomeration schedule. Once cluster numbers and centroids were decided a K-means cluster analysis was used to cluster cases to centroids (Clatworthy et al., 2007). This method of cluster analysis is described fully and justified in Chapter 7.

The selected cluster solution and the predetermined cluster membership (K-means clustering) was repeated on a random sample containing 50% of the cases (Clatworthy et al., 2007). The percentage of cases correctly classified was recorded.

#### 10.2.5. Between-cluster differences

The identified clusters were characterised by considering between-cluster differences in illness perceptions, demographics, hospital information, mood, health status, self-efficacy, physical activity (energy expenditure and step count) and previous exercise behaviour. Differences were investigated for acceptance, uptake and completion of PR following hospitalisation with an acute exacerbation of COPD.

Demographic data measured as a continuous variable were normally distributed and a one way Analysis of Variance was applied. However, due to unequal sample sizes and the kurtosis of data, between-group differences for all other variables were tested using a Kruskal-Wallis or Chi-squared test ( $\chi^2$ ) as appropriate. Significant results for non-binary variables were followed up by either an independent t-test or a Mann-Whitney U test applying a bonferroni correction to account for multiple comparisons ( $p < 0.01$ ). Effect sizes for any differences were calculated using Pearson's  $r$ . A negative binomial regression count model was used to assess between-cluster differences in hospital information.

#### 10.2.6. Inter-correlations

Bivariate inter-correlations between IPQ-R domains with each emergent cluster were investigated.

### **10.3. Results**

#### 10.3.1. Data analysis

##### *10.3.1.1. Preliminary data analysis*

A Shapiro-wilk test for normality was performed on each variable of the IPQ-R and was found to be significant ( $p < 0.05$ ) indicating that the data is non-normally distributed. Although normally distributed for skewness the data is non-normal in terms of kurtosis. Subsequently the appropriate non-parametric tests were applied.

All patients completed the IPQ-R during the study visit but only 67% of patients complete the HADS and all subscales of the CRQ-SR and just 62% of patients completed the PRAISE. This is in spite of me arranging to pick them up from patients' homes along with the activity monitor. A missing value analysis was performed including all variables ( $p = 0.131$ ) and it was assumed that all data was missing completely at random. Furthermore, the results of a Mann Whitney U comparing patients who complete the questionnaires and those for whom no data was available was not significant for all subscales of the IPQ-R ( $p > 0.05$ ) with the exception of timeline – chronic ( $p < 0.05$ ). It is likely that this result occurred as part of a type 1 error, due to the number of tests being performed.

#### 10.3.2. Cluster analysis

Although some small outliers were visible on box plots for treatment control and personal control none were consistent and therefore were not removed, maintaining the sample size.

Three clusters emerged from the analysis. In Cluster 1 (n=52) patients perceived higher personal control, associated fewer symptoms with their disease, perceived a less chronic and cyclical timeline, had lesser emotional representations and consequences. Patients in Cluster 1 were labelled as being '*in control*'. Patients in Cluster 2 (n=36) displayed lower illness coherence and personal control, associated more symptoms with their disease but had weaker emotional representations, reported fewer consequences and perceived a less chronic timeline. Patients in Cluster 2 were assigned as representing a '*disengaged*' illness schemata (n=36). In Cluster 3 (n=40) patients had high illness coherence, perceived a high number of symptoms to be associated with their disease and for it to have greater consequences and a cyclical timeline. These patients had very high emotional representations. Patients in Cluster 3 were designated as comprising of a '*distressed*' illness schemata (n=40).

Significant differences were noted between clusters on all illness perceptions domains except treatment control (identity:  $H(2) = 48.107$ ,  $p < 0.001$ ; timeline (acute/chronic):  $H(2) = 35.664$ ,  $p < 0.001$ ; timeline (cyclical):  $H(2) = 18.395$ ,  $p < 0.001$ ; consequences:  $H(2) = 60.332$ ,  $p < 0.001$ ; personal control  $H(2) = 19.759$ ,  $p < 0.001$ ; illness coherence  $H(2) = 35.809$ ,  $p < 0.001$ ; emotional representations  $H(2) = 80.174$ ,  $p < 0.001$ ). Table 12 shows the between-cluster differences for the eight subscales of the IPQ-R and Figure 10 displays a visual representation of the illness schema held within each of the three clusters.

In a validation exercise with a random 50% of the sample 87.5% were successfully reclassified into the same cluster, confirming the robustness of the clusters (Clatworthy et al., 2007).

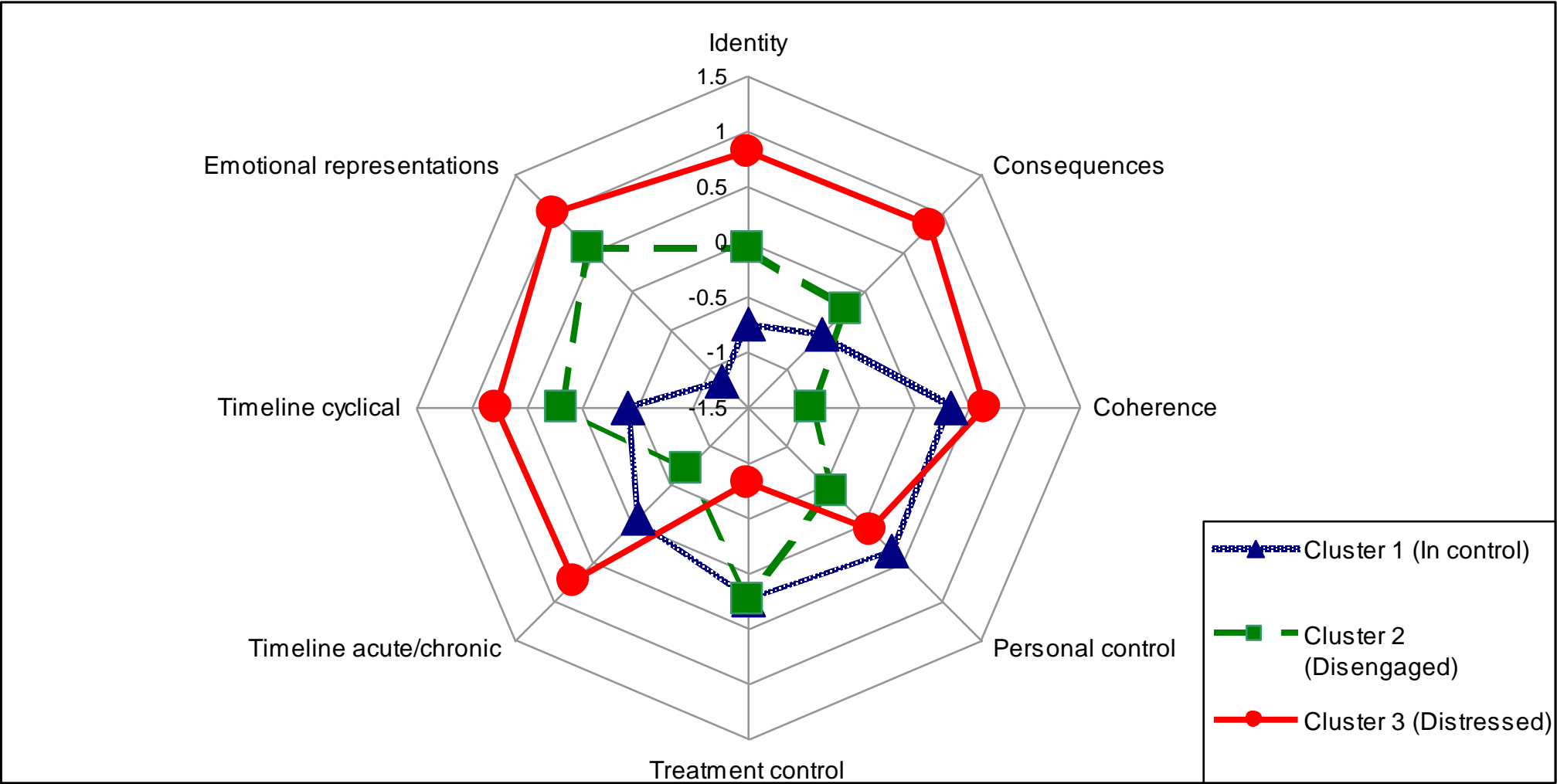
**Table 12. Illness perceptions. Medium (IQR) score for each cluster, between-cluster differences and effect size (Pearson's r) on all domains of the Illness Perceptions Questionnaire-Revised**

	Medium (IQR)				Effect sizes for between group differences (Pearson's r)		
	Whole group	Cluster 1 "In control"	Cluster 2 "Disengaged"	Cluster 3 "Distressed"	1 & 2	1 & 3	2 & 3
<b>Illness perceptions</b>	<b>N=128</b>	<b>N=52</b>	<b>N=36</b>	<b>N=40</b>			
Identity	6.00 (4.00-8.00)	4.00 (3.00-5.75)	6.00 (5.00-7.00)	8.50 (7.00-10.00)	r=-0.36*	r=-0.67**	r=0.49**
Consequences	22.00 (18.00-24.00)	18.50 (15.70-21.75)	20.00 (18.25-22.00)	25.00 (24.00-27.45)	r=-0.20	r=-0.74**	r=-0.70**
Timeline (acute/chronic)	24.00 (19.05-26.00)	22.50 (19.25-26.00)	19.60 (18.00-23.75)	26.50 (24.00-30.00)	r=-0.27	r=-0.43**	r=-0.65**
Timeline (cyclical)	14.00 (11.00-16.00)	12.00 (3.25-14.00)	14.00 (12.00-16.00)	16.00 (13.00-17.00)	r=-0.28*	r=-0.41**	r=-0.23
Personal control	20.00 (19.00-22.00)	21.00 (19.00-24.00)	18.00 (14.50-20.00)	20.00 (16.25-22.75)	r=-0.48**	r=-0.20	r=-0.25
Treatment control	16.00 (13.00-17.00)	16.00 (13.00-17.00)	16.00 (14.00-18.00)	15.00 (12.25-17.00)			
Illness coherence	17.00 (13.00-20.00)	18.00 (14.25-20.75)	12.00 (10.00-14.00)	19.50 (17.00-21.00)	r=-0.52**	r=-0.14	r=-0.63**
Emotional representations	18.50 (15.00-24.00)	12.00 (11.00-16.00)	22.00 (19.00-23.00)	24.50 (22.00-26.00)	r=-0.74**	r=-0.81**	r=-0.37*

\*p<0.01, \*\*p<0.001.

IQR = Inter Quartile Range

Figure 10. A visual representation of the three illness schema (mean/medium z-score)



### 10.3.3. Between-cluster differences

#### *10.3.3.1. Demographic and hospital information*

Differences were identified between the groups in terms of their age and disease severity (Medical Research Council (MRC) dyspnoea grade) ( $H(2) = 10.901, p < 0.01$ ). Patients in Cluster 1 (*'in control'*) were significantly older than Cluster 3 (*'distressed'*) ( $p < 0.001$ ) and were less disabled by their breathlessness (lower MRC grade) than Cluster 2 (*'disengaged'*) ( $p < 0.001$ ) or Cluster 3 (*'distressed'*) ( $p < 0.001$ ) (Table 13).

There were no significant differences between the groups in hospital information (all cause admissions, respiratory admissions, non-respiratory admissions) measured in the 12 months previous to the acute exacerbation ( $p > 0.01$ ). Number of all cause admissions measured in the six months following an acute exacerbation of COPD were not significantly different between cluster groups ( $p = 0.09$ ), although there appeared to be a trend for a greater number of admissions to have occurred in Cluster 2 (*'disengaged'*). When divided into respiratory admissions and non-respiratory admissions, those in Cluster 2 (*'disengaged'*) were identified as being 4.07 times more likely to be admitted for non-respiratory related problems ( $p < 0.01$ ), accounting for almost 50% of the total number of non-respiratory admissions (Table 14).

**Table 13. Demographic information. Mean (SD)/Medium (IQR) score for each cluster, between-cluster differences and effect size (Pearson's r) on all measured variables**

	Mean (SD)/Medium (IQR)			Effect sizes for between-cluster differences (Pearson's r)		
	Cluster 1 "In control"	Cluster 2 "Disengaged"	Cluster 3 "Distressed"	1 & 2	1 & 3	2 & 3
<b>Demographics</b>	<b>N=52</b>	<b>N=36</b>	<b>N=40</b>			
Gender (% male)	61.54	55.56	57.50			
Age (years) \$	73.04 (7.73)	72.17 (9.50)	66.78 (8.50)	r=0.05	r=0.36**	r=0.28
BMI \$	25.91 (5.55)	24.94 (7.01)	28.70 (7.36)			
Social support (% alone)	30.77	44.44	30.00			
Length of diagnosis (years) \$	5.65 (5.97)	6.39 (6.17)	5.68 (3.91)			
No. of co-morbidities \$	2.54 (1.80)	3.44 (1.66)	3.33 (2.18)			
Oxygen at home (% yes)	23.08	25.00	25.00			
Smoking status (% current)	32.69	33.33	35.00			
Pack years (years) \$	41.92 (28.55)	57.00 (25.54)	50.26 (33.66)			
FEV <sub>1</sub> (l) \$	1.16 (0.51)	1.03 (0.47)	1.09 (0.48)			
FEV <sub>1</sub> /FVC (%) \$	50.72 (12.26)	51.28 (14.55)	50.17 (13.55)			
MRC grade (%)				r=-0.44**	r=0.37**	r=-0.15
Grade 1	1.92	2.78	0.00			
Grade 2	26.92	5.56	5.00			
Grade 3	34.62	11.11	22.50			
Grade 4	23.08	33.33	42.50			
Grade 5	13.46	47.22	30.00			

\*p<0.01, \*\*p<0.001.

\$ = Medium Scores; SD = Standard Deviation; IQR = Inter Quartile Range; BMI = Body Mass Index; FEV<sub>1</sub>= Forced Expiratory Volume in One Second; FEV<sub>1</sub>/FVC = Forced Expiratory Volume in One Second/Forced Vital Capacity; l = Litres; MRC = Medical Research Council.

**Table 14. Hospital information. Total number for each cluster group**

	Count				
	Whole group	Cluster 1 “In control”	Cluster 2 “Disengaged”	Cluster 3 “Distressed”	Significance of the overall model
<b>Hospital information</b>	<b>n=128</b>	<b>n=52</b>	<b>n=36</b>	<b>n=40</b>	
Length of current hospital stay (days) (median and IQR)	3.00 (2.00 – 6.00)	4.00 (2.00-6.00)	4.00 (3.00-6.75)	3.00 (2.00-5.00)	p=0.41
Supported discharge (% yes)	71.01%	71.15%	69.44%	72.50%	
All cause admissions in the previous 12m.	327	117 (35.78%)	107 (32.72%)	103 (31.50%)	p=0.55
Respiratory admissions in the previous 12m.	266	96 (36.09%)	80 (30.08%)	90 (33.83%)	p=0.68
Non-respiratory admission in the previous 12m.	61	21 (34.43%)	27 (44.26%)	13 (21.31%)	p=0.08
All cause admissions in the following 6m.	158	49 (31.01%)	63 (39.87%)	46 (29.11%)	p=0.09
Respiratory admissions in the following 6m.	114	33 (28.95%)	41 (35.96%)	40 (35.09%)	p=0.15
Non-respiratory admission in the following 6m.	44	16 (36.36%)	22 (50.00%)	6 (13.64%)	p=0.02

IQR = Inter Quartile Range



#### 10.3.3.2. Mood, health status, self-efficacy

Between-cluster differences were revealed on both sub-scales of the HADS (anxiety:  $H(2) = 33.547$ ,  $p < 0.001$ ; depression:  $H(2) = 21.035$ ,  $p < 0.001$ ), in three out of the four domains on the CRQ-SR (fatigue:  $H(2) = 18.230$ ,  $p < 0.001$ ; emotion:  $H(2) = 18.230$ ,  $p < 0.001$ ; mastery:  $H(2) = 32.741$ ,  $p < 0.001$ ) and in self-efficacy ( $H(2) = 13.254$ ,  $p = 0.001$ ). Differences between clusters for the dyspnoea domain of the CRQ-SR only approached significance ( $p = 0.01$ ) (Table 15).

Patients in Cluster 2 (*'disengaged'*) experienced less anxiety than those in Cluster 3 (*'distressed'*) but more than Cluster 1 (*'in control'*) ( $p < 0.01$ ). There were no significant differences between Cluster 2 and 3 (*'distressed'*) or Cluster 1 (*'in control'*) and 2 (*'disengaged'*) in terms of depressive symptoms ( $p > 0.01$ ). Cluster 2 (*'disengaged'*) displayed significantly lower mastery than Cluster 1 (*'in control'*) ( $p < 0.01$ ) and lower fatigue and emotion than Cluster 3 (*'distressed'*) ( $p < 0.01$ ). Cluster 2 (*'disengaged'*) and 3 (*'distressed'*) were similar in terms of their self-efficacy and experienced less than Cluster 1 (*'in control'*) although this difference was not significant between Clusters 1 (*'in control'*) and 2 (*'disengaged'*) ( $p > 0.01$ ).

**Table 15. Mood, health status and self-efficacy. Medium (IQR) score for each cluster, between-cluster differences and effect size (Pearson's r)**

	Medium (IQR)				Effect sizes for between-cluster differences (Pearson's r)			
	Whole group	Cluster 1 "In control"	Cluster 2 "Disengaged"	Cluster 3 "Distressed"	Whole group	1 & 2	1 & 3	2 & 3
<b>Mood</b>	<b>N=86</b>	<b>N=39</b>	<b>N=20</b>	<b>N=27</b>				
HADS anxiety (%)					p<0.001	r=-0.38*	r=-0.68**	r=-0.49*
None	46.51	79.49	35.00	7.41				
Probable	17.44	5.13	40.00	18.52				
Presence	36.05	15.38	25.00	74.07				
HADS depression (%)					p<0.001	r=-0.20	r=-0.56**	r=-0.37
None	56.98	79.49	60.00	22.22				
Probable	30.23	15.38	30.00	51.85				
Presence	12.79	5.13	10.00	25.93				
<b>Health status</b>	<b>N=89 (N=86 dyspnoea)</b>	<b>N=39 (N=36 dyspnoea)</b>	<b>N=21</b>	<b>N=29</b>				
CRQ-SR dyspnoea	2.37 (1.95-3.20)	2.70 (2.00-3.75)	2.00 (1.60-2.90)	2.00 (1.90-2.80)	p=0.01			
CRQ-SR fatigue	3.00 (2.00-4.00)	3.50 (2.50-4.50)	3.25 (2.38-4.25)	2.00 (1.50-3.00)	p<0.001	r=-0.10	r=-0.48**	r=-0.45*
CRQ-SR emotion	3.71 (2.93-5.00)	4.86 (3.71-6.00)	3.86 (3.20-4.36)	2.71 (2.07-3.43)	p<0.001	r=-0.33	r=-0.69**	r=-0.49*
CRQ-SR mastery	4.00 (2.88-5.00)	4.75 (4.00-5.75)	3.75 (2.50-4.63)	3.00 (2.25-3.50)	p<0.001	r=-0.37*	r=-0.68**	r=-0.34
<b>Self-efficacy</b>	<b>N=79</b>	<b>N=37</b>	<b>N=17</b>	<b>N=25</b>				
PRAISE	42 (36.00-48.00)	47.00 (38.00-52.00)	40.00 (29.50-45.00)	37.00 (33.50-43.00)	p=0.001	r=-0.33	r=-0.43*	r=-0.07

\*p<0.01, \*\*p<0.001.

IQR = Inter Quartile Range; HADS = Hospital Anxiety and Depression Scale ('none' 0-7, 'probable' 8-10, 'presence' >11); CRQ-SR = Chronic Respiratory Questionnaire-Self-Reported; PRAISE = Pulmonary Rehabilitation Adapted Index of Self-Efficacy

#### *10.3.3.3. Physical activity, previous exercise behaviour, acceptance and uptake of Pulmonary Rehabilitation*

There were no differences between clusters in terms of physical activity (energy expenditure, step count), exercise behaviour, attendance and adherence to previous PR or acceptance and uptake and completion of PR at six months following hospitalisation with an acute exacerbation of COPD ( $p>0.01$ ) (Table 16).

#### 10.3.4. Inter-correlations

In Cluster 1 (*'in control'*) significant relationships existed between timeline and consequences ( $r=0.46$ ,  $p<0.01$ ), emotional representations and treatment control ( $r=0.32$ ,  $p<0.05$ ) and illness coherence and treatment control ( $r=0.34$ ,  $p<0.05$ ). In Cluster 2 (*'disengaged'*) personal and treatment control correlated with each other ( $r=0.46$ ,  $p<0.01$ ), identity and timeline cyclical ( $r=0.49$ ,  $p<0.01$ ) and timeline and consequences ( $r=0.42$ ,  $p<0.05$ ). In Cluster 3 (*'distressed'*) personal and treatment control were correlated ( $r=0.46$ ,  $p<0.01$ ), another association was between identity and personal control ( $r=0.43$ ,  $p<0.01$ ) (Table 17).

**Table 16. Physical activity, previous exercise behaviour, acceptance and uptake of Pulmonary Rehabilitation. Medium (IQR) score for each cluster, between-cluster differences and effect size (Pearson's r)**

	Medium (IQR)				
	Whole group	Cluster 1 "In control"	Cluster 2 "Disengaged"	Cluster 3 "Distressed"	Between-cluster differences
<b>Physical activity levels</b>	<b>N=128</b>	<b>N=39</b>	<b>N=15</b>	<b>N=25</b>	
Energy expenditure (Kcal)	1092.50 (934.40-1323.33)	1087.67 (934.40-1312.33)	1055.67 (844.80-1383.33)	1271.25 (936.77-1328.75)	p=0.68
Number of steps	1830.50 (746.25-3525.83)	1991.00 (1029.20-3815.33)	1084.25 (331.00-2418.33)	1562.67 (570.70-3360.42)	p=0.15
<b>Exercise behaviour/Pulmonary Rehabilitation</b>		<b>N=52</b>	<b>N=36</b>	<b>N=40</b>	
Current exercise behaviour (%)					p=0.57
Currently exercises	15.63	26.92	8.33	7.50	
Exercised previously	51.56	51.92	50.00	52.50	
Never exercised	32.81	21.15	41.67	40.00	
Previous PR (%)					p=0.20
referred	39.06	36.54	30.56	50.00	
completed (% of those referred)	48.00	57.89	72.73	25.00	
Accepted a referral to PR (%)	55.47 (n=71)	51.93 (n=28)	58.33 (n=21)	55.00 (n=22)	p=0.92
Attended initial Ax at 6m (% of those referred)	54.93 (n=39)	57.14 (n=16)	57.14 (n=12)	50.00 (n=11)	p=0.86
Accepted PR at 6m (% of those who attended initial Ax)	74.36 (n=29)	75.00 (n=12)	75.00 (n=9)	72.73 (n=8)	p=0.99
Completed at 6m (% of those accepting PR)	37.93 (n=11)	41.67 (n=5)	33.33 (n=3)	37.50 (n=3)	p=0.02

\*p<0.01, \*\*p<0.001.

IQR = Inter Quartile Range; PR = Pulmonary Rehabilitation; Ax = assessment.

**Table 17. The pattern of inter-correlations (Spearman's r) between Illness Perception Questionnaire-Revised domains within each cluster**

	<b>Identity</b>	<b>Consequences</b>	<b>Timeline (a/c)</b>	<b>Timeline (cyc)</b>	<b>P control</b>	<b>T control</b>	<b>Illness coh</b>
<b>Cluster 1 “In control”</b>							
Consequences	-0.02						
Timeline (acute/chronic)	0.14	0.46**					
Timeline (cyclical)	0.06	0.04	-0.01				
Personal control	0.07	-0.03	-0.06	0.12			
Treatment control	0.05	-0.09	-0.16	0.10	0.18		
Illness coherence	0.12	0.20	0.27	-0.06	0.03	0.34*	
Emotional representations	0.02	0.12	0.13	0.00	0.23	0.32*	0.25
<b>Cluster 2 “Disengaged”</b>							
Consequences	-0.15						
Timeline (acute/chronic)	-0.14	0.42*					
Timeline (cyclical)	0.49**	-0.11	-0.13				
Personal control	0.11	-0.05	-0.24	0.22			
Treatment control	-0.06	0.05	-0.09	0.02	0.46**		
Illness coherence	-0.31	-0.19	-0.17	-0.08	0.05	-0.04	
Emotional representations	0.13	0.08	0.22	0.12	0.01	-0.18	-0.04
<b>Cluster 3 “Distressed”</b>							
Consequences	0.21						
Timeline (acute/chronic)	-0.04	0.21					
Timeline (cyclical)	-0.19	-0.02	-0.22				
Personal control	-0.43**	-0.16	-0.13	0.10			
Treatment control	0.08	-0.07	-0.25	0.07	0.46**		
Illness coherence	-0.22	-0.13	0.16	0.27	-0.11	-0.16	
Emotional representations	0.12	0.16	-0.09	0.14	0.06	0.30	-0.14

\*p<0.05, \*\*p<0.01.

#### 10.4. Discussion

This is the first study to assess illness perceptions in patients with COPD following hospitalisation with an acute exacerbation. A cluster analysis technique was applied to identify meaningful groups of patients according to their illness perceptions. Three distinct cluster groups were identified. Despite there being no differences between clusters in terms of, disease duration and severity, Clusters 1 and Cluster 3 differed significantly in the perceived time course and consequences of the disease, and most importantly in emotional response to disease. They were labelled as '*in control*' and '*distressed*' accordingly. Cluster 2 comprised of a '*disengaged*' illness schema with patients displaying little illness coherence, fewer emotional representations, lower levels of personal control and had little awareness of disease consequences.

No between-cluster differences existed in acceptance or uptake of PR despite illness perceptions following acute events (MI) being associated with adherence to Cardiac Rehabilitation (French et al., 2006; Petrie et al., 2002). Perhaps this is not surprising given the potential floor effect with only small numbers of patients accepting a referral to PR and attending their initial assessment for the programme (Chapter 8). A cluster analysis may be useful in potentially identifying those patients most likely to benefit from an intervention designed to shape maladaptive illness perceptions.

The cluster groups identified, in particular Cluster 1 and Cluster 3, are similar to those profiles detected in other chronic diseases. Cluster 1 ('*in control*') is similar to the '*low seriousness*' group detected in patients with Addison's disease and Cluster 3 ('*distressed*') reflects the '*high seriousness*' group (Heijmans, 1999). However, perceptions of disease severity could not be explained by differences in objective measures of disease severity (Forced Expiratory Volume in one second (FEV<sub>1</sub>) or FEV<sub>1</sub>/Forced vital capacity (FVC). Furthermore, Cluster 1 ('*in control*') can be compared to the '*low distress/active approach group*' detected in patients with breast cancer (Charlier et al., 2012). This group were identified as adopting more problem-based coping and were more likely to have improved outcome in-terms of social support. Yet, following an acute exacerbation of COPD those individuals assigned to Cluster 1 did not have higher levels of social support than the other two clusters. Finally a study, exploring illness perceptions in individuals suffering from chronic pain, also

identified profiles similar to those represented by Cluster 1 (*'in control'*) and Cluster 3 (*'distressed'*) (Hobro, Weinman, & Hankins, 2004). Despite being labelled as *'adaptors'* and *'non-adaptors'* respectively, those patients considered to represent an *'adaptors'* profile (Cluster 1) still did not attend PR. A qualitative analysis described in Chapter 9 suggests that avoidance may stem from a reluctance to surrender feelings of control, highlighting the complexity of factors which influence decision-making, particularly in a population of patients post-acute exacerbation. For example, although perceived seriousness of disease consequences were found to be predictive of better health outcomes in patients, newly diagnosed with diabetes (Skinner et al., 2011), patients assigned to Cluster 3 (*'distressed'*) who scored highly on the consequences domain of the IPQ-R still did not attend PR, perhaps due to increased emotional arousal.

A study exploring illness schema in patients with a traumatic brain injury was the only study to identify a cluster profile similar to Cluster 2 (*'disengaged'*) (Medley, Powell, Worthington, Chohan, & Jones, 2010). This is surprising as the patients with traumatic brain injuries were considerably younger than patients who had experienced an acute exacerbation of COPD. Rather than being attributed to aging, ambivalence may be related to perceived personal culpability for their condition (Chapter 9), or a reluctance to accept a situation for which they assumed no personal responsibility (i.e. *You see my mother suffered with her breathing you know...I mean she was 94 when she died*" (patient ID 128) Chapter 9).

Cluster 1 (*'in control'*) and Cluster 3 (*'distressed'*) were quite distinct particularly in relation to emotional representations. Patients in Cluster 3 (*'distressed'*) displayed higher emotional representations and unsurprisingly experienced more severe symptoms of anxiety and depression than those in Cluster 1 (*'in control'*). It would appear that emotional representations play a key role in defining clusters in patients with COPD following an acute exacerbation, possibly because symptoms of breathlessness are so intimately associated with anxiety (Bailey, 2004). It is worth noting that Cluster 3 (*'distressed'*) reported more breathless symptoms, consistent with the associations found between increased symptoms and enhanced emotions in patients with other chronic illnesses (Heijmans, 1999). Given the prominence of heightened distress in patients with COPD, health care professionals caring for those during exacerbations should be alert to intense arousal and its impact on attention and be trained to respond

with empathy and reassurance to enable the patient to focus and manage symptoms (DeVito, 1990). If patients' very real expressions of intense fear are dismissed their confidence in health care professionals will be compromised, undermining therapeutic alliance and future need for adherence.

This information may have important implications for the timing of PR. In previous research studies post-exacerbation PR has been delivered within 10 days following hospital discharge, however a prospective observation of a PR service reveals that patients fail to attend their initial assessment for PR until three months have elapsed from hospital discharge (Chapter 8). No additional benefits of completing PR early (within two weeks of exacerbation) have been identified (Puhan et al., 2012) and uptake may be increased by liaising with Primary Care services following hospital discharge. It may be that by three months patients feels more able to participate in PR once symptoms of anxiety have resolved.

There were no differences in physical activity behaviour between the three cluster groups. A similar study conducted on patients with breast cancer found that cluster groups derived using illness perception data, differed in their levels of physical activity with 'distress' being a mediator (Charlier et al., 2012). However Charlier et al (2012) measured physical activity subjectively whereas in this study an objective measure of energy expenditure and step count was applied. This is the first study to measure the association between illness perceptions and an objective measure of health behaviour (level of physical activity). However, large standard deviations exist in both energy expenditure and step count suggesting that to accurately measure physical activity in this population of patients a larger sample size is required. This is despite previous studies exploring physical activity following hospitalisation with an acute exacerbation of COPD consisting of significantly fewer patients (n=17) (Pitta et al., 2006a).

Although it was not possible to detect between-cluster differences in acceptance/uptake of PR, nor in levels of physical activity, these findings highlight the variation which exists between patients' appraisals of their disease, advocating an individualised approach to PR delivery. By identifying cluster groups according to different combinations of illness perceptions, interventions can be focused to meet the specific needs of patients following an exacerbation.



In Cluster 1 (*'in control'*) and Cluster 2 (*'disengaged'*) significant associations exist between chronicity of disease and consequences. This association was not apparent in Cluster 3 (*'disengaged'*) nor were strong inter-correlations found between emotional representations and consequences. It would appear that distress is not related to perceptions of chronicity or perceived severity of disease. Given that illness perceptions were measured following an acute exacerbation it is plausible to assume that distress is caused by the sudden onset of intense breathlessness which may resolve over time.

High associations between personal control and treatment control in Cluster 2 (*'disengaged'*) and Cluster 3 (*'distressed'*) suggest the dependency of personal control on effectiveness of treatments. This may reflect passivity and deference which is not displayed in Cluster 1 (*'in control'*). Instead those in Cluster 1 (*'in control'*) possess high personal control, independent of treatment control, which may be threatened by accepting intervention (PR). Although not significant, a higher proportion of those assigned to Cluster 1 were male. Issues around stoicism and reduced help-seeking in males are well recognised and appear to be related to men's reluctance to acknowledge their illness. Reluctance to access health care services is likely associated with men's fear of appearing vulnerable (Gough, 2013).

The scores from the IPQ-R domain 'treatment control' are comparable to a stable population of patients with COPD across all three clusters (Fischer et al., 2010) but are lower than those found in other disease groups (Alsen et al., 2010; Charlier et al., 2012; French et al., 2006; Medley et al., 2010). This is likely to be a consequence of having a diagnosis of a chronic, progressive disease which is punctuated by fluctuations in symptoms. Acute exacerbations are unpredictable and have been suggested to promote constant monitoring of symptoms and hypervigilance in patients with COPD (Russell et al., 1998). Patients in Cluster 1 (*'in control'*) do not appear to be overwhelmed by the persistent threat of an acute exacerbation and are able to manage their emotions accordingly unlike those in Cluster 3 (*'distressed'*). Patients construe the sensation of increased breathlessness as a threat of dying and catastrophic cognitions have been identified explicitly in patients with COPD (Porzelius et al., 1992). It is worth noting that those in Cluster 1 (*'in control'*) are significantly older than patients in Cluster 3 (*'distressed'*) and therefore may be more able to attribute functional limitations to the process of aging or be more hopeful about mortality. It is known that people in their 70s

are more affected physically by aging than patients in their 60s (Lazarus & Harridge, 2007).

Information derived from developing cluster groups from illness perceptions data can further inform how health care professionals might intervene to shape and modify patients' illness perceptions to enhance disease-management strategies (i.e. PR). The disease presentations are conceptualised as distressing (Cluster 3 '*distressed*') providing the focus of several theory-based intervention models including; Cognitive Behavioural Therapy (CBT) (Brooks, Rimes, & Chalder, 2011), Mindfulness (Grossman et al., 2010) and Acceptance and Commitment Therapy (Forman et al., 2012).

#### 10.4.1. Cluster 3 '*distressed*'

CBT emphasises the identification and modification of maladaptive beliefs, this is likely to be difficult in the face of intense breathlessness as increased arousal and fear of death represent very real anxieties. Furthermore, it may not be a realistic therapeutic strategy to eliminate feelings of distress associated with breathless symptoms in this population of patients who, as part of the disease process, will experience shortness of breath several times a day triggering a psychological connection between breathing difficulties and the essentiality of breathing for survival. The appropriateness of solely CBT for use in this population is debatable and its effectiveness in reducing feelings of anxiety in patients with COPD is still unclear (Baraniak & Sheffield, 2011).

Instead of eliminating cognitions it may be more appropriate for patients to modify their involvement with their thoughts, proposing a role for Mindfulness. Mindfulness encourages patients to accept their feelings and disengage from the content of distressing thoughts by focusing on goal-based actions. In the United Kingdom a referral to PR is offered whilst patients are hospitalised with an acute exacerbation of COPD in accordance with the 'care bundle' (Hopkinson et al., 2012). However, used in combination with 'acceptance', Mindfulness may offer a more promising and less immediately threatening, treatment alternative to PR. By reducing intense feelings of distress such an intervention delivered following an acute exacerbation may subsequently promote engagement in PR undertaken at a slightly later date.

#### 10.4.2. Cluster 1 ‘in control’

Mindfulness may also serve as a useful intervention for those patients assigned to Cluster 1 ‘*in control*’. These patients appear to have successfully disengaged from unrealistic goals, leading to lower emotional distress, but may benefit from assistance in reframing new goals, supporting the delivery of Mindfulness as a stepped-care approach. This approach to delivering care has been noted to successfully address the psychological needs of patients attending a cardiac rehabilitation program without the burden of unnecessary intervention (Child, Sanders, Sigel, & Hunter, 2010). Delivering therapy which is aligned with the patients’ requirements may also reduce dismissive feelings (e.g. ‘this doesn’t apply to me’) leading to more active involvement.

#### 10.4.3. Cluster 2 ‘disengaged’

Supporting patients in Cluster 2 (*‘disengaged’*) in a way which promotes active engagement in treatment such as PR is likely to be very challenging. Patients in this cluster lack understanding and associate few symptoms and consequences with their disease, they may have activity chosen to avoid information about their disease, prompted by denial or ambivalence about the diagnosis of a disease with a degenerative process and poor prognosis. The mis-management of their disease appears to extend beyond their COPD, accounting for numerous non-respiratory admissions. It may be that patients seek inappropriate admissions due to a lack of understanding. However, delivering education and subsequently increasing disease awareness, may prompt feelings of distress, for example patients in Cluster 1 (*‘control’*) and Cluster 3 (*‘distressed’*) had the same level of understanding but the way in which the disease affected them emotionally differed significantly. With these considerations in mind it is unlikely that an education programme would be successful without the promotion of acceptance and control. This may be achieved through a therapeutic approach assisting with the maintenance of autonomy in the face of an unpredictable disease. For patients in Cluster 2 (*‘disengaged’*) a step-care approach to care involving acceptance and education may be most appropriate in promoting active disease management (Child et al., 2010).

#### 10.4.4. Strengths and limitations

The main advantage of cluster analysis is that it considers the relationship between multi-variables, in keeping with the recommendations of the Common Sense Model (CSM). Understanding how illness perceptions interact enables the formulation of targeted interventions which are tailored according to the needs of an individual. However, the cross-sectional nature of the data means that causal assumptions are speculative. For example, a profile similar to that assigned to Cluster 3 was identified in patients with muscle disease and labelled by the authors as '*realistic*' rather than '*distressed*' (Graham, Rose, Hankins, Chalder, & Weinman, 2012), emphasizing how the labelling of clusters, although informed by patient characteristics, disease-specific factors and other measures, are open to different interpretation. Furthermore, cluster analysis imposes a structure on the data which may not necessarily exist. However, the present study used a technique which limits manipulation by allowing the statistical program to establish the possible number of clusters. A more robust way to test the reliability of the cluster solution would be to run the analysis on another sample of data rather than 50% of our own. The replication of cluster analysis on another sample to establish external validity is important, particularly since cluster algorithms are exploratory (Milligan & Cooper, 1987). Such external validation has been conducted successfully on four large random samples, in the exploration of smoking behaviour (Anatchkova, Velicer, & Prochaska, 2006). Unfortunately, as this is the first study to collect illness perception information on patients with COPD following an exacerbation this type of validation was not possible but could perhaps be conducted in the future.

Although illness perceptions showed little variation over a 12 month period in patients diagnosed with oesophageal cancer (Dempster et al., 2012), over a longer term follow up (6 years) significant increases in the appraisal of duration of the disease and its controllability were observed in patients with osteoarthritis (Kaptein et al., 2010). The stability of the three illness profiles identified in patients with COPD over time may change as time lapses from the acute exacerbation. This notion is supported by findings described in Chapter 5, following an acute exacerbation patients are in an anxious state. Testing the stability of the groups could be the focus of future research and may provide guidance regarding the optimal time to offer a referral to PR.

#### 10.4.3. Future research

Future research focusing on patients in Cluster 2 (*'disengaged'*) would be beneficial in increasing understanding regarding this particular population and may inform interventions which could prevent hospital admissions for non-respiratory causes.

Most importantly, it may be beneficial for future research to examine the effectiveness of Mindfulness and 'acceptance' techniques in reducing feelings of distress and improving coherence when delivered to a target population following an exacerbation of COPD. Any subsequent impact on attendance to PR would also be worth scrutinising.

#### 10.4.3. Conclusions

Three meaningful cluster groups are likely to exist in a population of patients following hospitalisation for an acute exacerbation of COPD *'in control'*, *'disengaged'* and *'distressed'*. A technique of this kind may be helpful in developing interventions which are psychologically informed and flexible. The use of psychological techniques centred on Mindfulness and 'acceptance' therapies may be beneficial in forming patients' illness appraisals and facilitating disease management strategies, namely PR.

# **Chapter 11**

## **11. DISCUSSION**

The main aim of this thesis was to increase understanding, by use of robust psychological constructs and methods, of how a Pulmonary Rehabilitation (PR) intervention can be facilitated and enhanced for patients following hospitalisation with an acute exacerbation of Chronic Obstructive Pulmonary Disease (COPD). The body of research adopts principles proposed by Intervention Mapping (IM); a framework used in the development of health policy programmes which aim to promote positive health behaviour change, as well as applying contemporary, evidence-based models from health psychology. To increase the chances of developing a successful behavioural intervention a thorough needs assessment is necessary, involving gathering information about the target group (patients with COPD following hospitalisation with an acute exacerbation and more specifically those who refuse a referral to PR), and the desired health behaviour (uptake and adherence to PR) and its determinants (illness appraisals). By increasing understanding about this population, it is argued that health care professionals are better equipped to respond according to patients' needs.

The combined results of this thesis will be discussed in accordance with the IM framework (Chapter 4). In particular, the body of work conducted was shaped by Step 1 of IM (a 'needs assessment') and the results obtained enable progression through the subsequent developmental stages of the framework, eventually leading to suggestions for tailored psychologically-informed strategies which may be helpful in encouraging adherence to PR programs. Future research will be required to test the feasibility and appropriateness of such strategies for patients following an acute exacerbation of COPD (IM Step 4). If successful, these strategies will need to be implemented and evaluated accordingly (IM Steps 5 and 6).

### **11.1. Intervention Mapping Step 1: Needs Assessment**

The body of research presented in this thesis completes Step 1 of IM, a thorough needs assessment. A needs assessment can enable the identification of causal links for health behaviour (including refusal of interventions conducive to health), which may be amenable to intervention. This is done through three core processes: 1. the search for empirical findings from the existing literature: A review of the literature surrounding the role of patients' illness perceptions in predicting positive health behaviour was conducted and is described in Chapter 3. This evidence was considered in collaboration with the findings from a retrospective analysis exploring the usefulness of a current measure of psychological morbidity in predicting completion of PR (Chapter 6). 2. Assessing and using theory to inform strategies: The common models of health behaviour are reviewed in Chapter 3 ultimately alighting on the Common Sense Model (CSM). In line with the assumptions of the CSM, Chapter 5 contains a review of the literature exploring patients' appraisals of an acute exacerbation. 3. Collecting new data: An observation of the post-exacerbation PR service described in Chapter 8 confirms notions derived from indirect evidence, that attendance to post-exacerbation PR is indeed poor. Qualitative and quantitative research designs, described in Chapter 9 and 10 respectively, aim to distinguish causes of behaviour and identify maladaptive illness perceptions which may influence a patients' decision not to attend PR.

### **11.2. Intervention Mapping Step 2: Programme objectives**

Chapter 8 offers convincing evidence that PR is poorly adhered to by patients following an acute exacerbation and this is supported further by an audit published recently documenting that only 9.6% of all patients hospitalised with an acute exacerbation of COPD receive and complete PR (Jones et al., 2014). Furthermore, current programmes do not appear to be effective in addressing severe symptoms of anxiety and depression in those patients who do complete (Chapter 6).

The information gleaned from this thesis allows for the development of programme objectives which are tailored according to the specific needs of patients following an acute exacerbation of COPD. The results from the critical synthesis (Chapter 5) and the cluster analysis (Chapter 10) emphasise the necessity of addressing the intense fear and

heightened arousal prompted by symptoms experienced by patients during an episode of acute breathlessness. A second objective of psychological strategies ought to be to target patients' self-conscious cognitions, described in Chapter 9, and promote security by reducing vigilance associated with feelings of being dismissed by health care professionals. Finally, health care professionals need to utilise techniques to promote engagement in positive health behaviour whilst enabling patients to maintain feelings of control. The impact of such strategies on adherence to PR would be of future interest. Certainly PR delivered in its current form does not appear to be feasible for patients with COPD following an acute exacerbation and a step-care approach may provide patients with a less immediately threatening (to both fear and feelings of control) treatment option than PR.

### **11.3. Intervention Mapping Step 3: Theory-based methods and practical application**

#### 11.2.1. Theory-based methods

In addition to IM, the structure and content of this thesis is derived from an evaluation of potential health psychology models, ultimately alighting on the theory of the Common Sense Model (CSM) suggesting that patients form illness representations which, in turn, affect engagement in health promoting behaviour. The Illness Perceptions Question-Revised (IPQ-R) is a tool designed to assess patients' illness representations quantitatively. Unlike the Hospital Anxiety and Depression Scale the IPQ-R is descriptive informing the content of strategies tailored to address unhelpful cognitions and heightened emotional affect. Although the CSM adopts a Parallel-Processing Model which assumes cognitions and emotions occur simultaneously its focus is primarily on patients' cognitions surrounding their disease. Only one of the nine subscales is concerned with emotional affect and, given the prominence of emotional arousal following an acute exacerbation, perhaps the assessment of such emotions ought to be given greater focus. Furthermore, the emotional effect of COPD does not appear to be limited to anxiety, depression, worry and frustration, and it is important to consider an approach explicitly designed to look more broadly and phenomenologically at health, rather than being driven by biomedical approaches to anxiety and depression.



### 11.2.2. Practical implications

#### *11.2.2.1. Improving Access to Psychological Therapies*

Improving Access to Psychological Therapies was originally developed and delivered to people of working age (under 65 years). Recently there has been an emphasis on the necessity of delivering psychological therapies to patients of all ages, in particular older adults for whom psychological intervention is often warranted, not least because of the high prevalence of long term health conditions pertaining to symptoms of anxiety and depression. This thesis supports the necessity of psychological services for elderly adults with COPD, emphasising the prominence of distress, particularly following an acute exacerbation. Difficulties in engaging older adults in psychological therapies are unsurprising and likely associated with fear, diminished self-worth, fatalistic attitudes and issues surrounding stoicism. Currently understanding is circumscribed surrounding the needs of older adults, particularly patients with chronic conditions such as, COPD. Information derived from this thesis informs health care professionals of patients' sensitivities to dismissive behaviour and suggests the implementation of strategies to enhance partnership working and trust, perhaps promoting engagement in active interventions.

#### *11.2.2.2. Cognitive Behavioural Therapy*

The pervasive physical effects of a chronic condition like COPD, common in an elderly population, can further complicate psychological treatment. This thesis offers some insight into how patients with COPD experience their disease, the symptoms of which are frequently attuned to those of aging.

Many of the limitations of Cognitive Behavioural Therapy (CBT) pertain to its application in older adult populations. A key component of CBT is problem solving, yet the ability to problem solve appears diminished in older adults (Diehl, Willis, & Schaie, 1995; Burton, Strauss, Hultsch, & Hunter, 2006). Laidlaw and colleagues' (2004) conceptualisation framework offers one of the very few models of CBT for older adults, encouraging the consideration of individuals from a broader perspective (e.g. socio-cultural context, health status and cohort beliefs) to facilitate effectiveness of therapy

(Laidlaw, Thompson, & Gallagher-Thompson, 2004). Following an acute exacerbation patients express intense levels of arousal, associated with symptoms of breathlessness which impact on fears of dying. Such fears may not be unrealistic and attempts to modify these beliefs may serve to further heighten anxious emotions. Therefore the adoption of CBT for elderly patients with COPD may need to focus on supporting patients to accept these challenges to health rather than attempting to alter such cognitions (Laidlaw, 2010). However, the identification of three distinct clusters of patients highlights the variation between individuals' beliefs meaning the modification of current treatments may not be necessary for all patients; instead treatment ought to be tailored to the needs of the individual.

#### *11.2.2.3. Mindfulness*

Mindfulness is an approach which appears well suited to older adults. As people age it is necessary to reappraise expectations in the face of age-related losses. Wellbeing is enhanced by disengaging from unattainable goals and re-engaging in alternative goals which are realistic. Disengagement is not seen as 'giving up' or a reflection of personal inadequacy but instead it involves actively seeking an alternative opportunity to maximise control, protecting patients' sense of 'self' and emotional wellbeing (Heckhausen, Wrosch, & Schulz, 2010).

Mindfulness can be delivered independently; Mindfulness Based Stress Reduction (MBSR) therapy or in combination with CBT; Mindfulness Based Cognitive Therapy (MBCT). Both forms of training are similar in their approach, focusing on acceptance rather than challenging beliefs, but MBCT has a greater emphasis on patients' thoughts to prevent rumination. A review of a clinical service offering both forms of Mindfulness training to older adults (>65 years) with anxiety disorders and/or chronic pain found eight, two hour sessions to be feasible for delivery. Following the course patients reported feeling calmer and more relaxed, they enjoyed the therapy and importantly the training was completed by 95% of all participants (Smith, 2004).

Fjorback and colleagues (2011) have conducted a systematic review (n=21) looking at the effectiveness of MBSR therapy and MBCT. Overall the authors conclude that MBSR therapy is successful in reducing anxiety, stress and depression and eliciting

improvements in quality of life, whereas MBCT was most effective in recurrently depressed patients or patients who have relapsed (Fjorback, Arendt, Ornbol, Fink, & Walach, 2011). However, the one study including patients with COPD failed to document any therapeutic benefits although a 40% drop-out rate made it difficult to draw any firm conclusions (Mularski et al., 2009). Importantly Mindfulness was an effective therapy for those patients who chose to participate probably due to the need for active involvement.

Active involvement and willingness to engage is a pre-requisite for Mindfulness therapy and therefore this may not be an effective treatment for patients in Cluster 2 '*disengaged*' who by definition are difficult to engage in treatment due to the complexity of issues they face, both physical and social. This does not mean this group of patients can be ignored as they are likely to be frequently admitted for non-emergencies, but currently it is difficult to recommend a treatment that is likely to be accepted by this population.

Mindfulness may be most effectively applied in patients grouped to Cluster 3 '*distressed*' who can be understood as driven by their intense fear to participate in some form of treatment but not one which may be perceived as threatening (PR), provoking symptoms, i.e. breathlessness, already associated with a fear response. Patients in Cluster 1 '*in control*' may benefit from one particular component of Mindfulness; these patients appear to have successfully disengaged from unrealistic goals but may benefit from assistance in reframing new goals. Delivering therapy as a stepped-care approach enables the delivery of treatment within a group setting, increasing cost-effectiveness and feasibility, but still attends to the individual needs of the patient.

Since the conduction of Fjorback's review (2011) a further randomised controlled trial has evaluated the efficacy of MBSR therapy in improving disease-related quality of life and lung function in patients with asthma. Unlike the studies included in the previous review this trial involved a long term follow up, until 12 months. Despite no improvements in lung function patients who received MBSR therapy had greater reductions in perceived stress and improvements in quality of life compared to the control group. These improvements were clinically significant even at 12 months (Pbert et al., 2012) and are in excess of previous complementary programmes applied with

asthma patients (Markham & Wilkinson, 2004) suggesting that Mindfulness training may have uniquely supportive features for those with respiratory symptoms.

#### **11.4. Intervention Mapping Steps 4, 5 and 6: Program content, program implementation and program evaluation**

Given the findings of this thesis it would seem that strategies designed to reduce feelings of distress and increase feelings of controllability may be necessary in a population of patients following an acute exacerbation of COPD. The impact of such strategies on uptake and adherence to post-exacerbation PR services would also be of interest. Mindfulness, as discussed in the previous section, may have some applicability in this population who are generally older adults. However, IM advocates that movement between the six steps is iterative and therefore, before progressing onto Step 4: program content, it may be sensible to take a step back to Step 1 and consider the literature reviewing the usefulness of MBSR and MCBT delivered to patients with respiratory diseases. To date such a review has not been conducted and Mindfulness with its focus on breathing may have unique supportive features for this population.

Step 4 of IM involves the development of a program. When considering program delivery it is important to take into account both the views of the health care professionals who are likely to be responsible for delivering the intervention and the hospital environment in which the program will be implemented. A pilot test, consisting of a small, representative sample of patients, ought to be conducted to test the feasibility and acceptability of the intervention.

Step 5 of IM is concerned with the implementation of the program. Initially the intervention is likely to be delivered by researchers as part of a cohort study design. The outcomes of this study would serve to inform a large randomised controlled trial (RCT) designed to assess effectiveness (Step 6).

Obtaining positive results from a large RCT is often where researchers will stop, expecting that the dissemination of such findings will lead to adoption of the intervention as part of evidence-based practice. Unfortunately this is often not the case with only only 55% of patients in the United States receiving all recommended care

(McGlynn et al., 2003). Knowledge translation interventions aim to reduce the gap between evidence and clinical practice by exchanging, synthesizing and applying knowledge, gleaned from high quality research studies, through a series of interactions between researchers and clinicians. This process is likely to involve revisiting Step 5 of IM and testing the effectiveness of the same intervention when it is delivered by clinicians. Work of this kind would be extremely useful, as few knowledge translation projects have been conducted involving physiotherapists (Scott et al., 2012) and particularly those working within rehabilitation settings (Menon, Korner-Bitensky, Kastner, McKibbin, & Straus, 2009).

### **11.5. Alternatives to Intervention Mapping**

As an overarching framework utilised in this thesis, IM provides a systematic process underpinning design of behaviour change interventions, giving most attention to the nature of behaviour. This process of mapping has been used to successfully develop Human Immunodeficiency Virus interventions (Corbie-Smith et al., 2010) as well as an adolescent smoking cessation intervention leading to positive short term effects (Dalum, Schaalma, & Kok, 2012; Dalum, Paludan-Muller, Engholm, & Kok, 2012). It has also been applied to assist the development of a return to work tool for patients with cancer (Munir, Kalawsky, Wallis, & Donaldson-Feilder, 2013). However, the approach has come under scrutiny for not considering the target behaviour (i.e. PR) as part of a more complex system. From a systems theory perspective, changing one aspect of behaviour can have both positive and negative impacts, for example, attendance at a PR course where disease education is delivered may be successful in increasing patients' understanding of their disease, thus enhancing feelings of control yet, emotional distress may be heightened through increased awareness. This is a concern for those patients in Cluster 2 '*disengaged*' and it would appear that to be successful an education programme would need to be delivered alongside strategies to promote acceptance and control.

In an attempt to adopt a more comprehensive and cohesive approach to the development of behaviour change interventions an alternative that could have informed this work is the Behaviour Change Wheel (BCW) developed by Michie and colleagues (2011). The BCW places emphasis on the patient's context i.e. the opportunities available,

something which other frameworks (IM and Medical Research Council) have offered little consideration (Michie, van Stralen, & West, 2011). ‘Opportunity’ appears to be an important factor to consider for patients with COPD as the most commonly cited reason for refusing a referral to PR was transport (Chapter 8) and the prominence of social burdens (Chapter 9) again emphasizing apparently mundane but nonetheless significant burdens. Although promising the BCW is still undergoing development into an ‘intervention design tool’ and its ease of use has yet to be established.

### **11.6. Looking ahead...**

A review of the past 50 years of behaviour research within COPD has reported an increasing emphasis on the manner in which patients appraise their condition and treatment (Kaptein et al., 2009). Certainly shifts from hopelessness in the face of incurable, chronicity have been superseded by more optimistic and intervention-orientated approaches examining impacts of psychosocial determinants, quality of life and function rather than purely biomedical considerations of disease impact. This has been accompanied by chronic illness being considered in a far more multi-factorial way with physical pathology being just one factor determining psychological and social adjustment.

This thesis adds to rather circumscribed and pragmatic literature, to date, with its increased focus on understanding the existential reality of living with COPD informed by models with a substantial evidence base. Such information appears key to enable health care professionals to engage most effectively in the assessment, management and alleviation of patient distress. The importance of displaying understanding and empathy is heightened in the care of patients with COPD due to the perceived culpability of the disease and the fact that symptoms are not always visible, yet health care professionals who by definition are expected to be ‘caring’ are often perceived by patients as being dismissive of their symptoms evoking feelings of frustration and anxiety. Health care professionals may not be aware of the manner in which their actions are perceived because patients, who as an older generation possess stoical attitudes, are unlikely to assert themselves and complain. The burden of time restraints within the health care setting poses difficulties for health care professionals in appearing caring but patients’ anxiety prompts vigilance meaning they are more sensitive to dismissive behaviour.

Institutions and organisations offering health care should support professionals by enabling them to fulfil their '*caring*' role.

It is important to consider the potential and diverse various emotional effects of COPD and yet, to date, the focus has been primarily upon symptoms of anxiety and depression. From data gleaned within Chapter 9, patients with COPD appear to present with diminished self-worth stemming from self-conscious emotions, i.e. shame and guilt, associated with the personal culpability of the disease. The consideration of self-conscious emotions has particular impetus given meta-analytic evidence revealing increased psychological morbidity appears negatively associated with shame-based emotions and self-compassion (Macbeth & Gumley, 2012). Therefore, an intervention designed to target self-consciousness may subsequently impact on symptoms of anxiety and depression known to be elevated in patients with COPD (Chapter 6). Paul Gilbert's approach to compassion is rooted in the Social Mentality Theory, based on biological and evolutionary systems, where internal stimuli act like social stimuli which the brain treats like 'threats'. For example, self-critical thoughts (i.e. this disease is your fault, you don't deserve help, you are a bad person) provoke a stressed anxious and depressed response in the same way comments delivered by another (social stimuli) would initiate a similar reaction (Gilbert, Irons, Olsen, Gilbert, & McEwan, 2006). Such an approach, focused on compassion, sits comfortably alongside a Mindfulness therapy and the two are often delivered in conjunction. The ability to incorporate compassion into a Mindfulness approach offers further flexibility in delivering a therapeutic intervention to distinct populations of patients (Chapter 10). The feasibility of delivering this kind of tailored approach and any impact on reducing psychological morbidity and perhaps increasing attendance to PR would be of future interest.

According to the BCW and supported by the prominence of social burdens reported by patients with COPD, it would appear important to consider social environment as a possible barrier for intervention uptake. Patients seem acutely aware of the manner in which they are perceived by others, particularly during a time of vulnerability and possibly due to the prominence of self-conscious emotions. Informal carers are often family members, surrounding patients on a day to day basis they are an integral part of the disease support system. As the emphasis on home care for patients increases there has been more focus on research studies considering the experience of caring for

patients with COPD (Pinnock et al., 2011; Seamark, Blake, Seamark, & Halpin, 2004; Hynes, Stokes, & McCarron, 2012; Kanervisto, Kaistila, & Paavilainen, 2007). However the attitudes of informal carers towards patients are still unknown, perhaps because in most scenarios informal carers have been interviewed in conjunction with patients so are less likely to be open about their feelings (Kanervisto et al., 2007; Pinnock et al., 2011; Seamark et al., 2004). Informal carers may feel frustration caring for patients with COPD particularly if they themselves had given up smoking or perhaps advised them to give up smoking earlier. Furthermore, although informal carers experience similar emotional affects to patients such as loss and anxiety (Hynes et al., 2012) they rarely receive attention or are offered intervention. Some attempts have been made to incorporate informal carers into the education component of PR programmes (Figueiredo, Gabriel, Jacome, & Marques, 2013) which is likely to promote understanding and may allow for increased empathy towards patients but perhaps informal carers would also benefit from psychological strategies to promote acceptance. Such an intervention may be beneficial in alleviating any feelings of frustration and prompt communication between patients and their informal carers. More research needs to be conducted on informal carers, independent from patients, to encourage open dialogue and findings need to be synthesised to inform recommendations for best supporting informal carers in a way which not only addresses their own emotional issues, but perhaps enhances their ability to provide support to patients.



## **12. CONCLUSION**

This thesis offers a comprehensive insight into the experience of an acute exacerbation of COPD and the impact on patients' perceptions of their disease. The information gleaned is useful in suggesting psychological techniques which are tailored to meet the specific needs of patients following an acute exacerbation. This is of considerable importance as previously the needs of this vulnerable population have been largely ignored and PR delivered in its current form does not appear to be feasible following an acute exacerbation. Poor attrition to post-exacerbation PR may be a reflection of the intense emotional distress reported by patients. The timing of referring to PR needs careful consideration. Acceptance may be promoted by allowing symptom recovery and for anxiety to resolve. Furthermore, the way in which health care professionals broach the topic of PR may be significant as, during a period of vulnerability, patients are sensitive of perceived dismissive behaviour and may see a referral to PR as health care professionals failing to appreciate the seriousness of their condition. Targeted psychological techniques delivered via a stepped-care approach and centered on Mindfulness therapies may be beneficial in reducing distress. Future exploration into the emotional impact of the disease and consideration of other external influences, including informal carers, would be useful in continuing to refine the content and delivery of psychological strategies to facilitate and enhance PR. Any subsequent impact of such strategies on health promoting behaviour, including uptake of PR, would be of future interest.

### **13. BIBLIOGRAPHY**

Adams, R., Chavannes, N., Jones, K., Ostergaard, M. S., & Price, D. (2006). Exacerbations of chronic obstructive pulmonary disease - A patients' perspective. *Primary Care Respiratory Journal*, 15, 102-109.

Adshead, F., Cody, D. D., & Pitt, B. (1992). BASDEC: a novel screening instrument for depression in elderly medical inpatients. *British Medical Journal*, 305, 397.

Ajzen, I. (1991). The theory of planned behaviour. *Organizational behaviour and human decision processes*, 50, 179-211.

Ajzen, I. & Fishbein, M. (1980). *Understanding attitudes and predicting social behaviour*. NJ: Prentice-Hall.

Alsen, P., Brink, E., Persson, L. O., Brandstrom, Y., & Karlson, B. W. (2010). Illness perceptions after myocardial infarction: Relations to fatigue, emotional distress, and health-related quality of life. *Journal of Cardiovascular Nursing*, 25, E1-E10.

American Thoracic Society / European Respiratory Society Task Force (2004). *Standards for the diagnosis and management of patients with COPD*. New York: American Thoracic Society.

American Thoracic Society/ European Respiratory Society (1999). Skeletal muscle dysfunction in chronic obstructive pulmonary disease. A statement of the American Thoracic Society and European Respiratory Society. *American Journal of Respiratory and Critical Care Medicine*, 159, S1-40.

Anatchkova, M. D., Velicer, W. F., & Prochaska, J. O. (2006). Replication of subtypes for smoking cessation within the precontemplation stage of change. *Addictive Behaviors*, 31, 1101-1115.

Anthonisen, N. R., Connett, J. E., Kiley, J. P., Altose, M. D., Bailey, W. C., Buist, A. S. et al. (1994). Effects of smoking intervention and the use of an inhaled anticholinergic bronchodilator on the rate of decline of FEV1. The Lung Health Study. *The Journal of the American Medical Association*, 272, 1497-1505.

Anto, J. M., Vermeire, P., Vestbo, J., & Sunyer, J. (2001). Epidemiology of chronic obstructive pulmonary disease. *European Respiratory Journal*, 17, 982-994.

Armitage, C. J. & Conner, M. (2001). Efficacy of the theory of planned behaviour: A meta-analytic review. *British Journal of Social Psychology*, 40, 471-499.

Arne, M., Emtner, M., Janson, S., & Wilde-Larsson, B. (2007). COPD patients perspectives at the time of diagnosis: A qualitative study. *Primary Care Respiratory Journal*, 16, 215-221.

Arnold, E., Bruton, A., Donovan-Hall, M., Fenwick, A., Dibb, B., & Walker, E. (2011). Ambulatory oxygen: Why do COPD patients not use their portable systems as prescribed? A qualitative study. *BMC Pulmonary Medicine*, 11 (9), 1-7.

Arnold, E., Bruton, A., & Ellis-Hill, C. (2006). Adherence to pulmonary rehabilitation: A qualitative study. *Respiratory Medicine*, 100, 1716-1723.

Arnold, R., Ranchor, A. V., Koeter, G. H., de Jongste, M. J., Wempe, J. B., Ten Hacken, N. H. et al. (2006). Changes in personal control as a predictor of quality of life after pulmonary rehabilitation. *Patient Education and Counselling*, 61, 99-108.

Bailey, P. H. (2001). Death stories: Acute exacerbations of chronic obstructive pulmonary disease. *Qualitative Health Research*, 11, 322-338.

Bailey, P. H. (2004). The dyspnea-anxiety-dyspnea cycle - COPD patients' stories of breathlessness: "It's scary /when you can't breathe". *Qualitative Health Research*, 14, 760-778.

Balmes, J., Becklake, M., Blanc, P., Henneberger, P., Kreiss, K., Mapp, C. et al. (2003). American Thoracic Society statement: Occupational contribution to the burden of airway disease. *American Journal of Respiratory and Critical Care Medicine*, 167, 787-797.

Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*. N.J: Prentice-Hall.

Baraniak, A. & Sheffield, D. (2011). The efficacy of psychologically based interventions to improve anxiety, depression and quality of life in COPD: A systematic review and meta-analysis. *Patient Education and Counselling*, 83, 29-36.

Barbour, R. S. (2001). Checklists for improving rigour in qualitative research: A case of the tail wagging the dog? *British Medical Journal*, 322, 1115-1117.

Bartholomew, L. K., Parcel, G. S., & Kok, G. (1998). Intervention mapping: A process for developing theory-and evidence-based health education programs. *Health, Education and Behavior*, 25, 545-563.

Bartholomew, L. K., Parcel, G. S., Kok, G., Gottlieb, N. H., & Fernandez, M. E. (2011). *Planning health promotion programs: An intervention mapping approach*. (3rd ed.) San Francisco: John Wiley and Sons Inc.

Bauldoff, G. S., Hoffman, L. A., Zullo, T. G., & Sciurba, F. C. (2002). Exercise maintenance following pulmonary rehabilitation: Effect of distractive stimuli. *Chest*, 122, 948-954.

Beck, A. T., Epstein, N., Brown, G., & Steer, R. A. (1988). An inventory for measuring clinical anxiety: psychometric properties. *Journal of Consulting and Clinical Psychology*, 56, 893-897.

Beck, A. T., Ward, C. H., Medelson, M., Mock, J., & Erbaugh, J. (1961). An inventory for measuring depression. *Archives of General Psychiatry*, 4, 561-571.

Becker, M. H. (1974). The health belief model and personal health behaviour. *Health Education Monographs*, 2, 1-154.

Belcher, V. N., Fried, T. R., Agostini, J. V., & Tinetti, M. E. (2006). Views of older adults on patient participation in medication-related decision making. *Journal of General Internal Medicine*, 21, 298-303.

Berger, B. E., Kapella, M. C., & Larson, J. L. (2011). The experience of stigma in chronic obstructive pulmonary disease. *Western Journal of Nursing Research*, 33, 916-932.

Bishop, G. D. & Converse, S. A. (1986). Illness representations: A prototype approach. *Health Psychology, 5*, 95-114.

Blackburn, H., Hanley, B., & Staley, K. (2010). *Turning the pyramid upside down*. Eastleigh: INVOLVE.

Bolton, C. E., Bevan-Smith, E. F., Blakey, J. D., Crowe, P., Elkin, S. L., & Garrod, R. (2013). BTS guidelines on pulmonary rehabilitation in adults: Accredited by NICE. *Thorax, 68* (suppl 2), S1-S30.

Borges, R. C. & Carvalho, C. R. (2012). Physical activity in daily life in Brazilian COPD patients during and after exacerbation. *COPD, 9*, 596-602.

Bourbeau, J., Nault, D., & Dang-Tan, T. (2004). Self-management and behaviour modification in COPD. *Patient Education and Counseling, 52*, 271-277.

Boyd, C. M., Darer, J., Boulton, C., Fried, L. P., Boulton, L., & Wu, A. W. (2005). Clinical practice guidelines and quality of care for older patients with multiple comorbid diseases: Implications for pay for performance. *The Journal of the American Medical Association, 294*, 716-724.

Bradley, J. M., Lasserson, T., Elborn, S., MacMahon, J., & O'Neill, B. (2007). A systematic review of randomized controlled trials examining the short-term benefit of ambulatory oxygen in COPD. *Chest, 131*, 278-285.

Braido, F., Baiardini, I., Balestracci, S., Menoni, S., Balbi, F., Ferraioli, G. et al. (2011). Chronic obstructive pulmonary disease patient well-being and its relationship with clinical and patient-reported outcomes: a real-life observational study. *Respiration, 82*, 335-340.

Breckenridge, J. N. (2000). Validating cluster analysis: Consistent replication and symmetry. *Multivariate Behavioral Research, 35*, 261-285.

Brenes, G. A. (2003). Anxiety and chronic obstructive pulmonary disease: prevalence, impact, and treatment. *Psychosomatic Medicine, 65*, 963-970.

British Lung Foundation. (2007). *Invisible lives: Chronic obstructive pulmonary disease (COPD) finding the missing millions*. London: British Lung Foundation.

British Thoracic Society (2006). *Burden of lung disease*. London: British Thoracic Society.

Britten, N., Campbell, R., Pope, C., Donovan, J., Morgan, M., & Pill, R. (2002). Using meta ethnography to synthesise qualitative research: A worked example. *Journal of Health Service and Research Policy*, 7, 209-215.

Britton, M. (2003). The burden of COPD in the U.K: Results from the confronting COPD survey. *Respiratory Medicine*, 97 Suppl C, S71-S79.

Broadbent, E., Petrie, K. J., Main, J., & Weinman, J. (2006). The brief illness perception questionnaire. *Journal of Psychosomatic Research*, 60, 631-637.

Brooks, S. K., Rimes, K. A., & Chalder, T. (2011). The role of acceptance in chronic fatigue syndrome. *Journal of Psychosomatic Research*, 71, 411-415.

Bulley, C., Donaghy, M., Howden, S., Salisbury, L., Whiteford, S., & Mackay, E. (2009). A prospective qualitative exploration of views about attending pulmonary rehabilitation. *Physiotherapy Research International*, 14, 181-192.

Burrows, B., Knudson, R. J., Cline, M. G., & Lebowitz, M. D. (1977). Quantitative relationships between cigarette smoking and ventilatory function. *American Review of Respiratory Disease*, 115, 195-205.

Burton, C. L., Strauss, E., Hultsch, D. F., & Hunter, M. A. (2006). Cognitive functioning and everyday problem solving in older adults. *Clinical Neuropsychology*, 20, 432-452.

Butland, R. J., Pang, J., Gross, E. R., Woodcock, A. A., & Geddes, D. M. (1982). Two-, six-, and 12-minute walking tests in respiratory disease. *British Medical Journal (Clinical Research Ed)*, 284, 1607-1608.

Calverley, P. M. A. & Georgopoulos, D. (1998). Chronic obstructive pulmonary disease: Symptoms and signs. *European Respiratory Monograph*, 8, 6-24.

Campbell, D. T. & Frisk, D. W. (1959). Convergent and discriminant validation by the multitrait-multimethod. *Psychology Buletin*, 56, 81-105.

Campbell, M., Fitzpatrick, R., Haines, A., Kinmonth, A. L., Sandercock, P., Spiegelhalter, D. et al. (2000). Framework for design and evaluation of complex interventions to improve health. *British Medical Journal*, 321, 694-696.

Campbell, N. C., Murray, E., Darbyshire, J., Emery, J., Farmer, A., Griffiths, F. et al. (2007). Designing and evaluating complex interventions to improve health care. *British Medical Journal*, 334, 455-459.

Campbell, R., Pound, P., Pope, C., Britten, N., Pill, R., Morgan, M. et al. (2003). Evaluating meta-ethnography: A synthesis of qualitative research on lay experiences of diabetes and diabetes care. *Social Science and Medicine*, 56, 671-684.

Chajut, E. & Algom, D. (2003). Selective attention improves under stress: Implications for theories of social cognition. *Journal of Personal and Social Psychology*, 85, 231-248.

Chapman, K. R. (2004). Chronic obstructive pulmonary disease: Are women more susceptible than men? *Clinical Chest Medicine*, 25, 331-341.

Charlier, C., Pauwels, E., Lechner, L., Spittaels, H., Bourgois, J., De Bourdeaudhuij, I et al. (2012). Physical activity levels and supportive care needs for physical activity among breast cancer survivors with different psychosocial profiles: A cluster-analytical approach. *European Journal of Cancer Care*, 21, 790-799.

Child, A., Sanders, J., Sigel, P., & Hunter, M. S. (2010). Meeting the psychological needs of cardiac patients: An integrated stepped-care approach within a cardiac rehabilitation setting. *British Journal of Cardiology*, 17, 175-179.

Cilione, C., Lorenzi, C., Dell, O. D., Garuti, G., Rossi, G., Totaro, L. et al. (2002). Predictors of change in exercise capacity after comprehensive COPD inpatient rehabilitation. *Medical Science Monitoring*, 8, CR740-CR745.

Cindy Ng, L. W., Mackney, J., Jenkins, S., & Hill, K. (2012). Does exercise training change physical activity in people with COPD? A systematic review and meta-analysis. *Chronic Respiratory Disease*, 9, 17-26.

Clancy, K., Hallet, C., & Caress, A. (2009). The meaning of living with chronic obstructive pulmonary disease. *Journal of Nursing and Healthcare of Chronic Illness, 1*, 78-86.

Clark, D. M., Layard, R., Smithies, R., Richards, D. A., Suckling, R., & Wright, B. (2009). Improving access to psychological therapy: Initial evaluation of two UK demonstration sites. *Behaviour Research and Therapy, 47*, 910-920.

Clatworthy, J., Hankins, M., Buick, D., Weinman, J., & Horne, R. (2007). Cluster analysis in illness perceptions research: A Monte Carlo study to identify the most appropriate method. *Psychology and Health, 22*, 123-142.

Connors, A. F, Jr., Dawson, N. V., Thomas, C., Harrell, F. E, Jr., Desbiens, N., Fulkerson, W. J. et al. (1996). Outcomes following acute exacerbation of severe chronic obstructive lung disease. The SUPPORT investigators (study to understand prognoses and preferences for outcomes and risks of treatments). *American Journal of Respiratory and Critical Care Medicine, 154*, 959-967.

Cooper, A. F., Weinman, J., Hankins, M., Jackson, G., & Horne, R. (2007). Assessing patients' beliefs about cardiac rehabilitation as a basis for predicting attendance after acute myocardial infarction. *Heart, 93*, 53-58.

Corbie-Smith, G., Akers, A., Blumenthal, C., Council, B., Wynn, M., Muhammad, M. et al. (2010). Intervention mapping as a participatory approach to developing an HIV prevention intervention in rural African American communities. *AIDS Education and Prevention, 22*, 184-202.

Crothers, K., Huang, L., Goulet, J. L., Goetz, M. B., Brown, S. T., Rodriguez-Barradas, M. C. et al. (2011). HIV Infection and Risk for Incident Pulmonary Diseases in the Combination Antiretroviral Therapy Era. *American Journal of Respiratory and Critical Care Medicine, 183*, 388-395.

Cosco, T. D., Doyle, F., Ward, M., & McGee, H. (2012). Latent structure of the hospital anxiety and depression scale: A 10-year systematic review. *Journal of Psychosomatic Research, 72*, 180-184.



Costi, S., Brooks, D., & Goldstein, R. S. (2006). Perspectives that influence action plans for chronic obstructive pulmonary disease. *Canadian Respiratory Journal*, 13, 362-368.

Coventry, P. A. (2009). Does pulmonary rehabilitation reduce anxiety and depression in chronic obstructive pulmonary disease? *Current Opinion in Pulmonary Medicine*, 15, 143-149.

Coventry, P. A. & Gellatly, J. L. (2008). Improving outcomes for COPD patients with mild-to-moderate anxiety and depression: A systematic review of cognitive behavioural therapy. *British Journal of Health Psychology*, 13, 381-400.

Coventry, P. A. & Hind, D. (2007). Comprehensive pulmonary rehabilitation for anxiety and depression in adults with chronic obstructive pulmonary disease: Systematic review and meta-analysis. *Journal of Psychosomatic Research*, 63, 551-565.

Coyne, J. C. & van Sonderen, E. (2012). No further research needed: Abandoning the hospital anxiety and depression scale (HADS). *Journal of Psychosomatic Research*, 72, 173-174.

Crawford, J. R., Henry, J. D., Crombie, C., & Taylor, E. P. (2001). Normative data for the HADS from a large non-clinical sample. *British Journal of Clinical Psychology*, 40, 429-434.

Crombez, G., Eccleston, C., Baeyens, F., van Houdenhove, B., & van den Broeck, A. (1999). Attention to chronic pain is dependent upon pain-related fear. *Journal of Psychosomatic Research*, 47, 403-410.

Cully, J. A., Graham, D. P., Stanley, M. A., Ferguson, C. J., Sharafkhaneh, A., Soucek, J. et al. (2006). Quality of life in patients with chronic obstructive pulmonary disease and comorbid anxiety or depression. *Psychosomatics*, 47, 312-319.

Dalum, P., Paludan-Muller, G., Engholm, G., & Kok, G. (2012). A cluster randomised controlled trial of an adolescent smoking cessation intervention: Short and long-term effects. *Scandinavian Journal of Public Health*, 40, 167-176.

Dalum, P., Schaalma, H., & Kok, G. (2012). The development of an adolescent smoking cessation intervention- An intervention mapping approach to planning. *Health Education and Research*, 27, 172-181.

Dayal, H. H., Khuder, S., Sharrar, R., & Trieff, N. (1994). Passive smoking in obstructive respiratory disease in an industrialized urban population. *Environmental Research*, 65, 161-171.

Decramer, M., Lacquet, L. M., Fagard, R., & Rogiers, P. (1994). Corticosteroids contribute to muscle weakness in chronic airflow obstruction. *American Journal of Respiratory and Critical Care Medicine* 150, 11-16.

Decramer, M. & Stas, K. J. (1992). Corticosteroid-induced myopathy involving respiratory muscles in patients with chronic obstructive pulmonary disease or asthma. *American Review Respiratory Disease*, 146, 800-802.

de Marco, R., Accordini, S., Marcon, A., Cerveri, I., Anto, J. M., Gislason, T. et al. (2011). Risk factors for chronic obstructive pulmonary disease in a European cohort of young adults. *American Journal of Respiratory and Critical Care Medicine*, 183, 891-897.

Dempster, M., McCorry, N. K., Brennan, E., Donnelly, M., Murray, L., & Johnston, B. T. (2012). Psychological distress among survivors of esophageal cancer: the role of illness cognitions and coping. *Diseases of the Esophagus*, 25, 222-227.

Department of Health. (2004). *On the state of the public health: Annual report of the chief medical officer 2003*. London: Department of Health.

Department of Health (2005). *On the state of the public health: Annual report of the chief medical officer 2004*. London: Department of Health.

Department of Health (2008). IAPT implementation plan: National guidelines for regional delivery. London: Department of Health.

Department of Health (2010a). *Physical activity guidelines in the UK: Review and recommendations*. London: Department of Health.

Department of Health (2010b). *The national strategy for chronic obstructive pulmonary disease*. London: Department of Health.

Department of Health (2011). *Talking therapies: A 4 year plan*. London: Department of Health.

DeVito, A. J. (1990). Dyspnea during hospitalizations for acute phase of illness as recalled by patients with chronic obstructive pulmonary disease. *Heart and Lung*, 19, 186-191.

Diefenbach, M. & Leventhal, H. (1996). The common-sense model of illness representation: Theoretical and practical considerations. *Journal of Social Distress and the Homeless*, 5, 11-38.

Diehl, M., Willis, S. L., & Schaie, K. W. (1995). Everyday problem solving in older adults: Observational assessment and cognitive correlates. *Psychology and Aging*, 10, 478-491.

Dixon-Woods, M., Cavers, D., Agarwal, S., Annandale, E., Arthur, A., Harvey, J. et al. (2006). Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Medical Research Methodology*, 6, 35.

Dixon-Woods, M. & Fitzpatrick, R. (2001). Qualitative research in systematic reviews. Has established a place for itself. *British Medical Journal*, 323, 765-766.

Dixon-Woods, M., Sutton, A., Shaw, R., Miller, T., Smith, J., Young, B. et al. (2007). Appraising qualitative research for inclusion in systematic reviews: A quantitative and qualitative comparison of three methods. *Journal of Health Services Research and Policy*, 12, 42-47.

Dodd, J. W., Getov, S. V., & Jones, P. W. (2010). Cognitive function in COPD. *European Respiratory Journal*, 35, 913-922.

Dollard, J. & Miller, N. (1950). *Personality and psychotherapy: An analysis in terms of learning, thinking and culture*. New York: McGraw-Hill.

Donaldson, G. C., Wilkinson, T. M., Hurst, J. R., Perera, W. R., & Wedzicha, J. A. (2005). Exacerbations and time spent outdoors in chronic obstructive pulmonary disease. *American Journal of Respiratory and Critical Care Medicine*, 171, 446-452.

Dowell, J. & Hudson, H. (1997). A qualitative study of medication-taking behaviour in primary care. *Family Practice*, 14, 369-375.

Dowson, C., Laing, R., Barraclough, R., Town, I., Mulder, R., Norris, K. et al. (2001). The use of the Hospital Anxiety and Depression Scale (HADS) in patients with chronic obstructive pulmonary disease: a pilot study. *New Zealand Medical Journal*, 114, 447-449.

Dudley, D. L., Verhey, J. W., Masuda, M., Martin, C. J., & Holmes, T. H. (1969). Long-term adjustment, prognosis, and death in irreversible diffuse obstructive pulmonary syndromes. *Psychosomatic Medicine*, 31, 310-325.

Dunbar, M., Ford, G., Hunt, K., & Der, G. (2000). A confirmatory factor analysis of the hospital anxiety and depression scale: Comparing empirically and theoretically derived structures. *British Journal of Clinical Psychology*, 39, 79-94.

Earnest, M. A. (2002). Explaining adherence to supplemental oxygen therapy: The patient's perspective. *Journal of General Internal Medicine*, 17, 749-755.

Eaton, T., Garrett, J. E., Young, P., Fergusson, W., Kolbe, J., Rudkin, S. et al. (2002). Ambulatory oxygen improves quality of life of COPD patients: A randomised controlled study. *European Respiratory Journal*, 20, 306-312.

Eaton, T., Young, P., Fergusson, W., Moodie, L., Zeng, I., O'Kane, F. et al. (2009). Does early pulmonary rehabilitation reduce acute health-care utilization in COPD patients admitted with an exacerbation? A randomized controlled study. *Respirology*, 14, 230-238.

Eatough, V. & Smith, J. A. (2008). Interpretative phenomenological analysis. In Willig, C. & Stainton Rogers, W. (Eds.), *The SAGE handbook of qualitative research in psychology*. London: Sage.

Egede, L. E. (2007). Major depression in individuals with chronic medical disorders: prevalence, correlates and association with health resource utilization, lost productivity and functional disability. *General Hospital Psychiatry*, 29, 409-416.

Eisner, M. D. (2005). Environmental tobacco smoke and adult asthma. *Experimental Lung Research*, 31(Suppl 1), S8-S14.

Eisner, M. D., Blanc, P. D., Omachi, T. A., Yelin, E. H., Sidney, S., Katz, P. P. et al. (2009). Socioeconomic status, race and COPD health outcomes. *Journal of Epidemiology and Community Health*, 65, 26-34.

Eisner, M. D., Blanc, P. D., Yelin, E. H., Katz, P. P., Sanchez, G., Iribarren, C. et al. (2010). Influence of anxiety on health outcomes in COPD. *Thorax*, 65, 229-234.

Eisner, M. D., Jacob, P. 3rd, Benowitz, N. L., Balmes, J., & Blanc, P. D. (2009). Longer term exposure to secondhand smoke and health outcomes in COPD: Impact of urine 4-(methylnitrosamino)-1-(3-pyridyl)-1-butanol. *Nicotine and Tobacco Research*, 11, 945-953.

Emmerman, C. L., Effron, D., & Lukens, T. W. (1991). Spirometric criteria for hospital admission of patients with acute exacerbation of COPD. *Chest*, 99, 595-599.

European Respiratory Society (2003). *European lung white book: Respiratory health and disease across Europe*. In Gibson, G. J., Loddenkemper, R., Sibille, Y., & Lundback, B., (Eds), Huddersfield: European Respiratory Society Journals.

Evans, T. W., Waterhouse, J. C., Carter, A., Nicholl, J. F., & Howard, P. (1986). Short burst oxygen treatment for breathlessness in chronic obstructive airways disease. *Thorax*, 41, 611-615.

Fals-Stewart, W., Marks, A. P., & Schafer, J. (1993). A comparison of behavioral group therapy and individual behavior therapy in treating obsessive-compulsive disorder. *Journal of Nervous and Mental Disease*, 181, 189-193.

Fan, V. S., Gaziano, J. M., Lew, R., Bourbeau, J., Adams, S. G., Leatherman, S. et al. (2012). A comprehensive care management program to prevent chronic obstructive pulmonary disease hospitalizations: A randomized, controlled trial. *Annals of Internal Medicine*, 156, 673-683.

Fan, V. S., Giardino, N. D., Blough, D. K., Kaplan, R. M., & Ramsey, S. D. (2008). Costs of pulmonary rehabilitation and predictors of adherence in the national emphysema treatment trial. *COPD*, 5, 105-116.

Farr, M. (2010). *Readmission data file: 7, 14 and 28 day readmissions rates in conjunction with current tariffs to explore the impact of possible changes to funding levels in the NHS*. <http://www.drfoosterhealthintelligence.co.uk/newsPublications>. Last accessed: 29<sup>th</sup> June 2013.

Figueiredo, D., Gabriel, R., Jacome, C., & Marques, A. (2013). Caring for people with early and advanced chronic obstructive pulmonary disease: How do family carers cope? *Journal of Clinical Nursing*, in press.

Fiore, M. C. (2000). US public health service clinical practice guideline: Treating tobacco use and dependence. *Respiratory Care*, 45, 1200-1262.

Fischer, M., Scharloo, M., Abbink, J., van 't Hul, A., van Ranst, D., Rudolphus, A. et al. (2010). The dynamics of illness perceptions: testing assumptions of Leventhal's common-sense model in a pulmonary rehabilitation setting. *British Journal Health Psychology*, 15, 887-903.

Fischer, M. J., Scharloo, M., Abbink, J. J., Thijs-Van, A., Rudolphus, A., Snoei, L. et al. (2007). Participation and drop-out in pulmonary rehabilitation: A qualitative analysis of the patient's perspective. *Clinical Rehabilitation*, 21, 212-221.

Fischer, M. J., Scharloo, M., Abbink, J. J., van 't Hul, A. J., van Ranst, D., Rudolphus, A. et al. (2009). Drop-out and attendance in pulmonary rehabilitation: The role of clinical and psychosocial variables. *Respiratory Medicine*, 103, 1564-1571.

Fjorback, L. O., Arendt, M., Ornbol, E., Fink, P., & Walach, H. (2011). Mindfulness-based stress reduction and mindfulness-based cognitive therapy: A systematic review of randomized controlled trials. *Acta Psychiatrica Scandinavica*, 124, 102-119.

Forman, E. M., Chapman, J. E., Herbert, J. D., Goetter, E. M., Yuen, E. K., & Moitra, E. (2012). Using session-by-session measurement to compare mechanisms of action for acceptance and commitment therapy and cognitive therapy. *Behavior Therapy*, 43, 341-354.

French, D. P., Cooper, A., & Weinman, J. (2006). Illness perceptions predict attendance at cardiac rehabilitation following acute myocardial infarction: A systematic review with meta-analysis. *Journal of Psychosomatic Research*, 61, 757-767.

Friedman, S., Samuelian, J. C., Lancrenon, S., Even, C., & Chiarelli, P. (2001). Three-dimensional structure of the hospital anxiety and depression scale in a large French primary care population suffering from major depression. *Psychiatry Research*, 104, 247-257.

Furlanetto, K. C., Bisca, G. W., Oldenberg, N., Sant'anna, T. J., Morakami, F. K., Camillo, C. A. et al. (2010). Step counting and energy expenditure estimation in patients with chronic obstructive pulmonary disease and healthy elderly: Accuracy of 2 motion sensors. *Archives of Physical Medicine and Rehabilitation*, 91, 261-267.

Fuso, L., Incalzi, R. A., Pistelli, R., Muzzolon, R., Valente, S., Pagliari, G. et al. (1995). Predicting mortality of patients hospitalized for acutely exacerbated chronic obstructive pulmonary disease. *American Journal of Medicine*, 98, 272-277.

Galdas, P. M., Cheater, F., & Marshall, P. (2005). Men and health help-seeking behaviour: Literature review. *Journal of Advanced Nursing*, 49, 616-623.

Garcia-Aymerich, J., Lange, P., Benet, M., Schnohr, P., & Anto, J. M. (2006). Regular physical activity reduces hospital admission and mortality in chronic obstructive pulmonary disease: A population based cohort study. *Thorax*, 61, 772-778.

Garcia-Aymerich, J., Monso, E., Marrades, R. M., Escarrabill, J., Felez, M. A., Sunyer, J. et al. (2001). Risk factors for hospitalization for a chronic obstructive pulmonary disease exacerbation. EFRAM study. *American Journal of Respiratory and Critical Care Medicine*, 164, 1002-1007.

Garrod, R., Ford, K., Daly, C., Hoareau, C., Howard, M., & Simmonds, C. (2004). Pulmonary rehabilitation: Analysis of a clinical service. *Physiotherapy Research International*, 9, 111-120.

Garrod, R., Marshall, J., Barley, E., & Jones, P. W. (2006). Predictors of success and failure in pulmonary rehabilitation. *European Respiratory Journal*, 27, 788-794.

Gilbert, P., Irons, C., Olsen, K., Gilbert, J., & McEwan, K. (2006). Interpersonal sensitivities: Their links to mood, anger and gender. *Psychology and Psychotherapy*, 79, 37-51.

Gilbert, P. (2009). Introducing compassion-focused therapy. *Advances in Psychiatric Treatment*, 15, 199-208.

Global Initiative for Chronic Obstructive Lung Disease (GOLD). (2013). Global strategy for diagnosis, management and prevention of COPD. <http://www.goldcopd.org/>. Last accessed: 25<sup>th</sup> November 2013.

Gough, B. (2013). The psychology of men's health: maximizing masculine capital. *Health Psychology*, 32, 1-4.

Graham, C. D., Rose, M. R., Hankins, M., Chalder, T., & Weinman, J. (2012). Separating emotions from consequences in muscle disease: Comparing beneficial and unhelpful illness schemata to inform intervention development. *Journal of Psychosomatic Research*, 74, 320 – 326.

Grant M. (2000). *Searching for qualitative research studies on the MEDLINE database: The development of an optimal search strategy*. Aberystwyth: University of Wales, Department of Information and Library Studies.

Green, J. & Britten, N. (1998). Qualitative research and evidence based medicine. *British Medical Journal*, 316, 1230-1232.



Greene, J. C., Caracelli, V. J., & Graham, W. F. (1989). Toward a conceptual framework for mixed-method evaluation designs. *Educational Evaluation and Policy Analysis, 11*, 255-274.

Griffiths, T. L., Burr, M. L., Campbell, I. A., Lewis-Jenkins, V., Mullins, J., Shiels, K. et al. (2000). Results at 1 year of outpatient multidisciplinary pulmonary rehabilitation: A randomised controlled trial. *Lancet, 355*, 362-368.

Grossman, P., Kappos, L., Gensicke, H., D'Souza, M., Mohr, D. C., Penner, I. K. et al. (2010). MS quality of life, depression, and fatigue improve after mindfulness training: A randomized trial. *Neurology, 75*, 1141-1149.

Gruffydd-Jones, K., Langley-Johnson, C., Dyer, C., Badlan, K., & Ward, S. (2007). What are the needs of patients following discharge from hospital after an acute exacerbation of chronic obstructive pulmonary disease (COPD)? *Primary Care Respiratory Journal, 16*, 363-368.

Gudmundsson, G., Gislason, T., Janson, C., Lindberg, E., Hallin, R., Ulrik, C. S. et al. (2005). Risk factors for rehospitalisation in COPD: role of health status, anxiety and depression. *European Respiratory Journal, 26*, 414-419.

Guthrie, S. J., Hill, K. M., & Muers, M. E. (2001). Living with severe COPD. A qualitative exploration of the experience of patients in Leeds. *Respiratory Medicine, 95*, 196-204.

Guyatt, G. H., Berman, L. B., Townsend, M., Pugsley, S. O., & Chambers, L. W. (1987). A measure of quality of life for clinical trials in chronic lung disease. *Thorax, 42*, 773-778.

Hagger, M. S. & Orbell, S. (2003). A meta-analytic review of the common-sense model of illness representations. *Psychology and Health, 18*, 141-184.

Hallas, C. N., Howard, C., Theadom, A., & Wray, J. (2012). Negative beliefs about breathlessness increases panic for patients with chronic respiratory disease. *Psychology, Health and Medicine, 17*, 467-477.

Harris, D., Hayter, M., & Allender, S. (2008). Improving the uptake of pulmonary rehabilitation in patients with COPD: Qualitative study of experiences and attitudes. *British Journal of General Practice*, 58, 703-710.

Harrison, S. L., Horton, E. J., Smith, R., Sandland, C. J., Steiner, M. C., Morgan, M. D. et al. (2013). Physical activity monitoring: Addressing the difficulties of accurately detecting slow walking speeds. *Heart and Lung*, 42, 361-364.

Harrison, S. L., Robertson, N., Williams, J. E., Steiner, M. C., & Singh, S. J. (2012, September). Does Pulmonary Rehabilitation (PR) influence patient's perceptions of disease? Presented at the European Respiratory Society, Vienna.

Hart, T. L., Swartz, A. M., Cashin, S. E., & Strath, S. J. (2011). How many days of monitoring predict physical activity and sedentary behaviour in older adults? *International Journal of Behavioural Nutrition and Physical Activity*, 8(62), 1-7.

Hayton, C., Clark, A., Olive, S., Browne, P., Galey, P., Knights, E. et al. (2012). Barriers to pulmonary rehabilitation: Characteristics that predict patient attendance and adherence. *Respiratory Medicine*, 107, 401-407.

Healthcare Commission. (2006). Clearing the air: A national study of chronic obstructive pulmonary disease. London: Healthcare Commission.

Hecht, A., Ma, S., Porszasz, J., & Casaburi, R. (2009). Methodology for using long-term accelerometry monitoring to describe daily activity patterns in COPD. *COPD*, 6, 121-129.

Heckhausen, J., Wrosch, C., & Schulz, R. (2010). A motivational theory of life-span development. *Psychology Review*, 117, 32-60.

Heijmans, M. (1999). The role of patients' illness representations in coping and functioning with Addison's disease. *British Journal of Health Psychology*, 4, 137-149.

Higgins, B. G., Powell, R. M., Cooper, S., & Tattersfield, A. E. (1991). Effect of salbutamol and ipratropium bromide on airway calibre and bronchial reactivity in asthma and chronic bronchitis. *European Respiratory Journal*, 4, 415-420.

Hill, K., Dolmage, T. E., Woon, L., Goldstein, R., & Brooks, D. (2010). Measurement properties of the SenseWear armband in adults with chronic obstructive pulmonary disease. *Thorax*, 65, 486-491.

Hnizdo, E., Sullivan, P. A., Bang, K. M., & Wagner, G. (2002). Association between chronic obstructive pulmonary disease and employment by industry and occupation in the US population: A study of data from the third national health and nutrition examination survey. *American Journal of Epidemiology*, 156, 738-746.

Hobro, N., Weinman, J., & Hankins, M. (2004). Using the self-regulatory model to cluster chronic pain patients: The first step towards identifying relevant treatments? *Pain*, 108, 276-283.

Hogg, L., Garrod, R., Thornton, H., McDonnell, L., Bellas, H., & White, P. (2012). Effectiveness, attendance, and completion of an integrated, system-wide pulmonary rehabilitation service for COPD: Prospective observational study. *COPD*, 9, 546-554.

Holloway, A. & Watson, H. E. (2002). Role of self-efficacy and behaviour change. *International Journal of Nursing Practice*, 8, 106-115.

Holloway, I., Sofaer-Bennett, B., & Walker, J. (2007). The stigmatisation of people with chronic back pain. *Disability and Rehabilitation*, 29, 1456-1464.

Hopkinson, N. S., Englebrechtsen, C., Cooley, N., Kennie, K., Lim, M., Woodcock, T. et al. (2012). Designing and implementing a COPD discharge care bundle. *Thorax*, 67, 90-92.

Hoth, K. F., Wamboldt, F. S., Bowler, R., Make, B., & Holm, K. E. (2011). Attributions about cause of illness in chronic obstructive pulmonary disease. *Journal of Psychosomatic Research*, 70, 465-472.

Howard, C., Hallas, C. N., Wray, J., & Carby, M. (2009). The relationship between illness perceptions and panic in chronic obstructive pulmonary disease. *Behavior Research and Therapy*, 47, 71-76.

Hurst, J. R., Vestbo, J., Anzueto, A., Locantore, N., Mullerova, H., Tal-Singer, R. et al. (2010). Susceptibility to exacerbation in chronic obstructive pulmonary disease. *New England Journal of Medicine*, 363, 1128-1138.

Hynes, G., Stokes, A., & McCarron, M. (2012). Informal care-giving in advanced chronic obstructive pulmonary disease: Lay knowledge and experience. *Journal of Clinical Nursing*, 21, 1068-1077.

Hynninen, M. J., Bjerke, N., Pallesen, S., Bakke, P. S., & Nordhus, I. H. (2010). A randomized controlled trial of cognitive behavioral therapy for anxiety and depression in COPD. *Respiratory Medicine*, 104, 986-994.

Jaeschke, R., Singer, J., & Guyatt, G. H. (1989). Measurement of health status. Ascertaining the minimal clinically important difference. *Controlled Clinical Trials*, 10, 407-415.

Janssen, D. J., Spruit, M. A., Leue, C., Gijssen, C., Hameleers, H., Schols, J. M. et al. (2010). Symptoms of anxiety and depression in COPD patients entering pulmonary rehabilitation. *Chronic Respiratory Disease*, 7, 147-157.

Jansson, S. A., Andersson, F., Borg, S., Ericsson, A., Jonsson, E., & Lundback, B. (2002). Costs of COPD in Sweden according to disease severity. *Chest*, 122, 1994-2002.

Jeng, C., Tsao, L. I., Ho, C. H., & Chang, P. C. (2002). Experiences of daily activities within two weeks after hospital discharge among Taiwanese elderly patients with chronic obstructive pulmonary disease. *Journal of Nursing Research*, 10, 168-176.

Jick, T. D. (1979). Mixing qualitative and quantitative methods: Triangulation in action. *Administrative Science Quarterly*, 24, 602-611.

Johnson, R. B., Onwuegbuzie, A. J., & Turner, L. A. (2007). Toward a Definition of mixed methods research. *Journal of Mixed Methods Research*, 1, 112-133.

Johnston, M., Pollard, B., & Hennessey, P. (2000). Construct validation of the hospital anxiety and depression scale with clinical populations. *Journal of Psychosomatic Research*, 48, 579-584.

- Jones, P. W. (2001). Health status measurement in chronic obstructive pulmonary disease. *Thorax*, 56, 880-887.
- Jones, P. W., Quirk, F. H., Baveystock, C. M., & Littlejohns, P. (1992). A self-complete measure of health status for chronic airflow limitation. The St. George's respiratory questionnaire. *American Review of Respiratory Disease*, 145, 1321-1327.
- Jones, R. C., Harding, S. A., Chung, M. C., & Campbell, J. (2009). The prevalence of posttraumatic stress disorder in patients undergoing pulmonary rehabilitation and changes in PTSD symptoms following rehabilitation. *Journal of Cardiopulmonary Rehabilitation and Prevention*, 29, 49-56.
- Jones, R. C., Wang, X., Harding, S., Bott, J., & Hyland, M. (2008). Educational impact of pulmonary rehabilitation: Lung information needs questionnaire. *Respiratory Medicine*, 102, 1439-1445.
- Jones, S. E., Green, S. A., Clark, A. L., Dickson, M. J., Nolan, A., Moloney, C. et al. (2014). Pulmonary rehabilitation following hospitalisation for acute exacerbation of COPD: Referrals, uptake and adherence. *Thorax*, 69, 181-182.
- Jordan, T. S., Spencer, E. M., & Davies, P. (2010). Tuberculosis, bronchiectasis and chronic airflow obstruction. *Respirology*, 15, 623-628.
- Kanervisto, M., Kaistila, T., & Paavilainen, E. (2007). Severe chronic obstructive pulmonary disease in a family's everyday life in Finland: Perceptions of people with chronic obstructive pulmonary disease and their spouses. *Nursing and Health Sciences*, 9, 40-47.
- Kanner, R. E., Connett, J. E., Williams, D. E., & Buist, A. S. (1999). Effects of randomized assignment to a smoking cessation intervention and changes in smoking habits on respiratory symptoms in smokers with early chronic obstructive pulmonary disease: The Lung Health Study. *American Journal of Medicine*, 106, 410-416.
- Kaptein, A. A., Bijsterbosch, J., Scharloo, M., Hampson, S. E., Kroon, H. M., & Kloppenburg, M. (2010). Using the common sense model of illness perceptions to examine osteoarthritis change: a 6-year longitudinal study. *Health Psychology*, 29, 56-64.

Kaptein, A. A., Scharloo, M., Fischer, M. J., Snoei, L., Cameron, L. D., Sont, J. K. et al. (2008). Illness perceptions and COPD: An emerging field for COPD patient management. *Journal of Asthma*, 45, 625-629.

Kaptein, A. A., Scharloo, M., Fischer, M. J., Snoei, L., Hughes, B. M., Weinman, J. et al. (2009). 50 years of psychological research on patients with COPD: Road to ruin or highway to heaven? *Respiratory Medicine*, 103, 3-11.

Karajgi, B., Rifkin, A., Doddi, S., & Kolli, R. (1990). The prevalence of anxiety disorders in patients with chronic obstructive pulmonary disease. *American Journal of Psychiatry*, 147, 200-201.

Katsenos, S. & Constantopoulos, S. H. (2011). Long-term oxygen therapy in COPD: Factors affecting and ways of improving patient compliance. *Pulmonary Medicine*, 2011: 325362.

Keating, A., Lee, A. L., & Holland, A. E. (2011a). Lack of perceived benefit and inadequate transport influence uptake and completion of pulmonary rehabilitation in people with chronic obstructive pulmonary disease: A qualitative study. *Journal of Physiotherapy*, 57, 183-190.

Keating, A., Lee, A., & Holland, A. E. (2011b). What prevents people with chronic obstructive pulmonary disease from attending pulmonary rehabilitation? A systematic review. *Chronic Respiratory Disease*, 8, 89-99.

Keller, C., Fleury, J., Gregor-Holt, N., & Thompson, T. (1999). Predictive ability of social cognitive theory in exercise research: An integrated literature review. *Online Journal of Knowledge Synthesis for Nursing*, 6, 1-13.

Kessler, R., Stahl, E., Vogelmeier, C., Haughney, J., Trudeau, E., Lofdahl, C. G. et al. (2006). Patient understanding, detection, and experience of COPD exacerbations: An observational, interview-based study. *Chest*, 130, 133-142.

Kim, H. F. S., Kunik, M. E., Molinari, V. A., Hillman, S. L., Lalani, S., Orengo, C. A. et al. (2000). Functional impairment in COPD patients: The impact of anxiety and depression. *Psychosomatics*, 41, 465-471.

Lacasse, Y., Brosseau, L., Milne, S., Martin, S., Wong, E., Guyatt, G. H. et al. (2002). Pulmonary rehabilitation for chronic obstructive pulmonary disease. *Cochrane Database of Systematic Reviews*, CD003793.

Lacasse, Y., Goldstein, R., Lasserson, T. J., & Martin, S. (2006). Pulmonary rehabilitation for chronic obstructive pulmonary disease. *Cochrane Database of Systematic Reviews*, CD003793.

Lacroix, J. M., Martin, B., Avendano, M., & Goldstein, R. (1991). Symptom schemata in chronic respiratory patients. *Health Psychology*, 10, 268-273.

Laidlaw, K. (2010). Are attitudes to ageing and wisdom enhancement legitimate targets for CBT for late life depression and anxiety? *Nordic Psychology*, 62, 27-42.

Laidlaw, K., Thompson, L. W., & Gallagher-Thompson, D. (2004). Comprehensive conceptualization of cognitive behaviour therapy for late life depression. *Behavioural and Cognitive Psychotherapy*, 32, 389-399.

Langer, D., Gosselink, R., Sena, R., Burtin, C., Decramer, M., & Troosters, T. (2009). Validation of two activity monitors in patients with COPD. *Thorax*, 64, 641-642.

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, 3, 102-120.

Lau, R. R., Bernard, T. M., & Hartman, K. A. (1989). Further explorations of common-sense representations of common illnesses. *Health Psychology*, 8, 195-219.

Lazarus, R. S. & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer.

Lazarus, N. R. & Harridge, S. D. (2007). Inherent ageing in humans: The case for studying master athletes. *Scandinavian Journal of Medicine, Science and Sports*, 17, 461-463.

Leuenberger, P., Schwartz, J., Ackermann-Liebrich, U., Blaser, K., Bolognini, G., Bongard, J. P. et al. (1994). Passive smoking exposure in adults and chronic respiratory symptoms (SAPALDIA Study). Swiss study on air pollution and lung diseases in adults, SAPALDIA Team. *American Journal of Respiratory and Critical Care Medicine*, 150, 1222-1228.

Leventhal, H. & Niles, P. (1965). Persistence of influence for varying durations of exposure to threat stimuli. *Psychology Report*, 16, 223-233.

Leventhal, H., Benyamini, Y., Brownlee, S., Diefenbach, M., Leventhal, E. A., & Patrick -Miller, L. (1997). Illness perceptions: Theoretical foundations. In Petrie, K. & Weinman, J., (Eds), *Perceptions of health and illness: Current research and applications*. Amsterdam: Harwood Academic Publishers.

Leventhal, H., Nerenz, D. R., & Steele, D. S. (1984). Illness representations and coping with health threats. In Baum, A., (Eds), *Handbook of Psychology and Health*. Hillsdale, NJ: Erlbaum.

Macbeth, A. & Gumley, A. (2012). Exploring compassion: A meta-analysis of the association between self-compassion and psychopathology. *Clinical Psychology Review*, 32, 545-552.

MacLeod, C. & Rutherford, E. M. (1992). Anxiety and the selective processing of emotional information: Mediating roles of awareness, trait and state variables, and personal relevance of stimulus materials. *Behavior, Research and Therapy*, 30, 479-491.

Mahler, D. A., Donohue, J. F., Barbee, R. A., Goldman, M. D., Gross, N. J., Wisniewski, M. E. et al. (1999). Efficacy of salmeterol xinafoate in the treatment of COPD. *Chest*, 115, 957-965.

Mahler, D. A., Selecky, P. A., Harrod, C. G., Benditt, J. O., Carrieri-Kohlman, V., Curtis, J. R. et al. (2010). American College of Chest Physicians consensus statement on the management of dyspnea in patients with advanced lung or heart disease. *Chest*, 137, 674-691.



Man, W. D., Mustafa, N., Nikolettou, D., Kaul, S., Hart, N., Rafferty, G. F. et al. (2004). Effect of salmeterol on respiratory muscle activity during exercise in poorly reversible COPD. *Thorax*, 59, 471-476.

Man, W. D., Polkey, M. I., Donaldson, N., Gray, B. J., & Moxham, J. (2004). Community pulmonary rehabilitation after hospitalisation for acute exacerbations of chronic obstructive pulmonary disease: Randomised controlled study. *British Medical Journal*, 329, 1209.

Mannino, D. M. (2002). COPD: epidemiology, prevalence, morbidity and mortality, and disease heterogeneity. *Chest*, 121, 121S-126S.

Mannino, D. M., Gagnon, R. C., Petty, T. L., & Lydick, E. (2000). Obstructive lung disease and low lung function in adults in the United States: Data from the national health and nutrition examination survey, 1988-1994. *Archives of Internal Medicine*, 160, 1683-1689.

Marcus, B. H., Banspach, S. W., Lefebvre, R. C., Rossi, J. S., Carleton, R. A., & Abrams, D. B. (1992). Using the stages of change model to increase the adoption of physical activity among community participants. *American Journal of Health Promotion*, 6, 424-429.

Markham, A. W. & Wilkinson, J. M. (2004). Complementary and alternative medicines (CAM) in the management of asthma: An examination of the evidence. *Journal of Asthma*, 41, 131-139.

Mars, G. M., Proot, I. M., Janssen, P. P., van Eijk, J. T., & Kempen, G. I. (2007). How do people with COPD or diabetes type 2 experience autonomy? An exploratory study. *Disability and Rehabilitation*, 29, 485-493.

Martin, C. R. (2005). What does the hospital anxiety and depression scale (HADS) really measure in liaison psychiatry settings? *Current Psychiatry Review*, 1, 69-73.

Martin, R. C. & Dahlen, E. R. (2005). Cognitive emotion regulation in the prediction of depression, anxiety, stress, and anger. *Personality and Individual Differences*, 39, 1249-1260.

Matheson, M. C., Benke, G., Raven, J., Sim, M. R., Kromhout, H., Vermeulen, R. et al. (2005). Biological dust exposure in the workplace is a risk factor for chronic obstructive pulmonary disease. *Thorax*, 60, 645-651.

McGlynn, E. A., Asch, S. M., Adams, J., Keesey, J., Hicks, J., DeCristofaro, A. et al. (2003). The quality of health care delivered to adults in the United States. *New England Journal of Medicine*, 348, 2635-2645.

McNair, D. M., Lorr, M., & Doppleman, L. F. (1981). *Profile of mood states POMS*. San Diego, CA: Educational and Industrial Testing Service.

McPherson, C. J., Wilson, K. G., & Murray, M. A. (2007). Feeling like a burden to others: A systematic review focusing on the end of life. *Palliative Medicine*, 21, 115-128.

Medical Research Council Working Party. (1981). Long term domiciliary oxygen therapy in chronic hypoxic cor pulmonale complicating chronic bronchitis and emphysema. *Lancet*, 1, 681-686.

Medley, A. R., Powell, T., Worthington, A., Chohan, G., & Jones, C. (2010). Brain injury beliefs, self-awareness, and coping: a preliminary cluster analytic study based within the self-regulatory model. *Neuropsychological Rehabilitation*, 20, 899-921.

Meguro, M., Barley, E. A., Spencer, S., & Jones, P. W. (2007). Development and Validation of an Improved, COPD-Specific Version of the St. George Respiratory Questionnaire. *Chest*, 132, 456-463.

Menezes, A. M. B., Hallal, P. C., Perez-Padilla, R., Jardim, J. R. B., Muino, A., Lopez, M. V. et al. (2007). Tuberculosis and airflow obstruction: evidence from the PLATINO study in Latin America. *European Respiratory Journal*, 30, 1180-1185.

Menon, A., Korner-Bitensky, N., Kastner, M., McKibbin, K. A., & Straus, S. (2009). Strategies for rehabilitation professionals to move evidence-based knowledge into practice: a systematic review. *Journal of Rehabilitation Medicine*, 41, 1024-1032.

Meyer, D., Leventhal, H., & Gutmann, M. (1985). Common-sense models of illness: The example of hypertension. *Health Psychology, 4*, 115-135.

Michie, S., van Stralen, M. M., & West, R. (2011). The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Science, 6*, 42.

Miles, M. B. & Huberman, A. M. (1994). *Qualitative data analysis: An expanded source book*. Thousand Oaks, CA: Sage Publishing.

Miller, W. & Rollnick, S. (2002). *Motivational interviewing: Preparing people for change*. (2 ed.) New York: The Guildford Press.

Milligan, G. & Cooper, M. (1987). Methodological review: Clustering methods. *Applied Psychological Measurement, 11*, 329-354.

Milton Keynes Primary Care Trust (2005). *10 questions to help you make sense of qualitative research. Critical skills appraisal programme*. [web page]. Retrieved from <http://www.phru.nhs.uk/casp/qualitat.htm>. Last accessed: September 28th 2011.

Miravittles, M., Guerrero, T., Mayordomo, C., Sanchez-Agudo, L., Nicolau, F., & Segú, J. L. (2000). Factors associated with increased risk of exacerbation and hospital admission in a cohort of ambulatory COPD patients: A multiple logistic regression analysis. The EOLO study group. *Respiration, 67*, 495-501.

Moore, L., Hogg, L., & White, P. (2012). Acceptability and feasibility of pulmonary rehabilitation for COPD: A community qualitative study. *Primary Care Respiratory Journal, 21*, 419-424.

Morse, J. M. (1991). Approaches to qualitative-quantitative methodological triangulation. *Nursing Research, 40*, 120-123.

Moss-Morris, R., Weinman, J., Petrie, K., Horne, R., Cameron, L., & Buick, D. (2002). The revised illness perception questionnaire (IPQ-R) . *Psychology and Health, 17*, 1-16.

Mularski, R. A., Munjas, B. A., Lorenz, K. A., Sun, S., Robertson, S. J., Schmelzer, W. et al. (2009). Randomized controlled trial of mindfulness-based therapy for dyspnea in chronic obstructive lung disease. *Journal of Alternative and Complementary Medicine*, 15, 1083-1090.

Munir, F., Kalawsky, K., Wallis, D. J., & Donaldson-Feilder, E. (2013). Using intervention mapping to develop a work-related guidance tool for those affected by cancer. *BMC Public Health*, 13, 6.

Murray, C. J. & Lopez, A. D. (1997). Global mortality, disability, and the contribution of risk factors: Global burden of disease study. *Lancet*, 349, 1436-1442.

National Institute for Clinical Excellence. (2010). Chronic obstructive pulmonary disease: Management of chronic obstructive pulmonary disease in adults in primary and secondary care. [CG101]. London: National Institute of Health Care and Excellence.

Needle, J., Petchey, R., Benson, J., Scriven, A., Lawrenson, J., & Hilari, K. (2011). *The allied health professions and health promotion: A systematic literature review and narrative synthesis (Report No. Final)*. London: NIHR Service Delivery and Organisation programme.

Nguyen, H. Q., Burr, R. L., Gill, D. P., & Coleman, K. (2011). Validation of the StepWatch device for measurement of free-living ambulatory activity in patients with chronic obstructive pulmonary disease. *Journal of Nursing Measurement*, 19, 76-90.

Nicca, D., Fierz, K., Happ, M. B., Moody, K., & Spirig, R. (2012). Symptom management in HIV/AIDS: A mixed methods approach to describe collaboration and concordance between persons living with HIV and their close support persons. *Journal of Mixed Methods Research*, 6, 217-235.

Nici, L., Donner, C., Wouters, E., Zuwallack, R., Ambrosino, N., Bourbeau, J. et al. (2006). American Thoracic Society/European Respiratory Society statement on pulmonary rehabilitation. *American Journal of Respiratory and Critical Care Medicine*, 173, 1390-1413.

Nicolson, P. & Anderson, P. (2000). The patient's burden: Physical and psychological effects of acute exacerbations of chronic bronchitis. *Journal of Antimicrobial Chemotherapy*, 45, 25-32.

Noblit, G. & Hare, R. (1988). *Meta-ethnography: Synthesising qualitative studies*. Newbury park, CA: Sage.

Noyes, J. & Popay, J. (2007). Directly observed therapy and tuberculosis: How can a systematic review of qualitative research contribute to improving services? A qualitative meta-synthesis. *Journal of Advanced Nursing*, 57, 227-243.

O'Neill, E. S. (2002). Illness representations and coping of women with chronic obstructive pulmonary disease: a pilot study. *Heart and Lung*, 31, 295-302.

O'Shea, S. D., Taylor, N. F., & Paratz, J. (2004). Peripheral muscle strength training in COPD: A systematic review. *Chest*, 126, 903-914.

Office for National Statistics (2000). *Health Statistics Quarterly*, 8. London: HMSO.

Okubadejo, A. A., Paul, E. A., & Wedzicha, J. A. (1994). Domiciliary oxygen cylinders: Indications, prescription and usage. *Respiratory Medicine*, 88, 777-785.

Oliver, S. M. (2001). Living with failing lungs: The doctor-patient relationship. *Family Practice*, 18, 430-439.

Osborn, M. & Smith, J. A. (1998). The personal experience of chronic benign lower back pain: An interpretative phenomenological analysis. *British Journal of Health Psychology*, 3, 65-83.

Pauwels, R. A., Buist, A. S., Calverley, P. M., Jenkins, C. R., & Hurd, S. S. (2001). Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease. NHLBI/WHO Global Initiative for Chronic Obstructive Lung Disease (GOLD) workshop summary. *American Journal of Respiratory and Critical Care Medicine*, 163, 1256-1276.

Pbert, L., Madison, J. M., Druker, S., Olendzki, N., Magner, R., Reed, G. et al. (2012). Effect of mindfulness training on asthma quality of life and lung function: A randomised controlled trial. *Thorax*, 67, 769-776.

Perz, C. A., DiClemente, C. C., & Carbonari, J. P. (1996). Doing the right thing at the right time? The interaction of stages and processes of change in successful smoking cessation. *Health Psychology*, 15, 462-468.

Peters, E., Hess, T. M., Vastfjall, D., & Auman, C. (2007). Adult age differences in dual information processes: Implications for the role of affective and deliberative processes in older adults' decision making. *Perspectives on Psychological Science*, 2, 1-23.

Peters, K. D., Kochanek, K. D., & Murphy, S. L. (1998). Deaths: Final data for 1996. *National Vital Statistics Report*, 47, 1-100.

Petersen, S., Taube, K., Lehmann, K., van den Bergh, O., & von Leupoldt, A. (2012). Social comparison and anxious mood in pulmonary rehabilitation: The role of cognitive focus. *British Journal of Health Psychology*, 17, 463-476.

Petrie, K. J., Cameron, L. D., Ellis, C. J., Buick, D., & Weinman, J. (2002). Changing illness perceptions after myocardial infarction: An early intervention randomized controlled trial. *Psychosomatic Medicine*, 64, 580-586.

Petros, S. G. (2012). Use of a mixed methods approach to investigate the support needs of older caregivers to family members affected by HIV and AIDS in South Africa. *Journal of Mixed Methods Research*, 6, 275-293.

Pinnock, H., Kendall, M., Murray, S. A., Worth, A., Levack, P., Porter, M. et al. (2011). Living and dying with severe chronic obstructive pulmonary disease: Multi-perspective longitudinal qualitative study. *British Medical Journal*, 342, d142.

Pitta, F., Breyer, M. K., Hernandez, N. A., Teixeira, D., Sant'anna, T. J., Fontana, A. D. et al. (2009). Comparison of daily physical activity between COPD patients from Central Europe and South America. *Respiratory Medicine*, 103, 421-426.

Pitta, F., Troosters, T., Probst, V. S., Spruit, M. A., Decramer, M., & Gosselink, R. (2006a). Physical activity and hospitalization for exacerbation of COPD. *Chest*, 129, 536-544.

Pitta, F., Troosters, T., Probst, V. S., Spruit, M. A., Decramer, M., & Gosselink, R. (2006b). Quantifying physical activity in daily life with questionnaires and motion sensors in COPD. *European Respiratory Journal*, 27, 1040-1055.

Plaufcan, M. R., Wamboldt, F. S., & Holm, K. E. (2012). Behavioral and characterological self-blame in chronic obstructive pulmonary disease. *Journal of Psychosomatic Research*, 72, 78-83.

Porzelius, J., Vest, M., & Nochomovitz, M. (1992). Respiratory function, cognitions, and panic in chronic obstructive pulmonary patients. *Behaviour Research and Therapy*, 30, 75-77.

Pound, P., Britten, N., Morgan, M., Yardley, L., Pope, C., Daker-White, G. et al. (2005). Resisting medicines: A synthesis of qualitative studies of medicine taking. *Social Science and Medicine*, 61, 133-155.

Prescott, E., Lange, P., & Vestbo, J. (1999). Socioeconomic status, lung function and admission to hospital for COPD: Results from the Copenhagen City Heart Study. *European Respiratory Journal*, 13, 1109-1114.

Prochaska, J. O., DiClemente, C. C., & Norcross, J. C. (1992). In search of how people change. Applications to addictive behaviors. *American Psychologist*, 47, 1102-1114.

Prochaska, J. O. & Velicer, W. F. (1997). The transtheoretical model of health behavior change. *American Journal of Health Promotion*, 12, 38-48.

Puhan, M., Scharplatz, M., Troosters, T., Walters, E. H., & Steurer, J. (2009). Pulmonary rehabilitation following exacerbations of chronic obstructive pulmonary disease. *Cochrane Database of Systematic Reviews*, CD005305.

Puhan, M. A., Frey, M., Buchi, S., & Schunemann, H. J. (2008). The minimal important difference of the hospital anxiety and depression scale in patients with chronic obstructive pulmonary disease. *Health and Quality of Life Outcomes*, 6 (46), 1-6.

Puhan, M. A., Gimeno-Santos, E., Scharplatz, M., Troosters, T., Walters, E. H., & Steurer, J. (2011). Pulmonary rehabilitation following exacerbations of chronic obstructive pulmonary disease. *Cochrane Database of Systematic Reviews*, CD005305.

Puhan, M. A., Spaar, A., Frey, M., Turk, A., Brandli, O., Ritscher, D. et al. (2012). Early versus late pulmonary rehabilitation in chronic obstructive pulmonary disease patients with acute exacerbations: A randomized trial. *Respiration*, 83, 499-506.

Quantrill, S. J., White, R., Crawford, A., Barry, J. S., Batra, S., Whyte, P. et al. (2007). Short burst oxygen therapy after activities of daily living in the home in chronic obstructive pulmonary disease. *Thorax*, 62, 702-705.

Quint, J. K., Baghai-Ravary, R., Donaldson, G. C., & Wedzicha, J. A. (2008). Relationship between depression and exacerbations in COPD. *European Respiratory Journal*, 32, 53-60.

Radloff, L. S. (1977). The CES-D Scale: A Self-Report Depression Scale for Research in the General Population. *Applied Psychological Measurement*, 1, 385-401.

Revill, S. M., Morgan, M. D., Singh, S. J., Williams, J., & Hardman, A. E. (1999). The endurance shuttle walk: A new field test for the assessment of endurance capacity in chronic obstructive pulmonary disease. *Thorax*, 54, 213-222.

Roberts, C. M., Lowe, D., Bucknall, C. E., Ryland, I., Kelly, Y., & Pearson, M. G. (2002). Clinical audit indicators of outcome following admission to hospital with acute exacerbation of chronic obstructive pulmonary disease. *Thorax*, 57, 137-141.

Rose, C., Wallace, L., Dickson, R., Ayres, J., Lehman, R., Searle, Y. et al. (2002). The most effective psychologically-based treatments to reduce anxiety and panic in patients with chronic obstructive pulmonary disease (COPD): A systematic review. *Patient Education and Counseling*, 47, 311-318.



Rosenstock, I. M. (1966). "Why people use health services". *Milbank Memorial Fund Quarterly*, 44, 94-127.

Rotter, J. B. (1954). *Social Learning and Clinical Psychology*. N.Y: Prentice-Hall.

Russell, C. K., Geraci, T., Hooper, A., Shull, L., & Gregory, D. M. (1998). Patients' explanatory models for heart failure and COPD exacerbations. *Clinical Nursing Research*, 7, 164-188.

Scanlon, P. D., Connett, J. E., Waller, L. A., Altose, M. D., Bailey, W. C., & Buist, A. S. (2000). Smoking cessation and lung function in mild-to-moderate chronic obstructive pulmonary disease. The Lung Health Study. *American Journal of Respiratory and Critical Care Med*, 161, 381-390.

Scharloo, M., Kaptein, A. A., Schlosser, M., Pouwels, H., Bel, E. H., Rabe, K. F. et al. (2007). Illness perceptions and quality of life in patients with chronic obstructive pulmonary disease. *Journal of Asthma*, 44, 575-581.

Scharloo, M., Kaptein, A. A., Weinman, J., Hazes, J. M., Willems, L. N., Bergman, W. et al. (1998). Illness perceptions, coping and functioning in patients with rheumatoid arthritis, chronic obstructive pulmonary disease and psoriasis. *Journal of Psychosomatic Research*, 44, 573-585.

Scharloo, M., Kaptein, A. A., Weinman, J. A., Willems, L. N., & Rooijmans, H. G. (2000). Physical and psychological correlates of functioning in patients with chronic obstructive pulmonary disease. *Journal of Asthma*, 37, 17-29.

Schofield, I., Knussen, C., & Tolson, D. (2006). A mixed method study to compare use and experience of hospital care and a nurse-led acute respiratory assessment service offering home care to people with an acute exacerbation of chronic obstructive pulmonary disease. *International Journal of Nursing Studies*, 43, 465-476.

Schofield, I., Kerr, S., & Tolson, D. (2007). An exploration of the smoking-related health beliefs of older people with chronic obstructive pulmonary disease. *Journal of Clinical Nursing*, 16, 1726-1735.

Schwarzer, R. & Jerusalem, M. (1995). Generalised self-efficacy scale. In Wright, S., Johnston, M., & Weinman, J. *Measures in health psychology: A users portfolio. Causal and control beliefs*. Windsor, UK: NFER-Nelson.

Scott, S. D., Albrecht, L., O'Leary, K., Ball, G. D., Hartling, L., Hofmeyer, A. et al. (2012). Systematic review of knowledge translation strategies in the allied health professions. *Implementation Science*, 7, 70.

Seamark, D. A., Blake, S. D., Seamark, C. J., & Halpin, D. M. (2004). Living with severe chronic obstructive pulmonary disease (COPD): Perceptions of patients and their carers. An interpretative phenomenological analysis. *Palliative Medicine*, 18, 619-625.

Seemungal, T. A., Donaldson, G. C., Paul, E. A., Bestall, J. C., Jeffries, D. J., & Wedzicha, J. A. (1998). Effect of exacerbation on quality of life in patients with chronic obstructive pulmonary disease. *American Journal of Respiratory and Critical Care Medicine*, 157, 1418-1422.

Selzler, A. M., Simmonds, L., Rodgers, W. M., Wong, E. Y., & Stickland, M. K. (2012). Pulmonary rehabilitation in chronic obstructive pulmonary disease: Predictors of program completion and success. *COPD*, 9, 538-545.

Seneff, M. G., Wagner, D. P., Wagner, R. P., Zimmerman, J. E., & Knaus, W. A. (1995). Hospital and 1-year survival of patients admitted to intensive care units with acute exacerbation of chronic obstructive pulmonary disease. *Journal of the American Medical Association*, 274, 1852-1857.

Sestini, P., Renzoni, E., Robinson, S., Pool, P., & Ram, F. S. (2000). Short-acting beta 2 agonists for stable chronic obstructive pulmonary disease. *Cochrane database of Systematic Reviews*, CD001495.

Sewell, L., Singh, S. J., Williams, J. E., Collier, R., & Morgan, M. D. (2005). Can individualized rehabilitation improve functional independence in elderly patients with COPD? *Chest*, 128, 1194-1200.

Seymour, J. M., Moore, L., Jolley, C. J., Ward, K., Creasey, J., Steier, J. S. et al. (2010). Outpatient pulmonary rehabilitation following acute exacerbations of COPD. *Thorax*, 65, 423-428.

Shaw, R. (2011). Identifying and synthesizing qualitative literature. In Harper, D. A., Thompson, A.R (Eds). *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners*. Oxford: Wiley-Blackwell.

Sheldon, T. A. (2005). Making evidence synthesis more useful for management and policy-making. *Journal of Health Service and Research Policy*, 10 (Suppl 1), 1-5.

Siafakas, N. M., Vermeire, P., Pride, N. B., Paoletti, P., Gibson, J., Howard, P. et al. (1995). Optimal assessment and management of chronic obstructive pulmonary disease (COPD). The European Respiratory Society task force. *European Respiratory Journal*, 8, 1398-1420.

Silverman, E. K. & Speizer, F. E. (1996). Risk factors for the development of chronic obstructive pulmonary disease. *Medical Clinics of North America*, 80, 501-522.

Sin, D. D., Anthonisen, N. R., Soriano, J. B., & Agusti, A. G. (2006). Mortality in COPD: Role of comorbidities. *European Respiratory Journal*, 28, 1245-1257.

Singh, S. J., Boskett, C., Sewell, L., Williams, J., Collier, R., Morgan, M. D. L. et al. (2001, May). The effect of big band music on performance of the endurance shuttle walking test in COPD. Presented at the meeting of the American Thoracic Society, San Francisco, CA.

Singh, S. J., Jones, P. W., Evans, R., & Morgan, M. D. (2008). Minimum clinically important improvement for the incremental shuttle walking test. *Thorax*, 63, 775-777.

Singh, S. J., Morgan, M. D., Scott, S., Walters, D., & Hardman, A. E. (1992). Development of a shuttle walking test of disability in patients with chronic airways obstruction. *Thorax*, 47, 1019-1024.

Skinner, T. C., Carey, M. E., Cradock, S., Dallosso, H. M., Daly, H., Davies, M. J. et al. (2011). Comparison of illness representations dimensions and illness representation clusters in predicting outcomes in the first year following diagnosis of type 2 diabetes: Results from the DESMOND trial. *Psychology and Health*, 26, 321-335.

Small, S. P. & Graydon, J. E. (1993). Uncertainty in hospitalized patients with chronic obstructive pulmonary disease. *International Journal of Nursing Studies*, 30, 239-246.

Small, S. & Lamb, M. (1999). Fatigue in chronic illness: The experience of individuals with chronic obstructive pulmonary disease and with asthma. *Journal of Advanced Nursing*, 30, 469-478.

Smith, A. (2004). Clinical uses of mindfulness training for older people. *Behavioural and Cognitive Psychotherapy*, 32, 423-430.

Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. London: Sage Publications Limited.

Smith, J. (2007). Hermeneutics, human sciences and health: Linking theory and practice. *International Journal of Qualitative Studies on Health and Wellbeing*, 2, 3-11.

Soriano, J. B., Maier, W. C., Egger, P., Visick, G., Thakrar, B., Sykes, J. et al. (2000). Recent trends in physician diagnosed COPD in women and men in the UK. *Thorax*, 55, 789-794.

Spielberger, C. D., Gorsuch, R. L., Lushene, P. R., Vagg, P., & Jacobs, G. A. (1983). *Manual for the State-Trait Anxiety Inventory*. Palo Alto, CA: Consulting Psycholgy Press, Inc.

Spencer, S., Calverley, P. M., Burge, P. S., & Jones, P. W. (2004). Impact of preventing exacerbations on deterioration of health status in COPD. *European Respiratory Journal*, 23, 698-702.

Spruit, M. A., Singh, S. J., Garvey, C., Zuwallack, R., Nici, L., Rochester, C. et al. (2013). An official American Thoracic Society/European Respiratory Society statement: key concepts and advances in pulmonary rehabilitation. *American Journal of Respiratory and Critical Care Medicine*, 188, E13-E64.

Staley, K. & Minogue, V. (2006). User involvement in research leads to more ethically sound research. *Clinical Ethics*, 1, 95-100.

Stangier, U., Heidenreich, T., Peitz, M., Lauterbach, W., & Clark, D. M. (2003). Cognitive therapy for social phobia: Individual versus group treatment. *Behavior, Research and Therapy*, 41, 991-1007.

Stavrakaki, C. & Vargo, B. (1986). The relationship of anxiety and depression: A review of the literature. *British Journal of Psychiatry*, 149, 7-16.

Steele, B. G., Holt, L., Belza, B., Ferris, S., Lakshminaryan, S., & Buchner, D. M. (2000). Quantitating physical activity in COPD using a triaxial accelerometer. *Chest*, 117, 1359-1367.

Stoller, J. K. & Aboussouan, L. S. (2005). Alpha1-antitrypsin deficiency. *Lancet*, 365, 2225-2236.

Straat, J. H., van der Ark, L. A., & Sijtsma, K. (2013). Methodological artifacts in dimensionality assessment of the hospital anxiety and depression scale (HADS). *Journal of Psychosomatic Research*, 74, 116-121.

Suissa, S., Dell'aniello, S., & Ernst, P. (2012). Long-term natural history of chronic obstructive pulmonary disease: Severe exacerbations and mortality. *Thorax*, 67, 957-963.

Sullivan, S. D., Ramsey, S. D., & Lee, T. A. (2000). The economic burden of COPD. *Chest*, 117, 5S-9S.

The Surgeon General. (2006). *The health consequences of involuntary exposure to tobacco smoke*. Washington DC, US: Department of Health and Human Services.

Theander, K., Jakobsson, P., Jorgensen, N., & Unosson, M. (2009). Effects of pulmonary rehabilitation on fatigue, functional status and health perceptions in patients with chronic obstructive pulmonary disease: A randomized controlled trial. *Clinical Rehabilitation*, 23, 125-136.

Thorn, J., Björkelund, C., Bengtsson, C., Guo, X., Lissner, L., & Sundh, V. (2007). Socio-economic status, smoking, mental stress and obesity predict obstructive symptoms in women but only smoking also predicts subsequent experience of poor health. *International Journal of Medical Sciences*, 4, 7-12.

Tinetti, M. E. & Studenski, S. A. (2011). Comparative effectiveness research and patients with multiple chronic conditions. *New England Journal of Medicine*, 364, 2478-2481.

Troosters, T., Vilaro, J., Rabinovich, R., Casas, A., Barbera, J. A., Rodriguez-Roisin, R. et al. (2002). Physiological responses to the 6-min walk test in patients with chronic obstructive pulmonary disease. *European Respiratory Journal*, 20, 564-569.

Trupin, L., Earnest, G., San, P. M., Balmes, J. R., Eisner, M. D., Yelin, E. et al. (2003). The occupational burden of chronic obstructive pulmonary disease. *European Respiratory Journal*, 22, 462-469.

Tudor-Locke, C., Burkett, L., Reis, J. P., Ainsworth, B. E., Macera, C. A., & Wilson, D. K. (2005). How many days of pedometer monitoring predict weekly physical activity in adults? *Preventative Medicine*, 40, 293-298.

Tudor-Locke, C., Washington, T. L., & Hart, T. L. (2009). Expected values for steps/day in special populations. *Preventative Medicine*, 49, 3-11.

Turner, L. J., Houchen, L., Williams, J., & Singh, S. J. (2012). Reliability of pedometers to measure step counts in patients with chronic respiratory disease. *Journal of Cardiopulmonary Rehabilitation and Prevention*, 32, 284-291.

US Surgeon General. (1984). *The health consequences of smoking: Chronic obstructive pulmonary disease*. Washington DC: US Department of Health and Human Services.

van den Boom, G., van Schayck, C. P., van Mollen, M. P., Tirimanna, P. R., den Otter, J. J., van Grunsven, P. M. et al. (1998). Active detection of chronic obstructive pulmonary disease and asthma in the general population. Results and economic consequences of the DIMCA program. *American Journal of Respiratory and Critical Care Medicine*, 158, 1730-1738.

van der Meer, R. M., Wagena, E. J., Ostelo, R. W., Jacobs, J. E., & van Schayck, C. P. (2003). Smoking cessation for chronic obstructive pulmonary disease. *Cochrane Database of Systematic Reviews*, CD002999.

van Ede, L., Yzermans, C. J., & Brouwer, H. J. (1999). Prevalence of depression in patients with chronic obstructive pulmonary disease: A systematic review. *Thorax*, 54, 688-692.

van Wheel, C. & Schellevis, F. G. (2006). Comorbidity and guidelines: Conflicting interests. *Lancet*, 367, 550-551.

Vathenen, A. S., Britton, J. R., Ebden, P., Cookson, J. B., Wharrad, H. J., & Tattersfield, A. E. (1988). High-dose inhaled albuterol in severe chronic airflow limitation. *American Review of Respiratory Disease*, 138, 850-855.

Vestbo, J., Prescott, E., & Lange, P. (1996). Association of chronic mucus hypersecretion with FEV1 decline and chronic obstructive pulmonary disease morbidity. Copenhagen City Heart Study group. *American Journal of Respiratory and Critical Care Medicine*, 153, 1530-1535.

Vincent, E., Sewell, L., Wagg, K., Deacon, S., Williams, J., & Singh, S. (2011). Measuring a change in self-efficacy following pulmonary rehabilitation: An evaluation of the PRAISE tool. *Chest*, 140, 1534-1539.

von Leupoldt A., Taube, K., Lehmann, K., Fritzsche, A., & Magnussen, H. (2011). The impact of anxiety and depression on outcomes of pulmonary rehabilitation in patients with COPD. *Chest*, 140, 730-736.

Waschki, B., Kirsten, A., Holz, O., Muller, K. C., Meyer, T., Watz, H. et al. (2011). Physical activity is the strongest predictor of all-cause mortality in patients with COPD: A prospective cohort study. *Chest*, 140, 331-342.

Watz, H., Waschki, B., Boehme, C., Claussen, M., Meyer, T., & Magnussen, H. (2008). Extrapulmonary effects of chronic obstructive pulmonary disease on physical activity: A cross-sectional study. *American Journal of Respiratory and Critical Care Medicine*, 177, 743-751.

Watz, H., Waschki, B., Meyer, T., & Magnussen, H. (2009). Physical activity in patients with COPD. *European Respiratory Journal*, 33, 262-272.

Webb, E. J., Campbell, S. T., Schwartz, R. D., & Sechrest, L. (1999). *Unobtrusive measures: Non reactive measures in social sciences*, (Rev. ed.). In Laughton, C. D., (Eds), Thousand Oaks, CA: Sage Publications Ltd.

Weinman, J., Petrie, K. J., Moss-Morris, R., & Horne, R. (1996). The illness perception questionnaire: A new method for assessing the cognitive representation of illness. *Psychology and Health*, 11, 431-445.

Weldam, S. W., Lammers, J. W., Decates, R. L., & Schuurmans, M. J. (2013). Daily activities and health-related quality of life in patients with chronic obstructive pulmonary disease: psychological determinants: a cross-sectional study. *Health and Quality of Life Outcomes*, 11, 190.

Wijkstra, P. J., TenVergert, E. M., van Altena, R., Otten, V., Postma, D. S., Kraan, J. et al. (1994). Reliability and validity of the chronic respiratory questionnaire (CRQ). *Thorax*, 49, 465-467.

Williams, V., Bruton, A., Ellis-Hill, C., & McPherson, K. (2007). What really matters to patients living with chronic obstructive pulmonary disease? An exploratory study. *Chronic Respiratory Disease*, 4, 77-85.

Williams, J. E., Singh, S. J., Sewell, L., Guyatt, G. H., & Morgan, M. D. (2001). Development of a self-reported chronic respiratory questionnaire (CRQ-SR). *Thorax*, 56, 954-959.

Williams, J. E., Singh, S. J., Sewell, L., & Morgan, M. D. (2003). Health status measurement: sensitivity of the self-reported chronic respiratory questionnaire (CRQ-SR) in pulmonary rehabilitation. *Thorax*, 58, 515-518.



Winstanley, L. (2008). Risk assessment documentation in COC prescribing. *Journal of Family Planning and Reproductive Health Care*, 34, (137).

World Health Organization (2013). *Chronic obstructive pulmonary disease (COPD) Fact sheet 315*. [www.who.int/mediacentre/factsheets/fs315/en/print.html](http://www.who.int/mediacentre/factsheets/fs315/en/print.html). Last accessed: 19<sup>th</sup> November 2013.

Xu, W., Collet, J. P., Shapiro, S., Lin, Y., Yang, T., Platt, R. W. et al. (2008). Independent effect of depression and anxiety on chronic obstructive pulmonary disease exacerbations and hospitalizations. *American Journal of Respiratory and Critical Care Medicine*, 178, 913-920.

Yohannes, A. M., Baldwin, R. C., & Connolly, M. J. (2005). Predictors of 1-year mortality in patients discharged from hospital following acute exacerbation of chronic obstructive pulmonary disease. *Age and Ageing*, 34, 491-496.

Yohannes, A. M., Roomi, J., & Connolly, M. J. (1998). Elderly people at home disabled by chronic obstructive pulmonary disease. *Age and Ageing*, 27, 523-525.

Yohannes, A. M., Roomi, J., Waters, K., & Connolly, M. J. (1998). Quality of life in elderly patients with COPD: Measurement and predictive factors. *Respiratory Medicine*, 92, 1231-1236.

Yohannes, A. M., Willgoss, T. G., Baldwin, R. C., & Connolly, M. J. (2010). Depression and anxiety in chronic heart failure and chronic obstructive pulmonary disease: Prevalence, relevance, clinical implications and management principles. *International Journal of Geriatric Psychiatry*, 25, 1209-1221.

Yohannes, A. M., Baldwin, R. C., & Connolly, M. J. (2000). Mood disorders in elderly patients with chronic obstructive pulmonary disease. *Reviews in Clinical Gerontology*, 10, 193-202.

Yu, D. S., Lee, D. T., & Woo, J. (2007). The revolving door syndrome: The Chinese COPD patients' perspectives. *Journal of Clinical Nursing*, 16, 1758-1760.

Zigmond, A. S. & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, 67, 361-370.

Zoeckler, N., Kenn, K., Kuehl, K., Stenzel, N., & Rief, W. (2014). Illness perceptions predict exercise capacity and psychological well-being after pulmonary rehabilitation in COPD patients. *Journal of Psychosomatic Research*, 76, 146-151.

## **14. LIST OF APPENDICES**

**Appendix A.** Data extraction form.

**Appendix B.** Hospital Anxiety and Depression Scale.

**Appendix C.** Chronic Respiratory Questionnaire – Self-reported.

**Appendix D.** Patient Public Involvement group meeting minutes 10.02.2011.

**Appendix E.** Patient Public Involvement group: protocol feedback survey.

**Appendix F.** Patient information sheet, version 5.

**Appendix G.** Letters of ethical approval.

- i. National Research Ethics Service. East Midlands – Leicester
- ii. Comprehensive Local Research Network.

**Appendix H.** Interview schedule.

**Appendix I.** Patient Public Involvement group meeting minutes 27.02.2012.

**Appendix J.** Consent form, version 4.

**Appendix K.** General Practitioner letter.

**Appendix L.** Activity monitor instructions.

**Appendix M.** Data collection form – study demographics.

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**Appendix O.** Patient Public Involvement group meeting minutes 10.08.2012.

**Appendix P.** Collaborative workshop groups.

**Appendix Q.** Collaborative workshop meeting minutes 20.09.2012.

**Appendix R.** Illness Perceptions Questionnaire-Revised.

**Appendix S.** Pulmonary Rehabilitation Adapted Index of Self-Efficacy.

## Appendix A

### Data extraction form

#### Eligibility

Question		If yes	If no
1	Has the study been published?	Continue	Exclude
2	Is the document primary research?	Continue	Exclude
3	Is the study about an exacerbation of COPD?	Continue	Exclude
4	Does the study evaluate patient's responses, appraisals and understanding of an exacerbation of COPD?	Continue	Exclude

#### Study Characteristics

Study details	Research question	
	Location/setting	
	Theoretical framework	
Participants	Population	
	Age (range, mean)	
	Gender	
	Ethnicity	
	Socio-economic status	
	Disease severity (GOLD, MRC etc)	
	Recruitment method/sampling	
Data collection	Method	
	Who collected the data?	
	Was the data translated or interpreted?	
	How was the data prepared for analysis?	
Analysis	Method	
Validity	What validation methods were used?	
Reflexivity	Did the study report engaging in reflexivity?	
Findings	How are the results presented?	

	DESCRIPTION	QUOTES/COMMENTRY
Category 1	Title:	
(Title, description, quotes from participants, authors commentary)		
Category 2	Title:	
Category 3	Title	
Category 4	Title	

Category 5	Title	
Category 6	Title	
Category 7	Title	
	Main significant findings	

Authors conclusions	Conclusion (key findings, author remarks)	
	Limitations as identified by authors	
	Implications as identified by authors	
	Key references (not identified by search strategy)	
Comments		

## Appendix B

### Hospital Anxiety and Depression Scale

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings he or she will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Read each item below and underline the reply which comes closest to how you have been feeling in the past week. Ignore the numbers printed at the edge of the questionnaire.

Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long thought-out response.

A	D		A	D	
		<b>I feel tense or 'wound up'</b>			<b>I feel as if I am slowed down</b>
3		Most of the time			Nearly all the time
2		A lot of the time			Very often
1		From time to time, occasionally			Sometimes
0		Not at all			Not at all
		<b>I still enjoy things I used to enjoy</b>			<b>I get a sort of frightened feeling like 'butterflies' in the stomach</b>
	0	Definitely as much			Not at all
	1	Not quite as much			Occasionally
	2	Only a little			Quite often
	3	Hardly at all			Very often
		<b>I get a sort of frightened feeling as if something awful is about to happen</b>			<b>I have lost interest in my appearance</b>
3		Very definitely and quite badly			Definitely
2		Yes, but not too badly			I don't take as much care as I should
1		A little, but it doesn't worry me			I may not take quite as much care
0		Not at all			I take just as much care as ever
		<b>I can laugh and see the funny side of things</b>			<b>I feel restless as if I have to be on the move</b>
	0	As much as I always could			Very much indeed
	1	Not quite so much now			Quite a lot
	2	Definitely not so much			Not very much
	3	Not at all			Not at all
		<b>Worrying thoughts go through my mind</b>			<b>I look forward with enjoyment to things</b>
3		A great deal of the time			As much as I ever did
2		A lot of the time			Rather less than I used to
1		Not too often			Definitely less than I used to
0		Very little			Hardly at all
		<b>I feel cheerful</b>			<b>I get sudden feelings of panic</b>
	3	Never			Very often indeed
	2	Not often			Quite often
	1	Sometimes			Not very often
	0	Most of the time			Not at all
		<b>I can sit at ease and feel relaxed</b>			<b>I can enjoy a good book or radio or television programme</b>
0		Definitely			Often
1		Usually			Sometimes
2		Not often			Not often
3		Not at all			Very seldom

Now check that you have answered all the questions

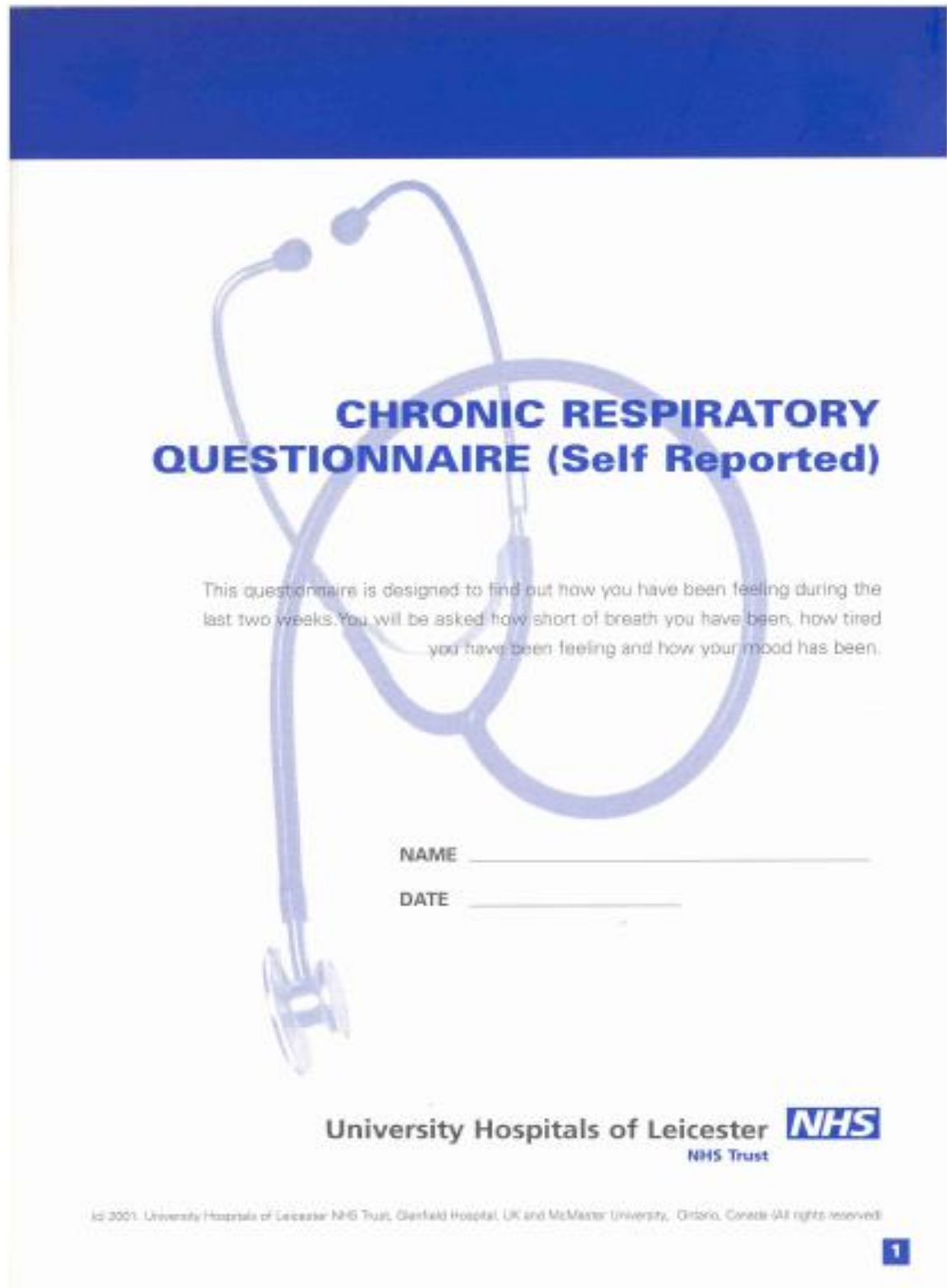
TOTAL

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## Appendix C

### Chronic Respiratory Questionnaire-Self-reported



The form features a large, faint background illustration of a stethoscope. At the top is a solid blue horizontal bar. The title 'CHRONIC RESPIRATORY QUESTIONNAIRE (Self Reported)' is centered in bold blue text. Below the title, a paragraph explains the purpose of the questionnaire. Further down are fields for 'NAME' and 'DATE'. The footer includes the 'University Hospitals of Leicester NHS Trust' logo and a small blue square with the number '1'.

**CHRONIC RESPIRATORY  
QUESTIONNAIRE (Self Reported)**

This questionnaire is designed to find out how you have been feeling during the last two weeks. You will be asked how short of breath you have been, how tired you have been feeling and how your mood has been.

NAME \_\_\_\_\_

DATE \_\_\_\_\_

University Hospitals of Leicester **NHS**  
NHS Trust

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**1**

## CHRONIC RESPIRATORY QUESTIONNAIRE (Self Reported)

We would like you to think of ways in which your shortness of breath limits your life. We are particularly interested in activities which you still do, but which are limited by your shortness of breath.

Listed below are some activities which can make people with lung problems feel short of breath.

If you have felt **short of breath** doing any of the **activities** listed below **during the last two weeks** then please tick each relevant activity. If you have **not** done the activity during the last two weeks or it does **not** make you short of breath then leave it blank.

### THE ACTIVITIES ARE:

<input type="checkbox"/> 1. BEING ANGRY OR UPSET	<input type="checkbox"/> 14. PLAYING SPORTS
<input type="checkbox"/> 2. HAVING A BATH OR SHOWER	<input type="checkbox"/> 15. REACHING OVER YOUR HEAD
<input type="checkbox"/> 3. BENDING	<input type="checkbox"/> 16. RUNNING - SUCH AS FOR A BUS
<input type="checkbox"/> 4. CARRYING - SUCH AS GROCERIES	<input type="checkbox"/> 17. SHOPPING
<input type="checkbox"/> 5. DRESSING	<input type="checkbox"/> 18. WHILE TRYING TO SLEEP
<input type="checkbox"/> 6. EATING	<input type="checkbox"/> 19. TALKING
<input type="checkbox"/> 7. GOING FOR A WALK	<input type="checkbox"/> 20. VACUUMING
<input type="checkbox"/> 8. DOING YOUR HOUSEWORK	<input type="checkbox"/> 21. WALKING AROUND YOUR OWN HOME
<input type="checkbox"/> 9. HURRYING	<input type="checkbox"/> 22. WALKING UPHILL
<input type="checkbox"/> 10. MAKING YOUR BED	<input type="checkbox"/> 23. WALKING UPSTAIRS
<input type="checkbox"/> 11. MOPPING OR SCRUBBING A FLOOR	<input type="checkbox"/> 24. WALKING WITH OTHERS ON LEVEL GROUND
<input type="checkbox"/> 12. MOVING FURNITURE	<input type="checkbox"/> 25. PREPARING MEALS
<input type="checkbox"/> 13. PLAYING WITH CHILDREN/GRANDCHILDREN	

Please list **any other activities** that you have done during the last two weeks which have made you feel short of breath. These should be activities which you do frequently and which are important in your day-to-day life.

---

---

We would now like you to identify the **most important activities** in which you have been limited by your **shortness of breath** in the last **two weeks**.

Using the list you have made on the previous page, write down the **five most important activities** that have made you short of breath on the lines below. We would then like you to tell us **how short of breath** you have been while performing each activity by ticking the box which best describes how you feel.

**HOW SHORT OF BREATH HAVE YOU BEEN DURING THE  
LAST TWO WEEKS WHILE PERFORMING THESE ACTIVITIES?**

	Extremely short of breath	Very short of breath	Quite short of breath	Moderate shortness of breath	Some shortness of breath	A little shortness of breath	Not at all short of breath
1. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**PLEASE MAKE SURE YOU HAVE COMPLETED THE ABOVE  
TABLE BEFORE TURNING THE PAGE**

**Thank you**

## CHRONIC RESPIRATORY QUESTIONNAIRE (Self Reported)

### 6. In general, how much of the time during the last 2 weeks have you felt frustrated or impatient?

Please indicate how often during the last 2 weeks you have felt frustrated or impatient by ticking one of the following options from the list below.

- |    |                        |                          |
|----|------------------------|--------------------------|
| 1. | ALL OF THE TIME        | <input type="checkbox"/> |
| 2. | MOST OF THE TIME       | <input type="checkbox"/> |
| 3. | A GOOD BIT OF THE TIME | <input type="checkbox"/> |
| 4. | SOME OF THE TIME       | <input type="checkbox"/> |
| 5. | A LITTLE OF THE TIME   | <input type="checkbox"/> |
| 6. | HARDLY ANY OF THE TIME | <input type="checkbox"/> |
| 7. | NONE OF THE TIME       | <input type="checkbox"/> |

### 7. How often during the past 2 weeks did you have a feeling of fear or panic when you had difficulty getting your breath?

Please indicate how often you had a feeling of fear or panic when you had difficulty getting your breath by ticking one of the following options from the list below.

- |    |                        |                          |
|----|------------------------|--------------------------|
| 1. | ALL OF THE TIME        | <input type="checkbox"/> |
| 2. | MOST OF THE TIME       | <input type="checkbox"/> |
| 3. | A GOOD BIT OF THE TIME | <input type="checkbox"/> |
| 4. | SOME OF THE TIME       | <input type="checkbox"/> |
| 5. | A LITTLE OF THE TIME   | <input type="checkbox"/> |
| 6. | HARDLY ANY OF THE TIME | <input type="checkbox"/> |
| 7. | NONE OF THE TIME       | <input type="checkbox"/> |

### 8. What about fatigue? How tired have you felt over the last 2 weeks?

Please indicate how tired you have felt over the last 2 weeks by ticking one of the following options from the list below.

- |    |                          |                          |
|----|--------------------------|--------------------------|
| 1. | EXTREMELY TIRED          | <input type="checkbox"/> |
| 2. | VERY TIRED               | <input type="checkbox"/> |
| 3. | QUITE A BIT OF TIREDNESS | <input type="checkbox"/> |
| 4. | MODERATELY TIRED         | <input type="checkbox"/> |
| 5. | SOMEWHAT TIRED           | <input type="checkbox"/> |
| 6. | A LITTLE TIRED           | <input type="checkbox"/> |
| 7. | NOT AT ALL TIRED         | <input type="checkbox"/> |

**9. How often during the last 2 weeks have you felt embarrassed by your coughing or heavy breathing?**

Please indicate how much of the time you felt embarrassed by your coughing or heavy breathing by ticking one of the following options from the list below.

- |    |                        |                          |
|----|------------------------|--------------------------|
| 1. | ALL OF THE TIME        | <input type="checkbox"/> |
| 2. | MOST OF THE TIME       | <input type="checkbox"/> |
| 3. | A GOOD BIT OF THE TIME | <input type="checkbox"/> |
| 4. | SOME OF THE TIME       | <input type="checkbox"/> |
| 5. | A LITTLE OF THE TIME   | <input type="checkbox"/> |
| 6. | HARDLY ANY OF THE TIME | <input type="checkbox"/> |
| 7. | NONE OF THE TIME       | <input type="checkbox"/> |

**10. In the last 2 weeks, how much of the time did you feel very confident and sure that you could deal with your illness?**

Please indicate how much of the time you felt very confident and sure that you could deal with your illness by ticking one of the following options from the list below.

- |    |                        |                          |
|----|------------------------|--------------------------|
| 1. | NONE OF THE TIME       | <input type="checkbox"/> |
| 2. | A LITTLE OF THE TIME   | <input type="checkbox"/> |
| 3. | SOME OF THE TIME       | <input type="checkbox"/> |
| 4. | A GOOD BIT OF THE TIME | <input type="checkbox"/> |
| 5. | MOST OF THE TIME       | <input type="checkbox"/> |
| 6. | ALMOST ALL OF THE TIME | <input type="checkbox"/> |
| 7. | ALL OF THE TIME        | <input type="checkbox"/> |

**11. How much energy have you had in the last 2 weeks?**

Please indicate how much energy you have had by ticking one of the following options from the list below.

- |    |                       |                          |
|----|-----------------------|--------------------------|
| 1. | NO ENERGY AT ALL      | <input type="checkbox"/> |
| 2. | A LITTLE ENERGY       | <input type="checkbox"/> |
| 3. | SOME ENERGY           | <input type="checkbox"/> |
| 4. | MODERATELY ENERGETIC  | <input type="checkbox"/> |
| 5. | QUITE A BIT OF ENERGY | <input type="checkbox"/> |
| 6. | VERY ENERGETIC        | <input type="checkbox"/> |
| 7. | FULL OF ENERGY        | <input type="checkbox"/> |



## CHRONIC RESPIRATORY QUESTIONNAIRE (Self Reported)

### 12. In general, how much of the time did you feel upset, worried or depressed during the past 2 weeks?

Please indicate how much of the time you felt upset, worried or depressed during the past 2 weeks by ticking one of the following options from the list below.

- |    |                        |                          |
|----|------------------------|--------------------------|
| 1. | ALL OF THE TIME        | <input type="checkbox"/> |
| 2. | MOST OF THE TIME       | <input type="checkbox"/> |
| 3. | A GOOD BIT OF THE TIME | <input type="checkbox"/> |
| 4. | SOME OF THE TIME       | <input type="checkbox"/> |
| 5. | A LITTLE OF THE TIME   | <input type="checkbox"/> |
| 6. | HARDLY ANY OF THE TIME | <input type="checkbox"/> |
| 7. | NONE OF THE TIME       | <input type="checkbox"/> |

### 13. How often during the last 2 weeks did you feel you had complete control of your breathing problems?

Please indicate how often you felt you had complete control of your breathing problems by ticking one of the following options from the list below.

- |    |                        |                          |
|----|------------------------|--------------------------|
| 1. | NONE OF THE TIME       | <input type="checkbox"/> |
| 2. | A LITTLE OF THE TIME   | <input type="checkbox"/> |
| 3. | SOME OF THE TIME       | <input type="checkbox"/> |
| 4. | A GOOD BIT OF THE TIME | <input type="checkbox"/> |
| 5. | MOST OF THE TIME       | <input type="checkbox"/> |
| 6. | ALMOST ALL OF THE TIME | <input type="checkbox"/> |
| 7. | ALL OF THE TIME        | <input type="checkbox"/> |

### 14. How much of the time during the last 2 weeks did you feel relaxed and free of tension?

Please indicate how much of the time you felt relaxed and free of tension by ticking one of the following options from the list below.

- |    |                        |                          |
|----|------------------------|--------------------------|
| 1. | NONE OF THE TIME       | <input type="checkbox"/> |
| 2. | A LITTLE OF THE TIME   | <input type="checkbox"/> |
| 3. | SOME OF THE TIME       | <input type="checkbox"/> |
| 4. | A GOOD BIT OF THE TIME | <input type="checkbox"/> |
| 5. | MOST OF THE TIME       | <input type="checkbox"/> |
| 6. | ALMOST ALL OF THE TIME | <input type="checkbox"/> |
| 7. | ALL OF THE TIME        | <input type="checkbox"/> |

**15. How often during the last 2 weeks have you felt low in energy?**

Please indicate how often during the last 2 weeks you have felt low in energy by ticking one of the following options from the list below.

- |    |                        |                          |
|----|------------------------|--------------------------|
| 1. | ALL OF THE TIME        | <input type="checkbox"/> |
| 2. | MOST OF THE TIME       | <input type="checkbox"/> |
| 3. | A GOOD BIT OF THE TIME | <input type="checkbox"/> |
| 4. | SOME OF THE TIME       | <input type="checkbox"/> |
| 5. | A LITTLE OF THE TIME   | <input type="checkbox"/> |
| 6. | HARDLY ANY OF THE TIME | <input type="checkbox"/> |
| 7. | NONE OF THE TIME       | <input type="checkbox"/> |

**16. In general, how often during the last 2 weeks have you felt discouraged or down in the dumps?**

Please indicate how often during the last 2 weeks you felt discouraged or down in the dumps by ticking one of the following options from the list below.

- |    |                        |                          |
|----|------------------------|--------------------------|
| 1. | ALL OF THE TIME        | <input type="checkbox"/> |
| 2. | MOST OF THE TIME       | <input type="checkbox"/> |
| 3. | A GOOD BIT OF THE TIME | <input type="checkbox"/> |
| 4. | SOME OF THE TIME       | <input type="checkbox"/> |
| 5. | A LITTLE OF THE TIME   | <input type="checkbox"/> |
| 6. | HARDLY ANY OF THE TIME | <input type="checkbox"/> |
| 7. | NONE OF THE TIME       | <input type="checkbox"/> |

**17. How often during the last 2 weeks have you felt worn out or sluggish?**

Please indicate how much of the time you felt worn out or sluggish by ticking one of the following options from the list below.

- |    |                        |                          |
|----|------------------------|--------------------------|
| 1. | ALL OF THE TIME        | <input type="checkbox"/> |
| 2. | MOST OF THE TIME       | <input type="checkbox"/> |
| 3. | A GOOD BIT OF THE TIME | <input type="checkbox"/> |
| 4. | SOME OF THE TIME       | <input type="checkbox"/> |
| 5. | A LITTLE OF THE TIME   | <input type="checkbox"/> |
| 6. | HARDLY ANY OF THE TIME | <input type="checkbox"/> |
| 7. | NONE OF THE TIME       | <input type="checkbox"/> |

## CHRONIC RESPIRATORY QUESTIONNAIRE (Self Reported)

### 18. How happy, satisfied or pleased have you been with your personal life during the last 2 weeks?

Please indicate how happy, satisfied or pleased you have been by ticking one of the following options from the list below.

- |    |  |                          |
|----|--|--------------------------|
| 1. | VERY DISSATISFIED, UNHAPPY MOST OF THE TIME                    | <input type="checkbox"/> |
| 2. | GENERALLY DISSATISFIED, UNHAPPY                                | <input type="checkbox"/> |
| 3. | SOMEWHAT DISSATISFIED, UNHAPPY                                 | <input type="checkbox"/> |
| 4. | GENERALLY SATISFIED, PLEASED                                   | <input type="checkbox"/> |
| 5. | HAPPY MOST OF THE TIME   | <input type="checkbox"/> |
| 6. | VERY HAPPY MOST OF THE TIME                                    | <input type="checkbox"/> |
| 7. | EXTREMELY HAPPY, COULD NOT HAVE BEEN MORE SATISFIED OR PLEASED | <input type="checkbox"/> |

### 19. How often during the last 2 weeks did you feel upset or scared when you had difficulty getting your breath?

Please indicate how often during the past 2 weeks you felt upset or scared when you had difficulty getting your breath by ticking one of the following options from the list below.

- |    |                        |                          |
|----|------------------------|--------------------------|
| 1. | ALL OF THE TIME        | <input type="checkbox"/> |
| 2. | MOST OF THE TIME       | <input type="checkbox"/> |
| 3. | A GOOD BIT OF THE TIME | <input type="checkbox"/> |
| 4. | SOME OF THE TIME       | <input type="checkbox"/> |
| 5. | A LITTLE OF THE TIME   | <input type="checkbox"/> |
| 6. | HARDLY ANY OF THE TIME | <input type="checkbox"/> |
| 7. | NONE OF THE TIME       | <input type="checkbox"/> |

### 20. In general how often during the last 2 weeks have you felt restless, tense or uptight?

Please indicate how often you have felt restless, tense or uptight by ticking one of the following options from the list below.

- |    |                        |                          |
|----|------------------------|--------------------------|
| 1. | ALL OF THE TIME        | <input type="checkbox"/> |
| 2. | MOST OF THE TIME       | <input type="checkbox"/> |
| 3. | A GOOD BIT OF THE TIME | <input type="checkbox"/> |
| 4. | SOME OF THE TIME       | <input type="checkbox"/> |
| 5. | A LITTLE OF THE TIME   | <input type="checkbox"/> |
| 6. | HARDLY ANY OF THE TIME | <input type="checkbox"/> |
| 7. | NONE OF THE TIME       | <input type="checkbox"/> |

Thank you very much for taking the time to complete this questionnaire.



## Appendix D

### Patient Public Involvement group meeting minutes 10.02.2011

<b>EXPAND study Patient/Public Involvement (PPI) Group</b> Minutes of Meeting held on Thursday 10 <sup>th</sup> Feb 2011 <i>Wd 17 Seminar room</i>
--

AGENDA	DISCUSSION	ACTION
Present	SH ( <i>facilitator</i> ), JW ( <i>facilitator</i> ), DB, ST, PB, PG, PH, (Mr H), MV.	
Welcome	<ul style="list-style-type: none"> <li>• Introductions</li> <li>• Purpose of the meeting</li> <li>• Background to PPI involvement – booklets given out and website (<a href="http://www.involve.org.uk">www.involve.org.uk</a>).</li> <li>• Background on Pulmonary and Cardiac Rehabilitation PPI advisory forum.</li> </ul>	SH to provide PG, MV, MA and DB with INVOLVE booklets. ALL to read the information and refer to the website. SH to contact everyone and check they are happy for their information to be passed onto the PPI champion.
DEEPER	<ul style="list-style-type: none"> <li>• Overview of the DEEPER research process – reviewed by the CLAHRC scientific committee and re-branded to EXPAND.</li> <li>• Overview of the study aims and research questions.</li> <li>• IPQ-R given out – feedback from the group.</li> <li>• Group discussion about the number of patients required for the interviews.</li> <li>• Description of Interpretative Phenomenological analysis (IPA).</li> <li>• Discussion around rehabilitation education and potential support.</li> <li>• Updated version of the study protocol was handed out.</li> </ul>	ALL to familiarise themselves with the updated version of the study protocol.
Patient information sheet	<ul style="list-style-type: none"> <li>• Review of the patient information sheet.</li> <li>• General discussion about the acceptability for patients.</li> <li>• Replace word ‘exacerbation’ with ‘chest infection’.</li> <li>• Take out some detail.</li> <li>• Make the sheet more ‘chatty’, take a less formal approach.</li> </ul>	SH will make amendments to the patient information sheet and post it to everyone. SH will then contact everyone by telephone to gather their opinions on the changes made.
Next step	<ul style="list-style-type: none"> <li>• SH will submit the study documentation back to the CLAHRC scientific committee and the Ethics board by the end of February.</li> <li>• Once approval has been gained SH will post everyone a finalised version of the study protocol.</li> <li>• SH will invite the group to another meeting to discuss the interview questions around April 2011.</li> </ul>	

## Appendix E

### **Patient Public Involvement group: Protocol feedback survey**

**Name** \_\_\_\_\_  
(Leave blank if you want to remain nameless)

Please read the following study protocol and make comments:

1. How much do you understand the purpose of the study?

Fully Understand	<input type="checkbox"/>	Understand Some	<input type="checkbox"/>
Understand Little	<input type="checkbox"/>	Don't Understand	<input type="checkbox"/>

2. Were the research aims clearly defined?

Very Clear	<input type="checkbox"/>	Quite Clear	<input type="checkbox"/>
Not Very Clear	<input type="checkbox"/>	Unclear	<input type="checkbox"/>

3. How important do you think the aims of the research are?

Very Important	<input type="checkbox"/>	Quite Important	<input type="checkbox"/>
Not very important	<input type="checkbox"/>	Not important at all	<input type="checkbox"/>

4. Do you think the study will answer the research questions?

Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Not Sure	<input type="checkbox"/>
-----	--------------------------	----	--------------------------	----------	--------------------------

5. If you have answered 'No' to Q 4 how do you think we could conduct the study differently?

6. Do you think patients will be happy to participate in the research study?

Yes ☐

No ☐

Not Sure ☐

7. If you have answered 'No' to Q 6 how do you think we could encourage patients to take part in the study?

8. Are the benefits of this research study clearly defined?

Very Clear ☐

Quite Clear ☐

Not Very Clear ☐

Unclear ☐

9. Do you think the study will lead onto future research studies?

Yes ☐


No ☐

Not Sure ☐

**General comments**

## Appendix F

Patient information sheet, version 5

University Hospitals of Leicester   
NHS Trust

Glenfield Hospital

Grobby Road

Leicester

LE3 9QP



## PATIENT INFORMATION SHEET

### **EXploring patients Perceptions following an Acute exacerbation of Chronic Obstructive Pulmonary Disease to iNform tailored strategies to enhance Pulmonary Rehabilitation (EXPAND)**

(Version 5 18/07/2011)

Principal Investigator: **Samantha Harrison**

Co-researchers:  
Prof Sally Singh  
Dr Michael Steiner  
Ms Joanna Williams  
Mrs Chrissie Mitchell-Issitt  
Mrs Lindsay Apps  
Dr Louise Sewell  
Dr Neil Greening

You may contact: **Samantha Harrison**  
**0116 2583652**

This study is funded by the Collaboration for Leadership in Allied Health Research and Care (CLAHRC).

You are being invited to take part in a research study, which is being conducted by The Pulmonary Rehabilitation Department. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take at least 24 hours to read the following information carefully and discuss it with others if you

wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this information.

**1. What is the purpose of the study?**

Patients with chronic obstructive pulmonary disease (COPD) experience an acute ‘flare up’ of their symptoms (often referred to as an exacerbation) which sometimes requires a hospital admission. Evidence strongly suggests that exacerbations cause a reduction in physical activity and an increase in the chance of a readmission to hospital. Pulmonary Rehabilitation has been proven to be beneficial for patients with COPD and improves levels of physical activity. Few patients recently admitted to hospital with an exacerbation of COPD take up the offer of Pulmonary Rehabilitation. The additional needs of patients following an exacerbation have not always been considered in Pulmonary Rehabilitation.

The aim of this study is to gather information about patient’s beliefs surrounding their illness following a recent admission to hospital with an exacerbation of COPD. This information should help us to identify the kind of psychological support some patients need following an exacerbation of COPD.

**2. Why have I been chosen?**

You have been identified by the team looking after you as a potential suitable participant for the study, because you have been admitted with a diagnosis of COPD. We would like to explore the beliefs patients hold about their illness in a group who have recently been admitted to hospital with an exacerbation of COPD. This information will help us to identify the kind of psychological support some patients need following an exacerbation of COPD.

**3. Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of any future care you receive.

**4. What will happen to me if I take part?**

Once you have agreed to being approached by the researcher regarding the study, Samantha Harrison (Principle Investigator) will contact you after you have been discharged from hospital. You will be given the opportunity to discuss the study in more detail and ask any questions you may have regarding the research. If you are happy to participate a study visit will be arranged. This visit can take place either at your home or

at the hospital. During this visit you will be asked to sign a consent form to confirm your participation. With your permission we will inform your GP and consultant of your involvement in the study.

During the study visit we will ask you information about your lung disease, other medical conditions you may have, any previous hospital admissions, whether you have attended Pulmonary Rehabilitation in the past. You will also be asked to complete a lung function test (spirometry) and 4 questionnaires.

If during the study visit you report not being offered Pulmonary Rehabilitation and would like to be referred Samantha will make the referral to Pulmonary Rehabilitation for you.

- Following the study visit you will be asked to wear an activity monitor which is worn on your arm (described in section 5). This is to be worn during the waking hours for 6 consecutive days (please do not allow the monitor to get wet, so please remove if going swimming or you are having a bath etc). You do not need to change your normal activity pattern while wearing this monitor. Samantha will arrange a convenient time to collect the activity monitor from your home after the 6 day period.

- Three months and six months after you have been discharged from hospital following an exacerbation of COPD Samantha will access the (*name of trust removed to preserve anonymity*) database to document any in-patient hospitalisations. Samantha will also view the Pulmonary Rehabilitation database at two secondary care centers within the East Midlands and from the local community Pulmonary Rehabilitation services to see if you have attended any of the programmes.

- If you have attended a Pulmonary Rehabilitation programme Samantha will access information from your Pulmonary Rehabilitation assessment including the results from 2 walking tests and the scores from 3 questionnaires. In addition you will be asked to complete one other questionnaire (IPQ-R) and wear the activity monitor again during the waking hours for 6 consecutive days. Samantha will arrange a convenient time to collect the activity monitor from your home.

- If having been referred to Pulmonary Rehabilitation you have not attended a programme or have attended but dropped out Samantha will contact you by telephone and record your reasons why. (You are free not to discuss this information).

- If at the study visit you do not wish to be referred to Pulmonary Rehabilitation you will be offered the opportunity to participate in an interview. If you agree to take part this will consist of an informal chat in which you will be asked questions relating to your thoughts and feelings about physical activity and your experience of being hospitalised with an acute exacerbation of COPD. The interview shouldn't last longer than 1.5 hours and will be digitally recorded, with your permission. The interview can also be arranged to take place either at your home or at the hospital.

## **5. What do I have to do?**

### **Assessments**

You will be asked to complete a lung function assessment (spirometry) and 4 questionnaires.

#### Lung function (Spirometry)

The lung function test involves breathing tests which require you to take deep breaths, hold your breath and blow down a tube.

#### Physical activity

Physical activity will be measured on 2 separate occasions: once you have been discharged from hospital and again if you complete a Pulmonary Rehabilitation programme. You will need to wear the monitor during the waking hours for 6 consecutive days. The monitor is a light portable device which is worn on the upper arm. You do not need to change your normal activity pattern while wearing this monitor. You will be provided with an activity monitor on your study visit and again at your discharge assessment for Pulmonary Rehabilitation. Samantha will arrange a convenient time to come and collect the activity monitor from your home.

#### Questionnaires

You will be asked to complete some questionnaires. One questionnaire will explore the beliefs you hold about your lung disease. The other three questionnaires ask about your health status; this will give us a guide to how your condition affects your daily life.

(A more in depth schedule of events can be found in appendix a)

## **6. What are the possible disadvantages and risks of taking part?**

There are no identified risks to taking part in this research.

We appreciate that the wearing of an activity monitor might be a slight inconvenience for some people. However we have used these monitors in recent research studies and they have been very well tolerated by patients.

If you wish to arrange for the study visit or interview to take place at the hospital travel expenses will be reimbursed or a taxi can be provided for the visits to limit any inconvenience.

## **7. What are the possible benefits of taking part?**

You may experience no benefit from taking part in the research. However, we hope that the research will aid you in your understanding of exercise and COPD and inform future psychological treatment programmes therefore benefiting COPD patients.

**8. What if something goes wrong?**

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms would be available to you. Advice can also be sought from the Patient Advice and Liaison Service. Furthermore you may contact the Head of the Pulmonary and Cardiac Rehabilitation Department;

Prof Sally Singh  
Pulmonary Rehabilitation Department  
Glenfield Hospital  
Groby Road  
Leicester  
LE3 9QP  
Tel. 0116 2582350  
Email; sally.singh@uhl-tr.nhs.uk

**9. Will my taking part in this study be kept confidential?**

All information that is collected about you during the course of the research will be kept strictly confidential. The NHS code of confidentiality will be followed at all times. Data containing non-identifiable information will be kept in a locked filing cabinet which is stored in a secure research office. All electronic data will be password protected and include your study number only with no reference to any identifiable data e.g. your name. Only the researcher will have access to the study data. Consent will be sought from you to allow the researcher to access your medical notes and information stored on the hospital databases. We will inform your GP and your consultant that you are taking part in the study.

**10. What will happen to the results of the research study?**

The results of this study will be used to inform future psychological strategies for patients with COPD following an exacerbation. The results will be peer reviewed and may be circulated in medical journals, professional publications and presentations made at relevant conferences. Results will be reported in such a way that preserves confidentiality.

**11. Who is organising and funding the research?**

The study is being funded by the national Institute for health Research ([www.nihr.ac.uk](http://www.nihr.ac.uk)) as part of the Collaboration for Leadership in Allied Health research and care (CLAHRC) in Leicestershire, Northamptonshire and Rutland (LNR).



## **12. Who has reviewed the study?**

All research that involves NHS patients or staff, information from NHS medical records or uses NHS premises or facilities must be approved by an NHS Research Ethics Committee before it goes ahead. Approval does not guarantee that you will not come to any harm if you take part. However, approval means that the committee is satisfied that your rights will be respected, that any risks have been reduced to a minimum and balanced against possible benefits and that you have been given sufficient information on which to make an informed decision.

## **13. Contact for Further Information**

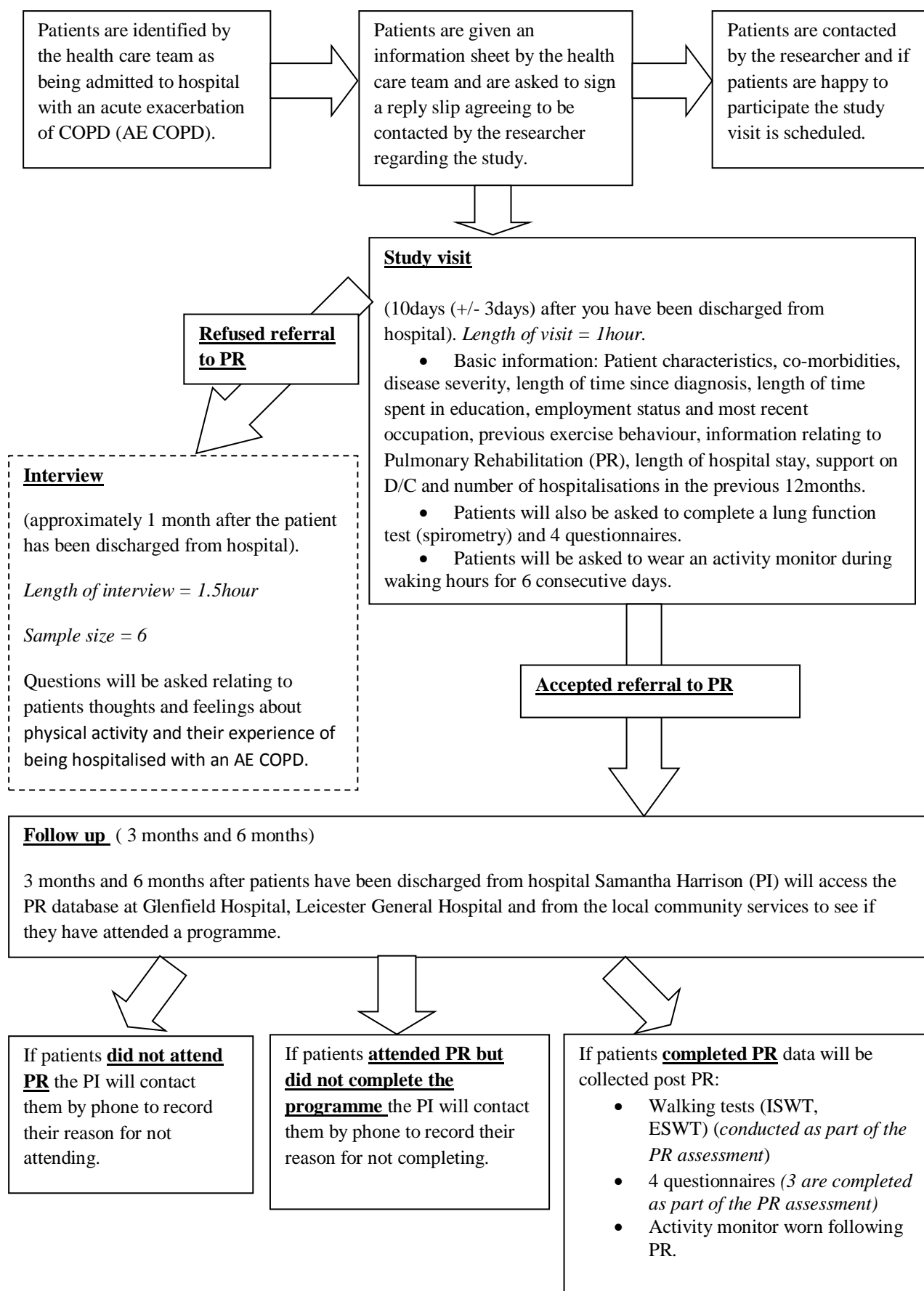
If you have any concerns or other questions about this study or the way in which it has been carried out, you should contact the principal researcher: Samantha Harrison– Tel: 0116 2583652.

For further information please contact

Samantha Harrison  
Research Physiotherapist  
Pulmonary Rehabilitation Department  
University Hospitals of Leicester NHS Trust  
Glenfield Hospital  
Groby Road  
Leicester  
LE3 9QP  
0116 2583652

Thank you for reading this information leaflet

## Appendix a - Study schedule



## Appendix G. i.

### Letter of ethical approval

#### National Research Ethics Service East Midlands-Leicester



### **National Research Ethics Service**

#### **NRES Committee East Midlands - Leicester**

The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

Telephone: 0115 8839425  
Facsimile: 0115 8839294

11 April 2011

Miss Samantha Harrison  
Band 5 Research Physiotherapist in Pulmonary Rehabilitation  
University Hospital of Leicester NHS Trust  
CLAHRC Research Office, Ward 25  
Glenfield Hospital  
Leicester  
LE3 9QP

Dear Miss Harrison,

**Study title:** EXploring patients Perceptions following an Acute exacerbation of Chronic Obstructive Pulmonary Disease to iNform tailored strategies to enhance Pulmonary Rehabilitation (EXPAND)

**REC reference:** 11/EM/0089

The Research Ethics Committee reviewed the above application at the meeting held on 01 April 2011. Thank you for attending to discuss the study.

#### **Ethical opinion**

- The committee asked you to clarify whether they would be individual or focus group interviews and whether these would be taking place in a hospital or home setting. You confirmed that the interviews will be done individually and that the option to have the interview at the participants home would be up to the preference of the individual to not travel to the hospital. You confirmed that there is a lone working policy document.
- The committee asked you why they intend to inform the participants GP that they are participating in the study. You explained that this is a standard process when the information being gathered is anonymous.
- The committee recommended to you that the references within the Participant Information Sheet 'to encourage them to attend the Pulmonary Rehabilitation' should be removed as can be deemed to put pressure on the participants. You agreed to remove all references to this sentence.
- The committee informed you that it should be made clear in the Participant Information Sheet that the study does not guarantee any benefits to the participants. You said that she would make this clear in the Participant Information Sheet.
- The committee stated to you that an additional complaints contact should be included in the Participant Information Sheet. You stated that she would include one of the key collaborators, Professor Sally Singh's contact details.

The members of the Committee present gave a favourable ethical opinion of the above

This Research Ethics Committee is an advisory committee to East Midlands Strategic Health Authority  
*The National Research Ethics Service (NRES) represents the NRES Directorate within the  
National Patient Safety Agency and Research Ethics Committees in England*

WPH 1370

research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

#### **Ethical review of research sites**

##### **NHS Sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### **Conditions of the favourable opinion**

1. The following amendments should be made to the Participant Information Sheet;
  - a) All references to participants being 'encouraged to attend Pulmonary Rehabilitation should be removed.
  - b) It should be made explicit that there are no guaranteed benefits from participating in the study.
  - c) An additional relevant contact number should be included.
2. The Consent Form should include 'I agree to take part in the study' for participants to initial

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

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

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

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations*

**It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

**You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation**

#### **Approved documents**

Interview Schedule	V1	03/03/2011
IPQ-R	N/A	N/A
Poster	V1	31/01/2011
Visit Schedule	V1	31/01/2011
Sponsorship Email from UHL	N/A	25/02/2011
CLAHRC funding Letter	N/A	30/04/2008

***Please be aware that any changes to these documents after approval may constitute an amendment. The process of approval for amendments should be followed. Failure to do so may invalidate the approval of the study at this trust.***

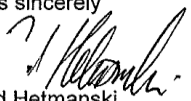
We are aware that undertaking research in the NHS comes with a range of regulatory responsibilities. Attached to this letter is a reminder of your responsibilities during the course of the research. Please ensure that you and the research team are familiar with and understand the roles and responsibilities both collectively and individually.

You are required to submit an annual progress report to the R&D Office and to the Research Ethics Committee. We will remind you when this is due.

The R&D Office is keen to support research, researchers and to facilitate approval. If you have any questions regarding this or other research you wish to undertake in the Trust, please contact this office.

We wish you every success with your research.

Yours sincerely

  
David Hetmanski  
Assistant Director, Research & Development


Encs: .Researcher Information Sheet.

Please note that some of the documents may not apply to your study.

## Appendix G. ii.

### Letter of ethical approval

#### Comprehensive Local Research Network

University Hospitals of Leicester   
NHS Trust

DIRECTORATE OF RESEARCH & DEVELOPMENT

Research & Development Office

Leicester General Hospital

Gwendolen Road

Leicester

LE5 4PW

**Director:** Professor D Rowbotham

**Assistant Director:** Dr David Hetmanski

**R&D Manager:** Carolyn Maloney

Direct Dial: (0116) 258 8351

Fax No: (0116) 258 4226

11 July 2011

Miss Samantha Harrison  
Band 5 Research Physiotherapist in Pulmonary Rehabilitation  
University Hospital of Leicester NHS Trust  
CLAHRC Research Office, Ward 25  
Glenfield Hospital  
Leicester  
LE3 9QP

Dear Miss Harrison,

Ref: 71766

Title: **EXploring patients Perceptions following an Acute exacerbation of Chronic Obstructive Pulmonary Disease to inform tailored strategies to enhance Pulmonary Rehabilitation (EXPAND)**

Project Status: **Approved**

End Date: 1<sup>st</sup> April 2013

I am pleased to confirm that with effect from the date of this letter, the above study now has Trust Research & Development permission to commence at University Hospitals of Leicester NHS Trust.

All documents received by this office have been reviewed and form part of the approval. The documents received and approved are as follows:

Document Name	Version Number	Date
Protocol	V2	31/01/2011
Participant Invitation Letter	V1	31/01/2011
GP Letter	V1	08/03/2011
Questionnaire: Chronic Respiratory Questionnaire	N/A	N/A
Questionnaire: Hospital Anxiety and Depression Scale	N/A	N/A
Questionnaire: Chronic Respiratory Questionnaire	N/A	N/A
Student's CV - Samantha Harrison	N/A	07/04/2011
Activity Monitor Instruction Sheet	N/A	N/A
Patient Information Sheet	V4	06/05/2011
Consent Form	V3	06/05/2011

Version 5, 20.04.10

## **Appendix H**

### **Interview schedule**

You have agreed to take part in an interview which is an informal chat with me and will take about an hour to an hour and a half. We will be discussing issues surrounding your recent exacerbation or ‘flare up’ of your breathlessness which resulted in you having to stay in hospital. Please answer all questions as fully and honestly as you can. The purpose of the interview is to inform health care professionals about the experience of an exacerbation, this can help improve treatments and care of patients.

Do you have any questions?

Are you happy for me to record the interview as it takes place?

For the benefit of the tape it is ...day.....time and present there is me, .....(the patient) and .....

Before we start I just have a few questions which you can answer yes or no to;

Do you understand what the interview is about?

Do you understand the purpose of the interview?

Are you happy to take part in the interview and be recorded?

### **Ground rules**

Everything that is said during the interview is confidential. If however you do disclose any information that highlights a breach of the law, or dangerous practice I will be duty bound to break confidentiality. This means that if during the session you tell me the law has been broken or something dangerous has been done that may result in harm to yourself or others I will have to report to the necessary people.

### **Withdrawal**

If anything we speak about today does make you feel uncomfortable you are free to not discuss a particular topic, request for the recorder to be switched off to resume the interview after a short break or you can ask to terminate the interview all together at any point. If after this discussion has taken place you wish to remove your comments from the study please contact me and none of your comments will be taken into account when performing the analysis.

### **Previous experience of managing lung disease**

- Can you describe the early symptoms of your breathing problems? *When did you first notice the symptoms? When did you feel they were serious?*
- How do you understand your disease?

### **Acute onset of acute exacerbation**

- Can you describe the symptoms you experienced before you were admitted to hospital? *What did you do when these symptoms came on?*
- How did you feel about going to hospital? *What happened when you arrived at hospital?*

**Hospital experience and D/C**

- Can you describe your time in hospital?
- Tell me about when you were discharged from hospital.
- How have you been managing since being home from hospital?

**Informal support**

- Do you have friends/relatives who help? *How do they help? How does this make you feel?*
- How do you think they understand your breathing problems? *What would you like to say to you friends/family to help them understand what having breathing problems is like?*
- How do you think they feel when you have exacerbations/attacks/flare ups of your breathlessness? *How does that make you feel?*

**Exercise/activities and breathing problems**

- How do you manage your disease? *What has helped with managing?*
- How do you manage keeping up activity? *How important is it to you that you are active? What stops you from being active?*
- How do you feel about doing exercise to increase your fitness? *Did you used to exercise? What do you believe will happen to you if you exercise?*

I have asked all the questions I would like to now. Is there anything else you think I should know to understand your experience better?

Thank you very much for all your time and comments.



## Appendix I

### Patient Public Involvement group meeting minute 27.02.2012

<b>EXPAND study Patient/Public Involvement (PPI) Group</b> Minutes of Meeting held on Friday 27 <sup>th</sup> Feb 2012 CEC, Lounge		
AGENDA	DISCUSSION	ACTION
Present	SH ( <i>facilitator</i> ), LA ( <i>facilitator</i> ), EE, PB, MV, MA, DB, PG. Apologies: GF, DA:	
Introduction	<ul style="list-style-type: none"> <li>• Introductions</li> <li>• Phone call form DA - importance of patient's feelings surrounding an exacerbation and confidence in managing their disease, perceptions about exercising with a chronic condition.</li> </ul>	
Presentation – progress	<ul style="list-style-type: none"> <li>• Presentation of progress so far</li> <li>• Discussion: There was overall agreement that intuitively, a stepped approach seems logical. General discussion about the role of emotions in illness – fear, feeling low, having to pick yourself back up after exacerbations. Discussion about barriers to attending Pulmonary Rehabilitation – travel, financial.</li> </ul>	
Presentation – findings	<ul style="list-style-type: none"> <li>• Presentation on findings from systematic review</li> <li>• Discussion: Group identified a need to back up education with written material, especially at time of admission as there is a lot of information to assimilate, which can be difficult to retain. No further questions about review results.</li> </ul>	
Presentation-qualitative methodology	<ul style="list-style-type: none"> <li>• Presentation on qualitative methodology</li> <li>• Discussion: Conflicting opinions regarding the appropriateness of including a multi-disciplinary team in the validation process. Important for the researcher to ensure the themes which are developed are grounded in the original data. Research idea: Multi-disciplinary team members' perceptions of how a patient understands the experience of an exacerbation Vs patient's actual perceptions and understanding.</li> </ul>	SH emailed Dr Michael Larkin (an expert in IPA) to seek his opinion regarding the involvement of PPI in qualitative methodologies. Awaiting response.
Development of schedule	<ul style="list-style-type: none"> <li>• Development of schedule</li> <li>• Timeline consisting of 4 stages: Experience prior to the exacerbation, the acute onset of the exacerbation, disease management, interactions with health care professionals/family members.</li> <li>• Prior experience – use of community services, symptoms, management.</li> <li>• Acute onset – emotions connected to breathlessness and being in hospital, feelings about discharge, help-seeking.</li> <li>• Management – knowledge, medications, activities, disease expectations, coping, impact of treatment.</li> <li>• Faith in health care professionals, social support.</li> </ul>	SH and LA to devise interview schedule and post out to PPI group for feedback.

## Appendix J

Consent form, version 4



University Hospitals of Leicester **NHS**  
NHS Trust

Participant Identification Number for this study.....

### CONSENT FORM

**EXploring patients Perceptions following an Acute exacerbation of Chronic  
Obstructive Pulmonary Disease to iNform tailored strategies to enhance  
Pulmonary Rehabilitation (EXPAND)**

**Principal Investigator: Samantha Harrison**

Co-researchers: Prof Sally Singh; Dr Michael Steiner; Mrs Joanna Williams; Mrs Chrissie Mitchell-Issitt; Mrs Lindsay Apps; Dr Louise Sewell; Dr Neil Greening.

**Please initial box**

1. I confirm that I have read and understand the information sheet dated 18/07/2011 (version 5) for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that any sections of my medical notes, information held on the hospital databases and research data may be looked at by responsible individuals from the University Hospitals of Leicester NHS Trust as well as regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records. ☐
4. I agree to take part in the above study. ☐
5. I agree to being contacted about participating in an in-depth interview. ☐
6. I agree to my GP and consultant being informed about my participation in the above study. ☐

\_\_\_\_\_  
Name of Patient

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature


\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

**Appendix K**

**General Practitioner letter**

**University Hospitals of Leicester**   
**NHS Trust**



**Glenfield Hospital**

Groby Road  
Leicester  
LE3 9QP

**☎ Direct Line: 0116 258 3652**

Tel: 0116 287 1471  
Fax: 0116 258 3950  
Minicom: 0116 287 9852

**E-mail: [samantha.harrison@uhl-tr.ac.uk](mailto:samantha.harrison@uhl-tr.ac.uk)**

Date

Dear Dr

Re: Your patient

Address:

DOB:

NHS No.

**Study title:** EXploring patients Perceptions following an Acute exacerbation of Chronic Obstructive Pulmonary Disease to iNform tailoreD strategies to enhance Pulmonary Rehabilitation (EXPAND)

Your patient has recently agreed to participate in the above study which is taking place at *(name of hospital removed to preserve anonymity)*. Details of the study are outlined in the enclosed patient information sheet.

If you require any further information please do not hesitate to contact me on (0116) 258 3652.

Yours Sincerely,

**Samantha Harrison (Principal Investigator)**

Research Physiotherapist

## Appendix L

### Activity monitor instructions



### Wearing your activity monitor

Please wear the monitor for 6 consecutive days during the waking hours.

Position the activity monitor on the right arm. The monitor should be placed on the back of the arm, half way up the upper arm (above the elbow).

There is no need to press any 'power on' button, the monitor will turn itself on after a few minutes (indicated by a vibration and a beep). Please remember to press the 'mark' button when you first put the monitor on.



**Marker button**

Also remember to press the 'mark' button if you have to remove the monitor for any reason.

The monitor is lightweight and shouldn't interfere with your everyday activity, just carry on with your daily routine as normal. Try to wear the monitor at all times unless it becomes uncomfortable.

Take off the monitor when having a bath or shower. Please do not get the monitors wet

**If you have any problems or questions please call: Samantha Harrison on 0116 2583652.**

**The monitor will be collected from your home as arranged on**

.....at.....

## Appendix M

### Data collection form – study demographics

<b>Study Number</b>				<b>Assessment Date and Time</b>				<b>Telephone number</b>	
<b>Recruiter</b>									
<b>Consultant Name</b>				<b>DOB</b>		<b>Height (m)</b>		<b>BMI</b>	
<b>GP Name &amp; Address</b>				<b>Gender</b>		<b>Weight (kgs)</b>			
				<b>Date retired</b>					
<b>Previous Spirometry</b>		Yes / No	Date:	<b>Occupation</b>					
FEV1	L	FVC	L	FEV/FVC		%			
<b>MRC grade</b>									
<b>Ethnic Origin</b>									
British	Indian	African		Any other White background			Any other Ethnic back ground		
Irish	Pakistani	Caribbean		Any other Asian background			Any other Black background		
<b>Social</b>									
<b>Housing</b>	House	Bungalow	Flat		<b>Stairs?</b>	Yes	No		
<b>Lives with</b>	Alone	Spouse	Family	Other:					
<b>Marital Status</b>		Divorced	Married	Single					
		Widow ed	Partner	Seperated	<b>Age left F/T education</b>				
<b>Diagnosis</b>									
<b>Date of diagnosis</b>				<b>Time since diagnosis</b>					
<b>Concurrent Diagnoses (Circle)</b>									
<b>Cardiac</b> - None		<b>Respiratory</b> - None		<b>Rheumatology</b> - None		<b>Gastro</b> - None		<b>Other</b> - None	
Aortic Valve Replacement		Bronchiectasis		Rheumatoid Arthritis		Ulcer disease		Depression	
Heart Failure		Lung Cancer		Osteoporosis		Liver disease		Dementia	
Ischaemic Heart Disease		OSA		Osteoarthritis		If liver dis:Mild/mod/severe		CKD Stage	
Aortic Stenosis		α1AT		Connective tissue		IBD		Diabetes	
Myocardial Infarction		ABPA		<b>Vascular</b> - None		<b>Cancer</b> - None		Diabetes (organ damage)	
Atrial Fibrillation		ILD		CVA/Stroke		lung cancer		AIDS	
Aortic Valve Disease		COPD		Intermittent Claudication		any other malignancy		Neurological	
Angina		Asthma		Peripheral Vascular		Specify:		Specify	
Hypertension				Hemiplegia		leukaemia			
Mitral Valve Replacement						lymphoma			
CABG						metastatic malignancy			
<b>Smoking</b>	Yes	No	Ex	<b>Pack Years:</b>		<b>Previous LVRS?</b>		Yes	No
<b>Medication (Circle)</b>									
<b>Acute</b> - None			<b>Normal</b> - None						
Hydrocortisone			Combination inhaler			Prednisolone (&dose)		ACE inhibitor/ARB	
Prednisolone (&dose) mg			Tiotropium					Beta blocker	
Salbutamol nebs			Steroid inhaler			Leukotriene antagonist		Statin	
Ipratropium nebs			Ipratropium inhaler			Oral theophylline		Warfarin	
IV Aminophylline			LABA inhaler			Anti-depressant		Digoxin	
Antibiotics (specify)			Salbutamol inhaler			Oral hypoglycaemic		Oral nitrate	
			Salbutamol nebs			Immunosuppressants		Amiodarone	
			Ipratropium nebs			PPI/ H2 antagonist		Diuretic	
			Colomycin nebs			Aspirin		Ca channel blocker	
			Mucolytic			Clopidogrel		Long term Antibiotics	



## Appendix N

### Data collection form - study assessment

Illness Perceptions Questionnaire - Revised (IPQ-R)									
Identity		Timeline		Timeline cyclical			Consequences		
Personal control		Treatment control		Illness coherence					
Emotional representation				Important factor 1					
Important factor 2				Important factor 3					
The General Self-Efficacy Scale Adapted for Pulmonary Rehabilitation (GSES-PR)									
Self Efficacy									
Hospital Anxiety and Depression Scale (HADS)									
Anxiety		Depression							
Chronic Respiratory Questionnaire (CRQ)									
Dyspnoea		Fatigue		Emotion		Mastery			
Physical Activity Data (12 hours of on body time)									
		Day 1	Day 2	Day 3	Day 4	Day 5	Day 6		
Day									
Minutes worn									
EE (Kals)									
EE over 3 METS (Kals)									
Steps									
Sedentary (below 3 METS)									
Moderate (3-6METS)									
Vigorous (6-9 METS)									
Very Vigorous (over 9 METS)									
Spirometry									
FEV1		L	FVC		L	FEV/FVC		%	
Hospital admission (UHL database)									
Length of current hospital stay						No. of hospitalisations in the past 12m			
Respiratory admissions				Non- respiratory admissions					
Hospital admission details:									
Supported D/C		Yes/No	Details:						
No. of hospitalisations within 6 month follow up period									
Details:									
Pulmonary Rehabilitation ( 6 months)									
Referred to PR		Yes/No	Details:						
Attended initial Ax		Yes/No	Date:				Location of PR		
Number of session attended						Completer		Yes/No	Date:
Attended D/C appt		Yes/No	Date:		Telephone call		Yes/No	Date:	
Reason for drop out or none attendance									
Qualitative data									
Invited to take part in interview				Yes/No		Interview conducted		Yes/No	
Exercise tests									
Pre ISWT				Pre ESWT		Speed		Time	
Post ISWT				Post ESWT		Speed		Time	
Illness Perceptions Questionnaire - Revised (IPQ-R) PR									
Pre Identity		Pre Timeline		Pre Timeline cyclical			Pre Consequences		
Pre Personal control		Pre Treatment control		Pre Illness coherence					
Pre Emotional representation				Pre Important factor 1					
Pre Important factor 2				Pre Important factor 3					





## Appendix O

### Patient Public Involvement group meeting minutes 10.08.2012

<b>EXPAND study Patient/Public Involvement (PPI) Group</b> Minutes of Meeting held on Friday 10 <sup>th</sup> August 2012 <i>Wd 17 Seminar room</i>
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AGENDA	DISCUSSION	ACTION
Present	SH ( <i>facilitator</i> ), LA ( <i>facilitator</i> ), VW ( <i>administrator</i> ), PG, MV	
Welcome	<ul style="list-style-type: none"> <li>• Introductions</li> <li>• Update on study progress.</li> <li>• Purpose of interviews.</li> </ul>	
Emerging themes	<p><b>Age and physical activity/exercise</b></p> <ul style="list-style-type: none"> <li>• Dependant on previous interests/social support/previous experiences.</li> <li>• Motivators to exercise for older adults (80+ years) – want to enjoy retirement.</li> <li>• Motivators to exercise for younger adults - family and work commitments.</li> <li>• Barriers to exercise for older adults – easier to ‘just sit’/more difficult to plan for the future, tenancy to live day by day/co-morbidities/PA was not part of their culture as it is today/friends and family have died - increased isolation, ‘why carry on?’</li> <li>• Barriers to exercise for younger adults – difficulty accepting the disease/depression.</li> <li>• Upward and downward social comparisons.</li> <li>• Increased awareness of the benefits of PA/PA promoted through the media.</li> <li>• Don’t like to exercise but: up for a challenge/given an opportunity that might help/positive outlook (<i>personality/intrinsic factors</i>).</li> </ul> <p><b>DNAR decision</b></p> <ul style="list-style-type: none"> <li>• More comfortable with people you know.</li> <li>• Importance of involving family as they may find it difficult to accept.</li> <li>• Patients are likely to interpret that Dr thinks they are near the end of their lives.</li> <li>• Timing – on ward patients have lots of time to think (<i>change perceptions of disease</i>)/not appropriate to discuss along side PR (<i>negative V positive</i>).</li> <li>• Blame Dr/health care professionals for bringing up the topic.</li> </ul>	

	<p><b>Rapport with health care professionals</b></p> <ul style="list-style-type: none"> <li>• Non verbal cues – important that Dr calls rather than secretary.</li> <li>• Patients want to feel they have the Drs focus (<i>they are the only patient</i>) especially if they are feeling very unwell.</li> <li>• Nurses – provide 1 to 1 care/put patients at ease/they are there all the time/make a joke/make patients feel part of the ward('family').</li> <li>• Drs – unease at seeing a junior/'float in and out'/although culture is changing they are viewed as an authoritative figure ('God')/talk to staff more than patients, patients feel ignored/large team (<i>not 1 to 1</i>)/Drs seen as superior but nurses more on patients level (<i>also influenced by social class</i>).</li> </ul> <p><b>Dichotomy/conflict</b></p> <ul style="list-style-type: none"> <li>• Necessary to accept disease daily but management is made difficult by acute shortness of breath.</li> <li>• Comparisons with current state of health compared to previous years.</li> <li>• Necessary to keep disease separate in order to get on with life.</li> <li>• First exacerbation – scared/not in control.</li> <li>• Once D/C from hospital perceive to be recovered.</li> </ul> <p><b>Social status</b></p> <ul style="list-style-type: none"> <li>• Not wanting to be a burden is a feeling which occurs frequently, heightened after an exacerbation.</li> <li>• British cultural promotes claiming to be 'fine' or 'ok'.</li> <li>• Easier to complain to a third person than immediate family.</li> <li>• Hard to accept role reversal (<i>male</i>).</li> <li>• Education about disease is particularly important if patient lives alone.</li> </ul> <p><b>Pulmonary Rehabilitation</b></p> <ul style="list-style-type: none"> <li>• Timing of PR – perception that it is not necessary unless breathlessness becomes an issue/difficult following an exacerbation as feeling unwell, happier to adopt exercise when in a stable state.</li> <li>• Referral – importance of being asked by each health care professionals to do PR/consistency in professionals attitudes towards PR may increase likelihood of accepting PR.</li> <li>• Delivery – education before PR?</li> </ul> <p><b>Legitimacy</b></p> <ul style="list-style-type: none"> <li>• Patients provide reasons for hospital admission.</li> <li>• Smoking – stigma increases as education regarding the effects increase.</li> <li>• Oxygen relives anxiety and shortness of breath – something is being done to 'help'.</li> </ul> <p><b>Action plans</b></p> <ul style="list-style-type: none"> <li>• Delay in starting medications - Ill enough to start (cold or exacerbation?)/ stigma with steroids ('bodybuilding').</li> </ul>	
--	--	--

	<ul style="list-style-type: none"> <li>• Rescue packs - confidence in self-administration is increased by reflection on previous experiences.</li> <li>• Cough is not necessarily a sign of an exacerbation/shortness of breath difficult to distinguish.</li> </ul> <p><b>Fatigue</b></p> <ul style="list-style-type: none"> <li>• Part of disease/could be due to other reasons – promotes fear/ignored by GPs/difficult to accept or give into/age or disease</li> </ul> <p><b>Describing shortness of breath</b></p> <ul style="list-style-type: none"> <li>• Difficult to imagine breathlessness unless it has been experienced.</li> <li>• Patients do not think health care professionals can empathise with their symptoms (shortness of breath).</li> <li>• More difficult to explain/describe shortness of breath – importance in relaying the emotional aspect of shortness of breath (<i>not just physical</i>).</li> </ul>	
Future plans	<ul style="list-style-type: none"> <li>• Refine emerging themes</li> <li>• Collaborative workshop</li> </ul>	SH and LA to refine emerging themes. Organise a collaborative workshop.

## **Appendix P**

### **Collaborative workshop groups**

<b>Group</b>	<b>Group members</b>
<b>Group 1</b> (Attended 5, Apologise 1)	<ul style="list-style-type: none"><li>▪ In-patient and out-patient pulmonary rehabilitation nurse specialist</li><li>▪ Respiratory Early Discharge Scheme (REDS) nurse</li><li>▪ Pulmonary rehabilitation team manager/Occupational therapist</li><li>▪ Specialist respiratory consultant/ LNR CLAHRC theme lead</li><li>▪ Lay advisor</li></ul>
<b>Group 2</b> (Attended 6, Apologise 1)	<ul style="list-style-type: none"><li>▪ In-patient and out-patient pulmonary rehabilitation nurse specialist</li><li>▪ Respiratory Early Discharge Scheme (REDS) nurse</li><li>▪ Senior respiratory research physiotherapist/Patient and Public Involvement (PPI) Champion</li><li>▪ Occupational therapist</li><li>▪ Pulmonary rehabilitation physiotherapist</li><li>▪ Head of the cardiac and pulmonary rehabilitation department/Academic</li></ul>
<b>Group 3</b> (Attended 6, Apologise 1)	<ul style="list-style-type: none"><li>▪ Pulmonary rehabilitation technical instructor</li><li>▪ Respiratory ward manager</li><li>▪ Respiratory physiotherapist</li><li>▪ Senior in-patient and out-patient pulmonary rehabilitation physiotherapist</li><li>▪ Specialist respiratory registrar/ Research fellow</li><li>▪ Lay advisor</li></ul>

## Appendix Q

### Collaborative workshop meeting minutes 20.09.2012

<b>EXPAND study Collaborative workshop</b> Minutes of Meeting held on Thursday 20 <sup>th</sup> Sept 2012 <i>Wd 17 Seminar room</i>
---

AGENDA	DISCUSSION	ACTION
Present	SH ( <i>lead facilitator</i> ), HY ( <i>facilitator</i> ), GM ( <i>administrator</i> ), RC, CC, Dr LS, Dr MS, PG, VW, SJ, EM, SW, Dr NG, MV, EV, KB, TH-D, MK, MG, Prof SS.	
Purpose of workshop	To assist with the analysis of a qualitative research study designed to explore the experiences of patients hospitalised with an acute exacerbation of COPD.	
Presentation	<ul style="list-style-type: none"> <li>• Study design</li> <li>• Research question</li> <li>• Analysis</li> <li>• Findings/themes</li> </ul>	
Group work	Each group given 2 of 6 main findings: <ul style="list-style-type: none"> <li>• Group 1 - Hospital admission and resignation</li> <li>• Group 2 - Social and emotional impact</li> <li>• Group 3 – Rapport with Dr/health care professionals and disease coherence.</li> </ul> Presented with 2 questions to consider: <ul style="list-style-type: none"> <li>• Question 1. Do you agree with our findings? Are there alternative explanations for the findings? Do they make sense clinically?</li> <li>• Questions 2. What are the implications of the findings for service development and implementation?</li> </ul>	
Feedback on question 1	<b>Hospital admission</b> <ul style="list-style-type: none"> <li>• Oxygen has a role in reducing anxiety and breathlessness.</li> <li>• ‘Magic oxygen’</li> <li>• Oxygen can be linked to the disease becoming more severe.</li> <li>• Patients don’t understand they are getting an opinion from the Dr and that another Drs opinion may be different.</li> <li>• Receiving too many explanations may be a source of confusion for patients and cause dissatisfaction with the Dr.</li> <li>• Patients complain because they are receiving numerous different (and sometimes conflicting) messages.</li> </ul> <b>Resignation</b> <ul style="list-style-type: none"> <li>• Could be displaying acceptance if they had experienced multiple exacerbations of COPD.</li> <li>• Coping mechanism – personality.</li> </ul>	

	<ul style="list-style-type: none"> <li>• May be a more important topic in this self-selected group who have refused a referral to PR.</li> </ul> <p><b>Social impact</b></p> <ul style="list-style-type: none"> <li>• Concern about being seen by others as a poorly person. Stigma of oxygen.</li> <li>• ‘Threat to identity’ – ‘threat’ is a strong word. More concerned with acceptance/adjustment. Some statements are more hopeful – embracing changes, partnership working. Changes in gender roles can be positive (men cooking).</li> <li>• Positive impact of the family but also guilt about becoming a burden. Lack of family support may lead to quicker loss of roles. Impact on wellbeing.</li> </ul> <p><b>Emotional impact</b></p> <ul style="list-style-type: none"> <li>• Withdrawal may be due to environmental issues i.e. access, physical limitations/logistics or mood/depression.</li> <li>• ‘Sense of loss’ – no actual loss. Never actually done activities in retirement. Unable to carry out plans.</li> </ul> <p><b>Rapport with health care professionals/Dr</b></p> <ul style="list-style-type: none"> <li>• There is differences in how patients view nurses and Dr. Drs rotate (particularly the juniors) so there isn’t that continuity of care. They also have different shift patterns. Nurses have more continuity and so don’t have to ask the patients the same questions that have been asked before. This can increase patient’s faith in the health care provider as they feel that person knows them. It can also reduce frustration.</li> <li>• Movement away from a model of paternalistic care. It is difficult to assess what patients want and at what level to pitch information. Nurses are often called back to clarify information to patients which was provided by the Dr.</li> <li>• Infection control limits some non-verbal communication strategies i.e. not being able to sit on the bed.</li> <li>• Specialist knowledge is not as important as building a rapport with patients and also patient’s prior experiences associated with that health care provider.</li> </ul> <p><b>Disease coherence</b></p> <ul style="list-style-type: none"> <li>• Terminology used by health care professionals needs to make messages to patient clearer. During ward round words like ‘severe’, ‘chronic’, ‘failure’ are used rather than factual information and numbers i.e. 50% lung function.</li> </ul>	
Feedback on question 2	<p><b>Rapport with health care professioals/Dr</b></p> <ul style="list-style-type: none"> <li>• Nurses – joint documentation to reduce replication of information for patients.</li> <li>• Continuity of staff is difficult with sickness/job losses but can be improved.</li> <li>• Reintroducing and reacquainting yourself with patients each time you meet to promote continuity and rapport.</li> <li>• Consultants need to be more easily identifiable.</li> <li>• Limit numbers on ward round to reduce patients fear and enhance question asking.</li> </ul>	

	<p><b>Disease coherence</b></p> <ul style="list-style-type: none"> <li>• Continue to provide quantifiable information for patients to increase understanding.</li> <li>• People may have never engaged in exercise before, they may not like a group setting and have preconceived ideas about exercise (aerobics in lycra). Day to day activities are seen as exercise.</li> </ul> <p><b>Patient's social world/ Emotional impact</b></p> <ul style="list-style-type: none"> <li>• Increase awareness of social support and community services. Pitch community services in a positive light and be able to provide specific information.</li> <li>• Important to get to the root of patients assumptions/fears/preconceptions about PR. Importance of rapport and consistent messages.</li> <li>• Lack of support available for patients who are younger – diagnosing patients earlier so mean age is reducing.</li> <li>• Support patients in different ways – phone support, 'buddy system' volunteers seeing patient in hospital.</li> <li>• Support provided by staff seen in the hospital may not be utilised in the community as they see the hospital as separate – need to bridge this gap.</li> </ul> <p><b>Description of the hospital admission</b></p> <ul style="list-style-type: none"> <li>• Increased education about oxygen provided by specialist nurses.</li> <li>• More consistency is important but perceived as unattainable.</li> <li>• SPACE manual given to all patients and importance of the care bundle.</li> <li>• Key worker when patients are admitted to hospital.</li> <li>• Phone line/ 24 hour.</li> <li>• It is important to recognise symptoms of depression but may need to be assessed away from the acute setting.</li> <li>• More psychological and talking therapies need to be available for these patients which are specific to chronic disease and post acute exacerbation.</li> </ul>	
Future plans	<ul style="list-style-type: none"> <li>• Refine master themes.</li> <li>• Thematic mapping.</li> <li>• Write up – publish.</li> </ul>	SH, LA, NR

## Appendix R

### Illness Perceptions Questionnaire - Revised

#### ILLNESS PERCEPTION QUESTIONNAIRE (IPQ-R)

*Name..... Date.....*

#### YOUR VIEWS ABOUT YOUR ILLNESS

Listed below are a number of symptoms that you may or may not have experienced since your lung disease. Please indicate by circling *Yes* or *No*, whether you have experienced any of these symptoms since your lung disease, and whether you believe that these symptoms are related to your lung disease.

	I have experienced this symptom <i>since my lung disease</i>		This symptom is <i>related to</i> <i>my lung disease</i>	
	Yes	No _____	Yes	No
Pain	Yes	No _____	Yes	No
Sore Throat	Yes	No _____	Yes	No
Nausea	Yes	No _____	Yes	No
Breathlessness	Yes	No _____	Yes	No
Weight Loss	Yes	No _____	Yes	No
Weight Gain	Yes	No _____	Yes	No
Fatigue	Yes	No _____	Yes	No
Stiff Joints	Yes	No _____	Yes	No
Sore Eyes	Yes	No _____	Yes	No
Wheeziness	Yes	No _____	Yes	No
Headaches	Yes	No _____	Yes	No
Upset Stomach	Yes	No _____	Yes	No
Sleep Difficulties	Yes	No _____	Yes	No
Dizziness	Yes	No _____	Yes	No
Loss of Strength	Yes	No _____	Yes	No



**We are interested in your own personal views of how you now see your current lung disease. Please indicate how much you agree or disagree with the following statements about your lung disease by ticking the appropriate box.**

	<b>VIEWS ABOUT YOUR LUNG DISEASE</b>	<b>STRONGLY DISAGREE</b>	<b>DISAGREE</b>	<b>NEITHER AGREE NOR DISAGREE</b>	<b>AGREE</b>	<b>STRONGLY AGREE</b>
<b>IP1</b>	<b>My lung disease will last a short time.</b>					
<b>IP2</b>	<b>My lung disease is likely to be permanent rather than temporary.</b>					
<b>IP3</b>	<b>My lung disease will last for a long time.</b>					
<b>IP4</b>	<b>This lung disease will pass quickly.</b>					
<b>IP5</b>	<b>I expect to have this lung disease for the rest of my life.</b>					
<b>IP6</b>	<b>My lung disease is a serious condition.</b>					
<b>IP7</b>	<b>My lung disease has major consequences on my life.</b>					
<b>IP8</b>	<b>My lung disease does not have much effect on my life.</b>					
<b>IP9</b>	<b>My lung disease strongly affects the way others see me.</b>					
<b>IP10</b>	<b>My lung disease has serious financial consequences.</b>					
<b>IP11</b>	<b>My lung disease causes difficulties for those who are close to me.</b>					
<b>IP12</b>	<b>There is a lot which I can do to control my symptoms.</b>					
<b>IP13</b>	<b>What I do can determine whether my lung disease gets better or worse.</b>					
<b>IP14</b>	<b>The course of my lung disease depends on me.</b>					
<b>IP15</b>	<b>Nothing I do will affect my lung disease.</b>					
<b>IP16</b>	<b>I have the power to influence my lung disease.</b>					
<b>IP17</b>	<b>My actions will have no affect on the outcome of my lung disease.</b>					

	<b>VIEWS ABOUT YOUR LUNG DISEASE</b>	<b>STRONGLY DISAGREE</b>	<b>DISAGREE</b>	<b>NEITHER AGREE NOR DISAGREE</b>	<b>AGREE</b>	<b>STRONGLY AGREE</b>
<b>IP18</b>	<b>My lung disease will improve in time.</b>					
<b>IP19</b>	<b>There is very little that can be done to improve my lung disease.</b>					
<b>IP20</b>	<b>My treatment will be effective in curing my illness</b>					
<b>IP21</b>	<b>The negative effects of my lung disease can be prevented (avoided) by my treatment.</b>					
<b>IP22</b>	<b>My treatment can control my lung disease.</b>					
<b>IP23</b>	<b>There is nothing which can help my condition</b>					
<b>IP24</b>	<b>The symptoms of my condition are puzzling to me.</b>					
<b>IP25</b>	<b>My lung disease is a mystery to me.</b>					
<b>IP26</b>	<b>I don't understand my lung disease.</b>					
<b>IP27</b>	<b>My lung disease doesn't make any sense to me.</b>					
<b>IP28</b>	<b>I have a clear picture or understanding of my condition</b>					
<b>IP29</b>	<b>The symptoms of my lung disease change a great deal from day to day.</b>					
<b>IP30</b>	<b>My symptoms come and go in cycles.</b>					
<b>IP31</b>	<b>My lung disease is very unpredictable.</b>					
<b>IP32</b>	<b>I go through cycles in which my lung disease gets better and worse.</b>					
<b>IP33</b>	<b>I get depressed when I think about my lung disease.</b>					
<b>IP34</b>	<b>When I think about my lung disease I get upset.</b>					
<b>IP35</b>	<b>My lung disease makes me feel angry.</b>					
<b>IP36</b>	<b>My lung disease does not worry me.</b>					

	<b>VIEWS ABOUT YOUR LUNG DISEASE</b>	<b>STRONGLY DISAGREE</b>	<b>DISAGREE</b>	<b>NEITHER AGREE NOR DISAGREE</b>	<b>AGREE</b>	<b>STRONGLY AGREE</b>
<b>IP37</b>	<b>Having this lung disease makes me feel anxious</b>					
<b>IP38</b>	<b>My lung disease makes me feel afraid.</b>					

## CAUSES OF MY ILLNESS

We are interested in what you consider may have been the cause of your lung condition. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your lung disease rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your lung disease. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

	POSSIBLE CAUSES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
C1	Stress or worry					
C2	Hereditary - it runs in my family					
C3	A Germ or virus					
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care in my past					
C7	Pollution in the environment					
C8	My own behaviour					
C9	My mental attitude e.g. thinking about life negatively					
C10	Family problems or worries caused my lung disease					
C11	Overwork					
C12	My emotional state e.g. feeling down, lonely, anxious, empty					
C13	Ageing					
C14	Alcohol					
C15	Smoking					
C16	Accident or injury					
C17	My personality					
C18	Altered immunity					

**In the table below, please list in rank-order the three most important factors that you now believe caused YOUR lung disease. You may use any of the items from the box above, or you may have additional ideas of your own.**

**The most important causes for me:-**

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

## **Appendix S**

### **Pulmonary Rehabilitation Adapted Index of Self-Efficacy**

Adapted, with permission, from the General Self-Efficacy Scale, Schwarzer R. & Jerusalem M. (1995)

Please circle where you feel you are now.

<u>Statement</u>	<b>Score</b>			
I can always manage to solve difficult problems if I try hard enough.	1	2	3	4
If someone opposes me, I can find the means and ways to get what I want.	1	2	3	4
It is easy for me to stick to my aims and accomplish my goals.	1	2	3	4
I am confident that I can walk for a good distance, at my own pace, despite it making me breathless.	1	2	3	4
I am confident that I could deal efficiently with unexpected events.	1	2	3	4
Thanks to my resourcefulness, I know how to handle unforeseen situations.	1	2	3	4
I feel confident that I will be able to perform the exercises asked of me during the course of rehabilitation, even if I find them difficult.	1	2	3	4
I can solve most problems if I invest the necessary effort.	1	2	3	4
I feel that I have an adequate amount of knowledge about my lung disease, despite it being a complex condition.	1	2	3	4
I can remain calm when facing difficulties because I can rely on my coping abilities.	1	2	3	4
When I am confronted with a problem, I can usually find several solutions.	1	2	3	4
I feel positive that I will be able to complete the exercises at home, despite there being no supervision from a health professional.	1	2	3	4
If I am in trouble, I can usually think of a solution.	1	2	3	4
I can handle whatever comes my way.	1	2	3	4
On a day to day basis I feel in control of my lung disease and how that affects my lifestyle, even when my symptoms become distressing.	1	2	3	4

#### **Response Format.**

1= Not at all true      2= Hardly true      3= Moderately true      4= Exactly true