UNIVERSITY OF SOUTHAMPTON

FACULTY OF HEALTH SCIENCES

Chronic Obstructive Pulmonary Disease (COPD) Patient Experiences of COPD and Pulmonary Rehabilitation: An Applied Phenomenological Study

by

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ABSTRACT

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CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD) PATIENT EXPERIENCES OF COPD AND PULMONARY REHABILITATION: AN APPLIED PHENOMENOLOGICAL STUDY.

By Adam Perry Lewis

Attendance at Pulmonary Rehabilitation (PR) in the UK is sub-optimal and reasons for this have been explored. However, Chronic Obstructive Pulmonary Disease (COPD) patient experiences have rarely been explored longitudinally through PR regardless of patient participation. Therefore, understanding sub-optimal attendance remains limited for the broad population who are referred. Furthermore, limited Primary Care PR research has been performed, where many programmes are run in the UK.

This research aimed to explore COPD patient experiences before and after PR, whether they completed, did not attend, or dropped out of PR.

Twenty five participants with COPD (14 males, 11 females) were recruited from two Primary Care Trusts in the UK. These 25 participants were interviewed before PR. Fifteen of the 25 participants were interviewed again after PR regardless of attendance or completion status. Data were collected during semi-structured interviews using phenomenological research methodology.

In the pre-programme interviews, participants experienced uncertainty living with COPD in their past, present and future. Uncertainty manifested itself in participants' experience of panic. However, participants compared their condition with others positively. Participants were uncertain about what to expect from PR and the causes and pathophysiology of their COPD. Prior to PR participation, participants were brought closer to the experience of dying, through their breathlessness. The experience of uncertainty reduced following PR programme completion. Non-completers seemed angry with their care, less able to cope with comorbidities or wished to remain naïve regarding COPD.

Pulmonary Rehabilitation seemed to enable participant completers to push their perception of being close to dying further into their future. This appeared to strengthen hope and enable a positive attitude to develop. The importance of social comparison in PR and how to manage patients who wish to remain ‘in the dark’ requires further research.

Contents

List of Figures

List of Tables

List of Diagrams

DECLARATION OF AUTHORSHIP

I, Adam Lewis, declare that the thesis entitled

Chronic Obstructive Pulmonary Disease (COPD) Patient Experiences of COPD and Pulmonary Rehabilitation: An Applied Phenomenological Study.

and the work presented in the thesis are both my own, and have been generated by me as the result of my own original research. I confirm that:

- this work was done wholly or mainly while in candidature for a research degree at this University;
- where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
- where I have consulted the published work of others, this is always clearly attributed;
- where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
- I have acknowledged all main sources of help;
- where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
- parts of this work have been published as:
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Signed: …………………………………………………………………..

Date:………………………………………………………………………….

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With the oversight of my main supervisor, editorial advice has been sought. No changes of intellectual content were made as a result of this advice.

I would like to dedicate this PhD candidature to my Grandad Jim. His inspiration made me want to do this.

Definitions and abbreviations

AIP: Applied Interpretive Phenomenology
CA: Conversation Analysis
CAP: Clinical Academic Pathway
COPD: Chronic Obstructive Pulmonary Disease
DH: Department of Health
FDA: Foucaldian Discourse Analysis
FEV1: Forced expiratory volume in one second
FEV1/FVC: Forced expiratory volume in one second/Forced vital capacity
GP: General Practitioner
GOIS: Group Opt-in Session
GT: Grounded Theory
IPA: Interpretive Phenomenological Analysis
MRC: Medical Research Council
NHS: National Health Service
NICE: National institute for Health and Clinical Excellence
OT: Occupational Therapy
PR: Pulmonary Rehabilitation
PT: Physiotherapy/Physical Therapy
UK: United Kingdom

1. Introduction and Background

This chapter will introduce why this PhD candidature was undertaken and informs the reader of the researcher's background. The chosen clinical disease and intervention that have been researched are discussed. The next section will be written in the first person because it includes a reflection of why the researcher carried out this PhD candidature.

1.1 The Clinical Academic Pathway (CAP)

I am a chartered physiotherapist in the UK. I worked in a musculoskeletal setting before starting the PhD candidature which led me to want to understand more about therapy involving chronic long term conditions after working with rehabilitation groups for people with osteoarthritis. The evidence suggested that group-based rehabilitation for this patient group was effective at improving health outcomes, and I perceived the classes to be beneficial for the patients. However, attendance at these classes was far from optimal and the perceptions of patients often differed from my own. At this point in time I started to look for opportunities to perform research in long-term conditions and patient perceptions.

In October 2008, I was offered a new role to become a postgraduate research student at The University of Southampton as part of a Clinical Academic Pathway (CAP) PhD candidature Studentship. I spent half of my time working as a physiotherapy clinician and the other half working towards a PhD candidature. The aim of the CAP was to encourage clinicians to become proficient researchers early in their career, to increase research capacity in the NHS, and to develop evidence-based practice that was clinically grounded. As part of this PhD candidature, clinical practice informed research and research informed clinical practice. The CAP PhD candidature was advertised with the intention of the researcher being given a clinical role within which they could develop their research. The clinical role given to me was based on a number of factors. I was required to apply for the CAP with a short research proposal based on neurology, respiratory or end of life patient care. These were the areas of research expertise that my potential PhD candidature supervisors involved in the CAP had at that time. I based my application on respiratory care due to my keen interest and confidence gained during my undergraduate degree. It was decided by the CAP interview panel that the NHS Trust which could cater for research in respiratory care was a Primary Care Trust. On accepting the Studentship offer, the clinical role that was given to me was a Band 5 physiotherapist in a multidisciplinary Community COPD Team. Part of that role was to deliver a Pulmonary Rehabilitation (PR) programme. My research had to match the research expertise in the University of Southampton and the available clinical roles in the Primary Care Trust in order for me to have the best chance of completing the PhD candidature in the time made available in the job offer which was initially a three year contract. Therefore, I believed that it was important to combine Chronic Obstructive Pulmonary Disease (COPD), PR and patients' perceptions as chosen areas of research because these were the fields within which I would be working over the coming years.

After working in the clinical team for a number of weeks I became interested in the different patient experiences of PR. I did not understand why many people who I saw at their initial assessment did not know what PR was and why so many of the patients who started the programme did not complete it. I wanted to explore the broader patient experience. I was also interested in how meaningful PR was for them. These concerns led me to review literature to explore these ideas. Furthermore, I completed a qualitative research project as part of my undergraduate degree in physiotherapy and therefore I was keen on further developing my skills in qualitative research.

I have been enrolled for four years (part time) on the MPhil/PhD candidature programme. This programme of work comprises a single longitudinal qualitative study. This study is longitudinal because the data collection involved the same cohort of participants providing interviews at two different occasions which were between three and eight months apart. This longitudinal element enabled the data collected from participants in their second interview to be linked with the analysis made from their first interview. This was important because their experiences of being referred to PR, and onward experiences of participation or lack of participation could be contextualised within their other lived experiences of COPD. Furthermore, the researcher believed that illuminating the development or change in patient perceptions over time would add rigour to the study.

The aim was to produce 15 ‘pairs’ of interviews and so, to allow for potential attrition, in the first phase of the study I interviewed 25 participants with COPD who had been referred for PR. They were interviewed after referral to PR but before they were seen clinically to be assessed for their suitability to enter their PR programme. It was at this point whereby there had been limited research previously performed and the earliest point at which patients could have been recruited after referral. Therefore, I believed that the patient perceptions would have been based on how they felt about COPD and PR. This would have represented a lay person’s perspective before further clinical information about their condition and PR was given by clinicians running the programmes. This information may have affected the way in which they discussed the topics and restricted insight into their lived experience prior to clinical intervention. In the second phase, 15 of the same 25 participants were interviewed again after the PR programme to which they had been referred, had ended. These participants were interviewed regardless of whether they participated in the programme or not. Bringing the two phases together has allowed me to analyse the participant experience in their journey through PR.

The next section of this chapter provides an introduction to the topics of COPD and PR and a review of the literature most relevant to the formulation of the research questions. The chapter will finish with the presentation of the research questions for the thesis.

1.2 Chronic Obstructive Pulmonary Disease

Chronic Obstructive Pulmonary Disease (COPD) is a major cause of morbidity and mortality worldwide. Its primary cause is smoking (National Clinical Guideline Centre, 2010). COPD is a respiratory condition that is characterised by persistent airflow limitation with underlying mechanisms including emphysema and chronic bronchitis (Global Initiative for Chronic Obstructive Lung Disease, 2011). In the western world COPD prevalence has been estimated between 4% and 10% (Halbert et al., 2003). However, in an international study of 12 countries including China, USA, South Africa and the Philippines, prevalence ranged from 8.5% and 22.2% (Buist et al., 2007). Furthermore, a recent Canadian study stated that the lifetime risk of developing COPD is 27.6% by 80 years of age (Gershon et al., 2011). The research by Gershon et al. (2011) is based on physician-diagnosed COPD. Therefore, the risk of developing COPD could be higher. For example, there is an estimated prevalence of 4.5 million people in England who may potentially have spirometrically diagnosed COPD, although actual numbers of physician reported COPD diagnoses are much lower than this (Shahab et al., 2006). Therefore, the disease should be considered a major public health concern. In 2010, there were 19,646 deaths caused by COPD in England and Wales (Office for National Statistics, 2011). Furthermore, in the South Central Region, Solent Healthcare had the highest COPD prevalence, emergency admission and mortality rates compared to other Trusts (Hill et al., 2010). These levels are significantly above the national averages. For example the national average for emergency admissions for COPD is around 155 per 100,000 (Hill et al., 2010). In Southampton it is around 225 per 100,000 (Hill et al., 2010). This increased rate of admissions may be due to Southampton being a British Lung Foundation ‘Hotspot’ for COPD due to higher than average poverty, smoking rates and industrial working environments in the docks (British Lung Foundation., 2007).

Common symptoms that occur in patients who can be clinically diagnosed with COPD include exertional breathlessness, chronic cough, regular sputum production, and a wheeze (National Clinical Guideline Centre, 2010). As a chronic progressive disease, it causes an individual's health to deteriorate which often impacts upon their quality of life, particularly if they experience an exacerbation requiring hospital admission, whereby their health status is likely to deteriorate further after discharge (O' Reilly et al., 2007).

COPD is a treatable condition but is not yet curable (Mannino and Buist, 2007). It is recommended that PR programmes offer rehabilitation aimed at improving a patient's health status, quality of life, reduced exacerbations and hospital admissions (National Clinical Guideline Centre, 2010).

1.3. Pulmonary Rehabilitation

Pulmonary rehabilitation (PR) encourages patients to take more of an active role in their health care delivery. PR reduces patients' healthcare use and improves patients' functional capacity (Carlin, 2009b). Ideally, PR should be a multi-disciplinary programme, offering patients the opportunity to exercise, receive self-management education related to their COPD and socialise with other individuals who have COPD (Carlin, 2009b, Coultas and Mckinlay, 2009). It has been suggested that it is important for patients with COPD to socialise as many patients can feel socially isolated with their condition (Department of Health, 2010). PR is an essential part of the treatment pathway for COPD patients who find themselves functionally disabled with the disease, and as such PR offers patients supervision during exercise training and comprehensive education (Department of Health, 2010, National Clinical Guideline Centre, 2010). The content and structure of PR programmes varies widely (Department of Health, 2012). And this makes comparisons between programmes very difficult. Variations could be the number of weeks a programme runs for, the type of exercise included on programmes and the number of sessions per week.

Lacasse et al. (2006) state this difficulty when they performed a meta-analysis of results in PR trials. The optimal length of a PR programme remains controversial (Dunne et al., 2012). It is recommended that PR programmes should run between six and 12 weeks and have between two and three sessions a week (Carlin, 2009a). Most PR programmes in the UK are hospital based but there is growing interest in running PR in community settings (National Clinical Guideline Centre, 2010). Furthermore, there is evidence that community based PR programmes produce comparable benefits to hospital based programmes (Waterhouse et al., 2010).

1.3.1 Effectiveness of PR

Pulmonary Rehabilitation has been shown to be effective in improving COPD patients' quality of life, dyspnoea, exercise capacity, and to reduce dynamic hyperinflation (Lacasse et al., 2006, Casaburi and ZuWallack, 2009, Dodd et al., 2011). Furthermore, PR has been reported to be effective at: improving patients respiratory and peripheral muscle strength, increasing muscle fibre cross sectional area and altering muscle fibre type, and reducing exercise-related metabolic stress, hospital readmissions and risk of mortality (Troosters et al., 2000, Puhan et al., 2009, Seymour et al., 2010, Calvert et al., 2011, Puhan et al., 2011, Vogiatzis et al., 2011). Two Cochrane systematic reviews (Puhan et al., 2009, Puhan et al., 2011) assessed hospital admission rates over 25 and 34 weeks, and both showed a reduction in admission rates in participants who completed a PR programme compared to control individuals. However, it has been suggested that PR may not be effective at reducing hospital readmissions over the course of a year (Ko et al., 2011).

PR has also been reported to be effective at improving psychosocial conditions such as anxiety and depression, and to have the potential to improve self-efficacy in patients who have COPD (Kayahan et al., 2006, Vincent et al., 2011). Research indicates that PR has comparable benefits across all disease stages

(Ergun et al., 2011, Vogiatzis et al., 2011). However, studies have also shown that the positive outcomes above do not necessarily correspond with an improvement in activity levels following rehabilitation (Canavan et al., 2011, Mador et al., 2011, Probst et al., 2011). Improving physical activity levels is one of the main goals of PR because it is associated with a wide range of health benefits for people with COPD including a reduced risk of mortality, reduced systemic inflammation, airway obstruction and potential risk of infections (Garcia-Aymerich et al., 2009, Bossenbroek et al., 2011, Waschki et al., 2011). Nevertheless, PR has been shown to be a more effective and cheaper intervention in COPD compared to bronchodilator drugs and is currently recommended as the cornerstone of treatment for COPD patients (Nici et al., 2006, National Clinical Guideline Centre, 2010, Department of Health, 2012).

1.3.2 PR attendance

Previous research has shown that many patients who are referred to PR programmes fail to attend or complete the programme to which they were referred (Taylor et al., 2007, Nici et al., 2009, Waterhouse et al., 2010, Ko et al., 2011). Poor attendance at PR programmes is likely to lead to suboptimal improvements in patient outcomes (Sabit et al., 2008). Attrition from programmes is common as a result of a variety of factors such as hospitalisation, exacerbation of illness, exclusion at initial assessment or the patient’s own decision (Fischer et al., 2009). Furthermore, it has been suggested that further qualitative research should be performed with patients with COPD in community based PR programmes in order to address issues of attendance in community settings (Waterhouse et al., 2010). The PR programmes to which participants were referred in this study were community based programmes funded through Primary Care Trusts. Patients are given independent responsibility to attend programmes if they are referred to PR. When patients choose to attend pulmonary rehabilitation programmes, the effectiveness of treatment is reliant on the patient agreeing to adhere to the regimen itself, which usually includes performing exercises at home. It is not yet fully understood the level of adherence that is required in order for Pulmonary Rehabilitation to be considered effective in the UK specifically (Bourbeau and Bartlett, 2008).

1.3.3 Adherence, Compliance and Concordance

Adherence is determined by a patient's behaviour, or a modification of patient behaviour which has been discussed and agreed upon with the patient's healthcare provider(s) (Bourbeau and Bartlett, 2008). Compared with compliance, adherence implies the patient's responsibility in the interaction between healthcare professionals and themselves (Bourbeau and Bartlett, 2008). Compliance indicates a more passive role for the patient in decision making. Concordance means that the patients' choice is paramount in agreeing a plan with the healthcare professional and themselves (Bourbeau and Bartlett, 2008) However, it is not clear whether patient choice and direction in the decision making is beneficial or harmful to patients, or how to recognise patients who would respond better to compliance or concordance (Aronson, 2007). Aronson (2007) prefers to use the term adherence which is more and more widely used because of the indication that it means sticking to a therapy. Therefore, it is of the researcher's opinion that adherence, rather than compliance is relevant to patient engagement in pulmonary rehabilitation programmes and will be used throughout this thesis.

According to Johnson et al. (2006) there are both intentional factors and non-intentional factors affecting adherence. Examples given from their research include:

- The overuse of medicated oxygen therapy due to symptoms (intentional non-adherence)

- Patient reliance on health professionals in making patient’s health care decisions can lead them to following medication regimes exactly (intentional adherence)
- Forgetting to attend to treatment regimens due to disruptions such as having guests visit, watching the television or alcohol consumption (non-intentional non-adherence).

Adherence can be assessed in a number of ways, which also causes confusion in interpretation of the literature. There is currently no consensus on estimates of adherence within respiratory physiotherapy literature (Bourbeau and Bartlett, 2008). According to Bourbeau and Bartlett (2008), clinically significant adherence to some pulmonary rehabilitation programmes may be defined as anything from 50% to 80% class attendance, while some programmes have defined non-adherence as being significant if patients fail to attend even a single session. Fan et al define PR adherence as 100% completion of a programme, but Seymour et al define adherence as 50% completion (Fan et al., 2008, Seymour et al., 2010). Other RCT’s and systematic reviews of trials in PR have given a cut off of 70% or 75% attendance at PR as patient adherence (Ko et al., 2011, Puhan et al., 2011). Adherence has been shown to be low among patients who enrol onto pulmonary rehabilitation and maintenance programmes in Australia and is also evident in the UK. This was evident by the number of patients who dropped out following an initial assessment to enter PR or following their initial PR session (Singh et al., 1998, Cockram et al., 2006).

In this thesis, participants were divided into two categories: those participants who completed a programme, and those who did not. Participants were divided in this way to be able to clearly answer the research questions that were formulated. The latter category also includes those who did not attend an assessment to determine eligibility to enter a PR programme. The PR programmes described in this thesis were rolling programmes, rather than cohort programmes. In the former, patients can step into and out of the programme at any time. In the latter, a group of patients start and finish together. Therefore, patients in the programmes studied in this thesis may have missed a number of sessions, but would still be able to complete the maximum number of sessions over a longer period of time. In a recent review of PR there was no agreement between studies on the percentage or number of classes participants needed to complete in order to classify them as adherers (Keating et al., 2011a). Therefore, the participants in this study are not separated into adherers and non-adherers, but completers and non-completers.

1.4 Literature Review

The literature review for this PhD candidature was performed in two stages. The first stage formulated the original research question. The second part of the literature review started after preliminary themes had been created as a result of the data analysis of the post programme interviews. The first stage of the literature review was restricted after the PhD candidature research questions were formulated and participant recruitment started, in order for analysis to be as inductive a process as possible. The following chapter describes the process of the first stage of the literature review. Relevant literature reviewed after the preliminary themes had been made have been included as part of the discussion chapter.

Research databases that were used for the literature search performed for both stages included CINAHL, Cochrane library, EMBASE, OVID MEDLINE and Zetoc. Web of Knowledge was used in the second stage only which is a possible limitation to the preliminary literature review. The search terms included “COPD”, “Chronic Obstructive Pulmonary Disease”, “Pulmonary Rehabilitation”, “Physiotherapy (and) Qualitative” and “patient adherence”. Articles were searched for since 1980. It was thought that articles before this date may have used terms other than COPD which has been redefined from Chronic Obstructive Airways Disease for example. Two other search strategies were used to keep up to date on literature from 2008 through to 2012. Firstly, a Zetoc Alert was set up from November 2008 including the terms previously stated. These alerts were reviewed approximately every three months for articles related to COPD and Pulmonary Rehabilitation. Articles which could not be accessed through the University of Southampton were accessed via a request to The British Library. Secondly, the researcher is a member of the Association of Chartered Physiotherapists in Respiratory Care (ACPRC) which provided an annual literature review in the areas of COPD and Pulmonary Rehabilitation from 2009 to 2010 and then biannually from 2011 onwards. These articles were reviewed in the second stage of the data analysis. The first stage of the review included articles published up until August 2009. This is when the first participant was interviewed.

1.5 Literature Search

Thirty seven articles were found to be of potential interest following the initial literature search. Research articles that led to the formulation of the research questions included those investigating COPD patient experiences of Pulmonary Rehabilitation using a qualitative methodology. Therefore many of the original 37 articles were excluded. The majority of these were because they did not explore specific experiences or perceptions relating to PR (Oliver, 1999, O' Neill, 2002, Nicolson and Anderson, 2003, Seamark et al., 2004, Barnett, 2005, Curry, 2006, George et al., 2006, Arne et al., 2007, O' Shea et al., 2007b, Schofield et al., 2007, Williams et al., 2007, Habraken et al., 2008, Parker et al., 2008, Walters et al., 2008, Spence et al., 2009). Some studies only explored the perceptions of those with severe or end-stage COPD (Guthrie et al., 2001, Fraser et al., 2006, Kanervisto et al., 2007, Gullick and Stainton, 2008, Wilson et al., 2008, Thomas, 2009). This may not correspond with the overall COPD population treated in Primary Care. Other studies focused more on the perceptions of Healthcare Professionals rather than the COPD patients themselves (Harris et al., 2008a).

Eleven papers were chosen following the exclusion of the others from the original 37 for reasons stated above. The final 11 papers were analysed against the EPICURE guidelines to judge their quality (Stige et al., 2009). The EPICURE guidelines were chosen over other criteria because of their applicability across all qualitative research methodologies in comparison to other criteria (Perakyla, 1997, Tong et al., 2007, Bryman, 2008). The applicability across methodologies is necessary in this appraisal due to the different methodologies used in the studies that have been reviewed. Moreover, the researcher believes that this agenda judges qualitative research in its own right and not against standards of quantitative research which is a further strength of the EPICURE agenda. The 11 articles are presented below in table one before the papers are critiqued against the EPICURE agenda.

Study	Research question/Aim	Methodology	Participants	Conclusion
Rodgers et al (2007)	Evaluation of the information needs of patients with COPD following PR	Template analysis	23	The lack of awareness of the label of COPD at the point of diagnosis in primary care is a particular concern. Patients perceive coming to terms with COPD a requirement to achieve successful self-management. Individual counselling was seen as important and should be part of PR.
Taylor et al (2007)	Why do patients decline to take part in a research project involving PR?	Framework analysis	39	Recruitment to PR research could be improved through better information, locations and timings. A video recording of a previous programme or completer comments may be useful. Many patients had negative perceptions of what to expect from a programme whereas others had family commitments.
Fischer et al (2007)	To examine patients pre- treatment beliefs and goals regarding pulmonary rehabilitation	Interpretive Phenomenological Analysis	12	Participation in PR requires a lot of patient effort, persistence and flexibility. The levels of PR uptake and drop out depend on subjective need for improvement, anticipation of benefits, confidence in capabilities, and concerns and barriers.
McBride (1994)	Examination of the impact of attitudes and beliefs on the intentions of patients with COPD to engage in activities	Content analysis	32	Interventions should enable patients to become more aware of obstacles that interfere with intentions to engage in activities. These interventions should also develop creative problem solving skills. Reinforcing positive

	thought to increase activity tolerance.			behaviours may enhance perceived control.
Harris et al (2008)	To identify a strategy for improving the uptake of pulmonary rehabilitation	Grounded Theory	16	The benefits of PR could be explained by telling patients it is a way of regaining control. GP’s should anticipate, acknowledge and normalise patient concerns. GP’s should also establish patient goals and motivations in order to implement behaviour change.
Arnold et al (2006)	To explore experiences of COPD patients invited to join a PR programme	Grounded Theory	20	The referring doctor plays a key role in patient adherence to PR. Improving care for patient social support may improve adherence to PR.
Norweg et al (2008)	To analyse patient perceptions of a pulmonary rehabilitation programme with OT component.	Grounded Theory (Strauss and Corbin (1998))	4	Patients perceived Occupational Therapy complimenting Physical Therapy and should be considered as standard care. Patients were satisfied with their newly aquired self-management skills
Wilson et al (2007)	To ascertain patients perspectives of what should be included in PR education sessions and compare these views with that of health care professionals	Grounded Theory	32	Patients had deficits in knowledge regarding disease understanding and management. More research is needed to examine efficacy of education packages.

Bulley et al (2009)	How do individuals describe their views about participating in pulmonary rehabilitation, following referral and prior to attendance?	Interpretive Phenomenological Analysis	9	The experiences of patients were summarised as spiralling disability, with symptoms leading to avoidance of activities. However, patients had developed self-management strategies but wished to learn more. Patients should be informed that PR can substantially lessen the daily burden of living with COPD.
Chan (2004)	To explore the patients perspective of the experience of COPD related to engagement in daily occupations and their perspectives and experiences of an occupational therapy intervention as part of PR.	Phenomenological (non-specific)	3	Patients isolate themselves due to their deteriorating respiratory condition, followed by social isolation and deprivation of occupational engagement. This leads to psychological distress. The Occupational Therapy component facilitated a more positive, engaged life pattern.
Camp et al (2000)	Determination of quality of life changes for people with COPD who have gone through PR	Quantitative and qualitative (non-specific)	29 (7 in the qualitative interviews)	Physical and emotional health are affected by pulmonary rehabilitation. Obtaining knowledge, increasing activity and controlling breathlessness combine to improve quality of life. Control over COPD may influence long term benefits of PR.

Table 1: Eleven final articles from the literature search

1.5.1 EPICURE Agenda

1.5.1.1 E - Engagement

Engagement is the degree to which the researcher has prolonged exposure with the research phenomena or situations (Stige et al., 2009). It is difficult to judge the level of engagement in the above studies because it is often not communicated. However, the engagement in the studies appears poor overall. Fischer et al. (2007) comment that the participants who gave consent to the study were contacted by the lead author. However, it is not clear whether the lead authors had any clinical experience in the PR setting in which the research had been undertaken. Arnold et al. (2006) inform the reader that the researcher had clinical experience of PR. However, the authors discuss this clinical experience as a possible limitation which required other people to analyse the data. Arnold et al. (2006) also acknowledge a limitation to their study in terms of its retrospective nature which also limits the engagement of the study as it is not clear whether the authors were part of that programme at the time the participants were involved in PR. Alternatively, in the study by Norweg et al. (2008) the authors explain that the participants were recruited by one of the researchers who had experience in treating the participants as part of the activity training aspect of the PR. This shows strong engagement with the study situation. However, due to a lack of discussion of the author’s subjectivity in the research process, this engagement reduces the quality of the study in the researcher’s opinion because the author’s engagement may have led to a selection bias (Norweg et al., 2008). Harris et al. (2008b) show engagement in their study because the interviewer is a GP concerned with the problems with the uptake of PR by patients in Primary Care and ask questions specifically related to these issues.

1.5.1.2 P – Processing

Processing is the process of data preparation, collection, analysis and preservation of the research material (Stige et al., 2009). Processing in the above studies is of a high standard. Elements of the data collection process have been presented by the authors which strengthens the processing. Strengths include the description of the piloting process for the interviews, provision of sample questions of the interviews, methods of data analysis and in depth information regarding the recruitment process (Arnold et al., 2006, Harris et al., 2008b, Norweg et al., 2008, Bulley et al., 2009). However, McBride (1994) stated that a convenience sample of 32 patients was selected and all of these participated in the study. This seems an inconsistently low level of drop out in comparison to the other studies. With regard to data preparation, Taylor et al. (2007) performed a retrospective study which involved interviewing patients who declined to take part in a randomised trial which included PR. Twelve months after patients declined, ethical permission was then sought to interview the patients. This significantly delayed data collection which may have impacted on the depth of findings. Details of patient recruitment were also lacking in the study by Wilson et al (2007). The information provided by Chan (2004) provides the reader with a greater understanding of the processing due to the communication of the different purposes of each interview and how the data were preserved in a timely manner.

1.5.1.3 I – Interpretation

Stige et al. (2009) state that interpretation is the act of creating meaning through the identification of patterns and development of contexts in order to understand the experiences and descriptions of participants. The studies included in this review all showed the same strengths and weaknesses with their interpretation. The focus of their research was linked closely with the themes that were presented to the reader and often these themes would be interpreted using many different patient quotes for illustration accompanied with clinical references. Reflexivity was communicated by Bulley et al. (2009), regarding the interviewer's positive attitudes towards exercise potentially affecting the data collection. The researcher believes that as a result, the presentation of themes and discussion in this article presented a good balance of positive and negative patient experiences. However, reflexivity was poor in the other articles. Moreover, there was no reference in the interpretations to how the research related to the theoretical framework of the studies, which is seen as a limitation (Stige et al., 2009). For example, Chan (2004) describes that the purpose of the interviews was to allow participants to tell their stories through conversations, then explains this is similar to a phenomenological approach. However, Chan (2004) does not state specifically that his methodology was phenomenological or indeed what type of phenomenology he used. Nevertheless, Chan (2004) strengthened the interpretation of the article by commenting on aspects of the local environment of Hong Kong and the fact that in Chinese culture many people believe in fate which may have affected some of the participants' views.

1.5.1.4 C – Critique

There are two elements of critique to be evaluated in qualitative research including self-critique and social critique (Stige et al., 2009). Self-critique evaluation depends on the extent to which the researchers have addressed engagement, processing and interpretation using critical and reflexive approaches (Stige et al., 2009). As discussed previously, the authors of these studies do not communicate their role in the research extensively. McBride (1994) highlighted what her beliefs were in the introduction of her paper but then did not reflect on how her research related to her beliefs later in the discussion. Camp et al (2000) discuss that the researchers were not part of the PR programme from which they recruited participants thereby potentially reducing any potential Hawthorne effect. It is this researcher's opinion that it has been assumed in the studies above that a researcher is separated from any decisions made about the chosen methodology, the process of data collection or how preconceptions may influence analysis of the data. This may be a negative aspect to the level of critique in the studies. The evaluation of social critique in a study involves deciding to what extent the study contributes to social change and empowerment of participants, or repression and disempowerment (Stige et al., 2009). These studies may be viewed as empowering participants by giving them the opportunity to talk about their condition and giving them time to be heard. This may be a way in which they feel they have gained some authority in discussion about them and their health. In these circumstances it may be important to give them time to talk as communication has been shown to be a problem when patients are involved in discussions regarding their COPD. COPD patients have perceived receiving little information from their GP and were reluctant to discuss their breathlessness (Oliver, 2001). However, it is not necessarily the case that increased discussion about one’s health condition for the purposes of research will lead to an engendered change in behaviour or patient care that strengthens the patient’s life to have more power to comfortably live with their COPD. The link between the patients’ role in the research and their associated empowerment in living with COPD as part of the normal care they were receiving was not made explicit in these studies.

Wilson et al. (2007) performed a multiple focus group study with patients who had and had not participated in PR to ascertain the educational needs of these individuals. It was not clear whether those who had not participated in a programme had been offered the opportunity to participate in PR prior to the study commencing. It may have enhanced the social critique of the study if the authors offered those who had not previously participated in PR the opportunity to enter a programme following the completion of their study. Some of the research articles above have discussed the potential implications of their research to clinical practice and the increased understanding of the experiences of a COPD patient (Chan, 2004, Harris et al., 2008b, Bulley et al., 2009). However, these clinical implications do not affect those participants in their studies.

1.5.1.5 U – Usefulness

The usefulness of a study refers to the study's value in terms of its applicability to practical contexts, the study's contribution to an enhanced understanding and the ability to implement the proposed knowledge (Stige et al., 2009). The studies that have been included in this review are seen to have a high standard of usefulness to the practical context of PR because the main focus of all these articles is about patient experiences and expectations of PR. However, there are limitations in the literature. For example, in some of the articles the researcher was unable to establish the structure or content of the PR programme to which patients had been referred, nor did the authors discuss issues regarding the uptake to PR (Fischer et al., 2007, Wilson et al., 2007, Harris et al., 2008b, Bulley et al., 2009). All of these authors interviewed patients before they participated in PR. Therefore the findings may be useful for clinicians referring patients to PR and for clinicians who perform the initial assessment to enter PR. Four of the articles were from the UK (Arnold et al., 2006, Rodgers et al., 2007, Harris et al., 2008b, Bulley et al., 2009) and these are therefore more useful for this researcher due his knowledge of the UK healthcare system. It is the author's belief that because all participants in the UK studies were recruited with approval from NHS Ethical committees, they were managed in a healthcare system with uniform guidelines (National Clinical Guideline Centre, 2010). Therefore the patient experiences in these studies may be more comparable to participants recruited in the researcher's study than studies performed abroad. Unlike some of the authors (Fischer et al., 2007, Harris et al., 2008b, Bulley et al., 2009), Arnold et al. (2006) interviewed patients up to two years after they had completed or not completed a PR programme. Harris et al interviewed patients before they had been referred to PR and Bulley et al interviewed patients after they were referred but before they were seen at their initial assessment (Harris et al., 2008b, Bulley et al., 2009). The information about data collection time scales in the studies allowed the researcher to begin to understand perspectives of patients before and after they have been assessed to enter a PR programme.

The different attitudes to treatment proposed by Fischer et al. (2007) offers clinicians a new way of understanding patient's perspectives based on their beliefs, concerns and prior healthcare experiences. Harris et al. (2008b) proposes a model of patients losing control and regaining control, which could be used in a PR education session informing patients about the benefits of PR. The sense of gaining control was also discussed as part of the experience of improving quality of life following the completion of a PR programme (Camp et al., 2000). Camp et al. (2000) interviewed five women and two men, two weeks post PR programme completion. The inclusion of more women in a study is valuable because the majority of other studies recruited a predominantly male cohort. The inclusion criteria in some of the studies included a COPD diagnosis by spirometry which is a test of lung function (Harris et al., 2008b, Bulley et al., 2009). A spirometry diagnosis can act as a weakness to the usefulness of a study. If spirometry measurements are used as an inclusion criterion this may limit the recruitment of study participants to a particular severity of COPD as shown in the study by Bulley et al. (2009). This may have limited usefulness to PR programmes, which receive patient referrals with ranging COPD severities and other respiratory conditions besides COPD. In these PR programmes spirometry may not be deemed necessary for the patient to enter a programme. Moreover, many COPD patients referred to the researcher's PR programme in Primary Care had not had a confirmed spirometry diagnosis. The same issue is present when excluding patients with comorbidities (Bulley et al., 2009). Fischer et al. (2007) strengthened the usefulness of their thematic analysis and discussion because of their focus on psychosocial issues. This discussion enables clinicians to apply a greater understanding of psychosocial issues in their assessments for patients to enter PR programmes. For example, participants in the study by Fischer et al. (2007) were thought to drop out because of unsupportive remarks made by staff or other patients, homesickness and possible conflict with other patients.

1.5.1.6 R- Relevance

According to Stige et al. (2009), the relevance of a study is the extent to which the study contributes to the development of a discipline, how the study fits with relevant literature and its originality. Apart from the study by Chan (2004) which was carried out in Hong Kong, the selected studies contain a good standard of relevance in terms of their use and reference to literature in the introduction then referring to the relevant literature in the discussion. These studies are seen as original because they have all explored patient perspectives regarding PR at different points in the participants' PR journey. Taylor et al. (2007) studied patients who declined potential participation in a PR programme. The originality of their work gives their study high relevance. However, this is somewhat negated by the fact that the focus of the study was on patient perceptions of participating in research involving PR, rather than PR itself. Therefore, not all of the themes related to PR and not all of those who would have entered the study would have received PR. The relevance of the study by Wilson et al. (2007) was high because of its originality in combining focus groups of patients who had and had not attended PR with views from a focus group of healthcare professionals. The study used the information to develop the education component within PR programmes. It is understood that PR should be a multi-disciplinary intervention. Therefore, not all research in PR will be relevant specifically to the physiotherapy component of PR. However, if the studies were to be relevant specifically to physiotherapy which is important to the researcher because it is his profession, the studies are less specifically relevant. Only one of the studies above seemed to be performed by a physiotherapist with experience of PR (Arnold et al., 2006). Due to the subjective nature of qualitative research, this is seen as a potential limitation to the relevance of the other studies (Stige et al., 2009). In the study by Norweg et al. (2008) the implications and discussion related to the benefits of PR could be relevant to physiotherapy as there seems to be some overlap between what Occupational Therapists (OT) undertake in the United States of America and Physiotherapists (PT) in the UK. For example, the authors commented that controlled breathing was found to be beneficial by patients. The controlled breathing education was performed by OT's in the study whereas in the researcher’s clinical setting this is performed by PT’s. The relevance of the study by Chan (2004) is more focused to OT because the second of the two participant interviews was specifically investigating the participant experience of an OT intervention as part of PR.

1.5.1.7 E- Ethics

The evaluation of the quality of the ethics of the study depends on the extent to which the researchers have been respectful to participants, communicated their relationship with the participants and whether all participant perspectives have been included in the analysis (Stige et al., 2009). All studies ensured anonymity of patients in their studies and all but one study by Chan (2004) communicated that they gained ethical approval from an institutional board to commence the study. This could be due to potential cultural differences in the ethics process in Hong Kong. For example, compared to western research publications, the documentation of ethical approval may be deemed less important in Hong Kong. Therefore it is unclear how this research was judged to be ethically appropriate. Indeed, at the beginning of the study, Chan (2004) describes that four participants were included in the study. However, the views of one participant were not included in the analysis because s/he dropped out of the programme. The researcher interprets that the fourth participant would have therefore had an initial interview at the beginning of the programme, the analysis of which was not included in the published study. Another ethical uncertainty is apparent in the study by Harris et al (2008b) where the interviewer asked patients about their feelings towards a potential referral to PR. However, it was not made clear by the authors whether any of the patients involved in the study were referred to a PR programme. If they were framed an offer of PR but then did not offer the participants a place on a programme this may be viewed unethical. One of the studies specifically mentioned the relationship between the researcher and the patients (Norweg et al., 2008). In this study the researcher was an OT who treated patients as part of their activity training in the PR intervention, which was part of a larger study studying the effects of PR (Norweg et al., 2008).

Consequently, the participants may have felt pressured to give positive responses to questions as socially acceptable answers. All themes provided were positive towards rehabilitation and the OT intervention. Therefore, it is questionable whether a true representation of the diversity of views was included in the study. However, this reflexivity was not discussed in the study (Norweg et al., 2008). Conversely, Rodgers et al. (2007) used researchers who were not involved in the PR programme to run the focus groups. This study presented a good balance of positive and negative participant views. Furthermore, at the end of each focus group, participants had the opportunity to discuss any clinical issues that arose with a member of the respiratory healthcare team.

1.6 Evaluation Summary

The strength of research can be summarised using different size fonts with the different letters of EPICURE to show the strengths of the research in a large font and weaknesses in a smaller font (Stige et al., 2009). For the research in the table above the researcher’s representation is as follows:

EPICURE

The weighted acronym above illustrates that the best communicated element of the literature is processing because it has the largest font. The researcher views the focus of communication in processing in the qualitative research above as an attempt to justify the qualitative approaches chosen to an audience who will be mainly familiar with quantitative approaches to research. The researcher believes that this comes with a sacrifice of a limited word count in communicating the true value of qualitative research which is possibly in the researcher’s quality of reflexivity and acknowledgement of the strength of subjectivity. Throughout all of the articles above there was little reflexive discussion or subjective impact on the research process. For this reason the areas of engagement, interpretation, critique and ethics were poor. However, within the restricted word count permissible in many journals, it is doubtful if it would be possible to do equal justice to all elements of EPICURE within a single article. The overall quality of usefulness was high in these articles, because it is thought that the findings relate specifically to the clinical context of PR. Usefulness could be further improved by further description of the structure and content of the PR programmes with less strict exclusion criteria that would be more reflective of clinical practice. The studies above also showed good relevance to the related articles in their field of research and incorporated these articles in the introduction and discussion sections of their work. However, the relevance of the articles to physiotherapy intervention as part of PR was limited and could be improved by further work being performed by a physiotherapist working in PR.

Other limitations existed in the literature in table one which were not fully covered in the EPICURE analysis but are nevertheless important to consider in the interpretation of the research. The inclusion and exclusion criteria varied between studies. This is particularly the case with the inclusion criterion of a diagnosis of COPD. Some studies defined COPD as chronic bronchitis, emphysema or asthma or a FEV1 % predicted value of less than 70 (McBride, 1994, Camp et al., 2000). This does not reflect current diagnostic guidelines for COPD. The use of conceptual frameworks embedded in the introduction, analysis and discussion of some of the articles could lead to the interpretation that the data collection and analysis in these studies was more deductive than inductive. This may have limited the exploratory nature of the qualitative studies. There was a lack of clear theoretical explanation in the methodology sections of the papers making interpretation difficult. Moreover, the exclusion of patients with significant comorbidities in some of these studies reduces the relevance of the findings to many people with COPD who have comorbidities. Only certain elements of PR, such as education, were investigated in some studies, limiting the applicability of those findings to that particular component of the programme. Limited information was available about the structure and content of the programmes in many of the studies. Nevertheless, it still appears that the majority of studies have investigated patient perceptions and experiences of secondary care PR programmes, with very limited data based on Primary Care PR programmes.

1.7 Themes in the Literature

The strengths and limitations of existing research prior to August 2009 have now been discussed. A thematic summary is presented in order for the reader to understand current knowledge that has been gained from the published research.

Motivators and barriers to enter PR have previously been explored by many researchers. For example, these include providing continuing motivation for the patient, or patients having competing commitments, responsibilities, or demands (Arnold et al., 2006, Fischer et al., 2007, Taylor et al., 2007, Wilson et al., 2007, Harris et al., 2008b). It appears patient transport was not consistently perceived as a barrier to participation in PR. The positive and negative influences of the referring practitioner to a PR programme have also been explored (Arnold et al., 2006, Harris et al., 2008a, Harris et al., 2008b, Bulley et al., 2009). Many of the same studies have also shown a lack of participant knowledge regarding COPD, how to recognise and treat exacerbations, PR and on-going support following PR. Both positive and negative perceptions of group work and exercise at PR have been explored with COPD patients. However, a more consistent perception was that PR was a safe environment to exercise because of the reassuring supervision provided by staff (Fischer et al., 2007, Rodgers et al., 2007, Norweg et al., 2008). PR has also previously been perceived by patients to increase their coping and control of their condition, regain hope and relieve the mental burden of COPD and social isolation (McBride, 1994, Camp et al., 2000, Chan, 2004, Rodgers et al., 2007, Wilson et al., 2007, Norweg et al., 2008).

1.8 A comparison with a recent systematic review

The process of the literature review was described in the introduction of this chapter. There was a suspension of the literature review during data collection and preliminary analysis of this PhD candidature study. This was to ensure that the researcher maintained as open an attitude as possible towards the data and restrict the influence of reading further research on the themes that were created in this thesis's data analysis. However, one paper has been included in this chapter even though it was read after the data analysis, because of its relevance to the literature review presented in this chapter (Keating et al., 2011a).

Keating et al (2011a) performed a systematic review of the literature investigating what prevents people with COPD from attending and completing PR. This review found 11 relevant articles to review. However, only five of these were based on qualitative research. Consequently, the researcher believes that the criteria used to assess the quality of studies were biased towards quantitative paradigm qualities. Nevertheless, the studies were judged as having good quality overall by the authors own marking criteria (between eight and 12/12). Some of the same articles were reviewed in the systematic review compared with the author's own literature review (Arnold et al., 2006, Fischer et al., 2007, Taylor et al., 2007, Harris et al., 2008b). One qualitative study that was included in the systematic review that was not included in this literature review was by O'Shea et al. (2007a). This was excluded by this researcher because of its limited applicability to multidisciplinary PR currently performed in the UK and the quality of data reporting. O'Shea et al. (2007a) recruited participants from a randomised controlled trial of a predominantly home-based 12 week programme of progressive resistance exercises using a theraband. No participant quotes were used in this study despite the authors stating they were using qualitative methodology. This was seen as a significant limitation to this study.

There are significant differences between the systematic review performed by Keating et al and this literature review. Nevertheless, the additional themes provided by these authors are seen to be valuable in order for the reader to contextualise the data and analysis in the following chapters (Keating et al., 2011a). The additional major themes associated with non-attendance at a PR programme include the inconvenient timing of programmes and participants preferring PR in the afternoon (Keating et al., 2011a). Additional major themes associated with non-completion of a PR programme were participant comorbidities, a current smoking status and having depression. This literature review produced themes that were not deemed significant by Keating et al(Keating et al., 2011a). These include, a lack of participant knowledge, and perceptions regarding staff on a programme. Moreover, the literature review in this thesis has a balanced mixture of positive and negative participant perceptions regarding PR, compared to the predominantly negative participant perceptions described by Keating et al(2011a).

Keating et al. (2011a) stated that it is still not possible to predict PR completion using commonly used clinical and demographic data prior to PR. The most significant theme associated with both non-attendance and non-completion to PR was patient difficulty with transport (Keating et al., 2011a). These authors included the study by Harris et al. (2008b). However, they fail to indicate that participants in Harris et al’s study reported no perceived difficulty in getting transport to PR. Keating et al. (2011a) conclude their review by stating that more information is needed regarding patient decisions about attendance at PR and that there are few studies which examine participant failure to attend PR, which is of clinical concern.

1.9 Conclusion

COPD is a major health concern in the UK. PR is an intervention that has been recommended for patients with COPD, but patients’ perceptions and experience of PR seem to be complex. Moreover, the patients' perceptions and experience of COPD and PR provided in the literature have limited relevance to the physiotherapy profession. The credibility of the literature above is limited in the areas of engagement, interpretation, critique and ethics due to weaknesses in the discussion of reflexivity and a lack of subjective empowerment. Furthermore, limitations in the literature exist due to the lack of community based research and poor descriptions of the PR programmes. Little is known about the experience of patients who choose to drop out of, or do not start on, their journey through PR. From the studies above it is clear that different researchers have studied patients' perceptions and experiences of PR at different parts of their PR journey. However, we currently know little about patients' beliefs and expectations about PR before they start a programme and how these relate to their experience of their rehabilitation journey from that point onwards. To the authors knowledge, up to August 2009 there was no published research that had explored patient experiences and perceptions relating to their COPD and PR before their initial intake assessment to a PR programme, and post-programme, whether the participants in the study attended the PR programme or not.

1.10 The research questions

The overall aim of this PhD candidature programme of research was therefore to increase the understanding of patient experiences of their COPD and PR journey, from the point after which they had been referred to a programme, to when that programme ended. The increased understanding of the patient experience of their PR journey, from referral onwards, should enable clinicians to treat patients with more empathy in order for the quality of patient care to improve. Furthermore, clinicians will be able to use this understanding to develop new approaches to PR programmes, or change the way in which patients are referred or assessed to enter PR programmes in the future. This thesis aims to explore the following research question:

What are the experiences, expectations and perceptions of patients with Chronic Obstructive Pulmonary Disease (COPD) who get referred to a pulmonary rehabilitation (PR) programme?

The research question associated with the first phase of this study was:

1. What are the experiences and expectations of patients with Chronic Obstructive Pulmonary Disease (COPD) who are referred to a pulmonary rehabilitation (PR) programme, but have not yet started it?

Research questions for the second phase of the study were:

2. What are the experiences and perceptions of patients with COPD who are referred to a PR programme after that programme has ended?

And:

3. What are the experiences and perceptions of patients with COPD who are referred to a PR programme but do not complete or start that programme?

2. Methodology

The aim of this chapter is to provide a guide for the reader to understand the decision trail the researcher took to judge an appropriate methodology to answer the research questions. This chapter also introduces some complex areas of research methodology where a consensus has not been reached in the literature with regard to the most appropriate use of a methodology. At that point in the methodology, the researcher will justify the decisions that were made based on literature, and the context within which the research was performed.

This chapter describes and explains the researcher's epistemological and ontological stance. Epistemology is the study of the nature and status of knowledge to be researched, whereas ontology is the study of what reality is like and the basic elements that reality contains (Silverman, 2005) . The methodological approach selected for this research will be justified through discussion of other methodologies used in research with similar epistemological and ontological stances. Finally, this chapter will focus on the use of phenomenology in healthcare research and the justification of the particular phenomenological methodology chosen to answer the research questions.

2.1 Epistemology

The research questions are exploratory in nature. After the literature review was completed from the previous chapter, the researcher's understanding at the beginning of this PhD candidature was that little was known about the experiences of individuals with COPD who are referred to PR. To understand these experiences in more depth a research journey of discovery needed to be taken. No hypotheses were to be tested as the research question was not driven by testing a theory. To answer this research question the researcher chose to use an epistemological position that was aligned with interpretivism rather than a positivist position (Bryman, 2008). Theory and observation are separate in positivism and positivism assumes the scientific method is one of true objectivity (Ritchie and Lewis, 2003). However, in order to research people and their social environments, interpretivism offers a contrasting methodology to that used in the natural sciences (Bryman, 2008). In interpretivism, social reality and the researcher impact on each other. It is therefore accepted that the research findings will be influenced by the researcher and there is a recognition that the social world is not governed by certain predefined laws (Ritchie and Lewis, 2003). This means that social reality is complex in nature and exploration of this complexity is needed to uncover this reality.

As the core epistemology of this project is interpretivism, a qualitative rather than quantitative methodology was used. The difference between the two can be described by stating that qualitative data collection, analysis and interpretation involves investigating phenomena that are not easily reduced to numbers or might not be explored sufficiently in the attempt to do so (Bradley, 1997). It has been argued that reducing data hinders the purposes of exploratory research which aims to expand on current knowledge and ideas (Bryman, 2008). It is often found that exploratory research may produce more questions and fewer answers compared to quantitative research data that aims to accept or reject a clear objective statement often relating to the hypothesis. Qualitative research aims to seek insight and understanding of people's experiences and perceptions of the world, rather than statistical significations within the world (Bell, 2005). Thus, quantitative methods are deductive, whereby the researcher aims to deduce an answer to the research question. Deductive research often begins from a well-defined theory or where significant research already exists in the research area. The researcher would then use this knowledge to formulate a hypothesis which could be tested by further research (Bryman, 2008).

Qualitative methods are mostly inductive and exploratory in nature (Holliday, 2002). Inductive research can be initiated with little or no knowledge about a research area. No pre-existing theories are tested as part of inductive research. The aim of inductive research is to create new knowledge, capturing the individual's point of view, securing rich descriptions and contextual conditions are taken into account (Flick, 2009, Denzin and Lincoln, 2011). The aim of this research was to increase the researcher's knowledge and understanding of patients' experiences. Qualitative research appreciates subjectivity in research. For example, value is given to the researchers' interpretation in this instance, that patients may attend PR because they want to please somebody that they will see on a regular basis (Arnold et al., 2006). This interpretation would not have necessarily come directly from a research participant discussing this possibility specifically and therefore adds depth to the analysis of the particular social world that was investigated. Another way in which researcher subjectivity is appreciated in qualitative research is the role reflexivity plays throughout the research process (Finlay, 2002). Reflexivity will be discussed in more detail throughout this thesis, particularly later in the methodology and method chapters. Quantitative research investigates cause and effect using objective measurements. For these reasons, a qualitative rather than quantitative research paradigm will be used.

2.2 Ontology

The following diagram is a representation of where this research lies on a scale of ontological positions.

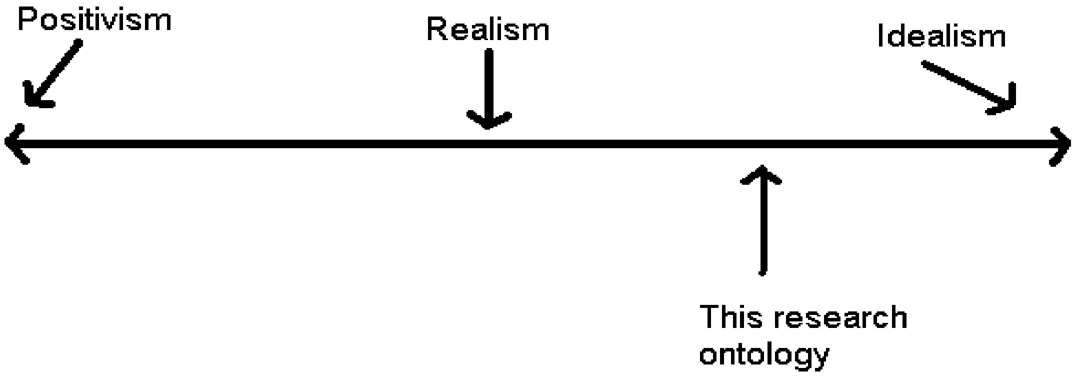


Figure 1: Ontological Position

This diagram has been drawn by the researcher. On the left of this diagram the qualitative methodologies use more of an objective stance which changes to those on the right of the diagram, which are more subjective. If the researcher was more of the opinion that there is one true reality and the aim of research was to elucidate this reality, the researcher would use a methodology to the left of the diagram, such as content analysis. To the extreme right of the diagram the researcher believes that everybody's reality is different.

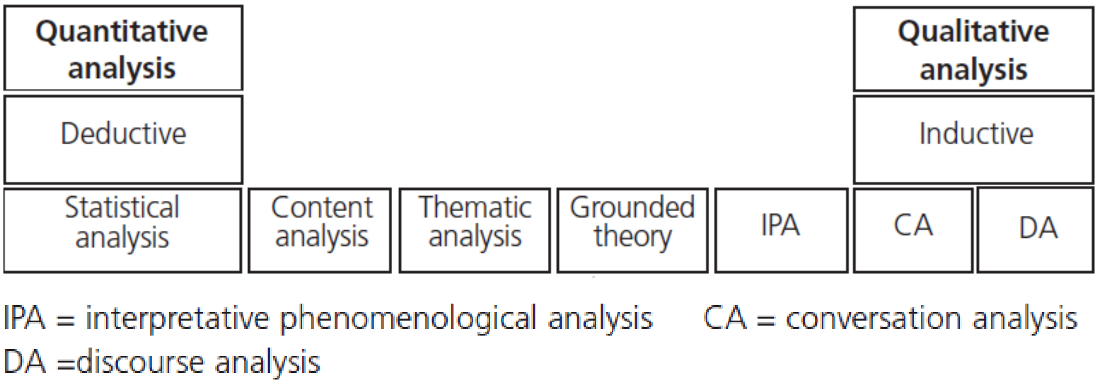
Realism asserts that "…there is an external reality to which scientists direct their attention." (Bryman, 2008) p 14. A provisional reality compared to a predetermined reality is what can distinguish critical realism from empirical realism whereby critical realism adopts the assumption of a provisional reality. It is of the researcher's opinion that interpretivism can be used in the ontologies of constructionism or realism. Either the researcher believes that a collective reality is possible within which meanings and representations can be shared, or only a series of social constructions exists rather than one reality (Ritchie and Lewis, 2003). Others assert that in constructionism an external reality exists but is a reference for social actors which is constantly revised (Bryman, 2008). In Constructionism social phenomena and associated meanings can only be accomplished by social actors and not constrained by a predetermined objectivist social reality (Bryman, 2008). Furthermore, for people to live and socialise with each other in society, events and experiences are usually understood in a similar fashion, particularly if they share experiential circumstances (Barritt et al., 1983).

An interpretivist epistemology and constructionist ontology would account for the researcher's role in the research process. Therefore, the social reality of people who have COPD will be understood by continual comparisons and revisions of individual interpretations of their own reality. The researcher followed this ontological position with the understanding that he is a physiotherapist who has worked in PR for the last four years. Therefore, he has related the participant's experiences to the provisional reality with which he has worked clinically. The researcher's interest to relate the research findings to his clinical experience is seen as an essential part of the CAP PhD candidature studentship within which this research was undertaken. The importance of the researcher's background and influence on the research are key concepts in interpretivism and reflexivity. However, to ensure the research questions were answered appropriately, the experiences of the participants have been given more priority and therefore should have greater impact on the reader compared to the experiences of the researcher.

In PR, patients function in groups and have all been referred to a programme by a health care professional. For these reasons it was thought that these patients would have some shared experiences. However, it was important that individuals' experiences that are not shared were also explored as patients went through their rehabilitation journey. These unique experiences will further our understanding of what it is like for an individual with COPD to be referred to PR. Moreover, this may lead to further questioning of our current knowledge and the need for justification or modification of what is currently known.

2.3 Qualitative inquiry

Within qualitative research there are broad and more specific qualitative methodological approaches. Broader methodological frameworks include phenomenology, ethnomethodology, symbolic interactionism, feminist research and postmodernism. Grounded theory methodology is a specific methodology which is associated with symbolic interactionism, whereas discourse analysis and conversation analysis fit into the broader methodology of ethnomethodology (Ritchie and Lewis, 2003). Other specific methodologies include narrative psychology which is interpreted by this researcher as being aligned with post-modernism, and content analysis which is seen by this researcher as being almost quantitative in nature, as can be seen in the diagram below. This will be explained later in the methodology. Some authors may describe the above as methods. The understanding of how some of the methodologies relate to one another can be illustrated by the figure below:



(Smith et al., 2011)

Figure 2: Research Method Associations

Various potential methodologies that could have been used in this research will now be discussed. Reasons why particular methodologies were not chosen will be justified and will illustrate why a phenomenological methodology was used for this research.

2.3.1 Ethnomethodology

Ethnomethodology is the study of the properties of everyday practical actions as practical reasoning (Garfinkel, 1984). Through the analysis of these actions people attribute meanings which make clear actions that may have been ambiguous and challenging before reflection (Taylor and Bogdan, 1998). Day to day actions of COPD patients were not studied to see how they interpreted these as reasoned activities to create normal social interaction. The researcher believes that the different methods patients employ to make sense of their external reality were not seen as appropriate in order to answer the research questions in this study. Rather, achieving a greater understanding of the patients' experiences from their perspective was necessary to answer the research question.

2.3.2 Feminist Research

Feminist research is part of a broader feminist sociology that involves research, theory and politics. Feminist research aims to "...document and describe the main social differences and inequalities between men and women." (Abbott et al., 2005) p 16. The feminist theory behind the research attempts to explain the differences and inequalities, and the politics attempts to confront and dispute the gender inequalities (Abbott et al., 2005). It is agreed that in areas of society there are gender inequalities. Moreover, where the experiences of males and females differed in this research it will not be overlooked. However, it is not the aim of this research to report specifically on inequalities and differences in those experiences with the intention of challenging these inequalities in practice.

2.3.3 Symbolic Interactionism

Symbolic Interactionism is the study of human group life and conduct (Blumer, 1969). In Symbolic Interactionism it is thought that humans act towards things based on the meaning they have attributed to them. This meaning comes from social interaction with others. Meanings are modified and changed by the interpretative process one has with those things (Blumer, 1969). Using symbolic interactionism the researcher analyses the meanings that come from the behaviour of individuals within social settings. It is understood in symbolic interactionism that individuals interpret the same objective situation in contrasting ways according to their theoretical perspectives (Lauer and Handel, 1977). Symbolic Interactionism is the study of the social meaning of their behaviour and the world they live in. The researcher sees similarities between the study of symbolic interactionism and phenomenology. They both are focused on the participant's own perspective in research according to the meanings they have attributed to things. In phenomenology the meaning comes from individual's lived experiences and perceptions related to those experiences and phenomena. Symbolic Interactionism was not used for this research because of its focus being on interaction and conduct within a group of individuals. The researcher believed that in order to study the experiences of both completers and non-completers of a PR programme, a research methodology that would initially focus on individual experiences and would be flexible in exploring differences in experience would be more appropriate. Furthermore, it was unlikely that individuals who participated in this research would be part of the same group because of the longitudinal, multicentre design of the study.

2.3.4 Grounded Theory

Grounded Theory is a methodology which fits into the broader methodology of symbolic interactionism as the researcher is interested in the way reality is socially constructed (Richards and Morse, 2007). Grounded Theory consists of systematic guidelines for collecting and analysing data in order to construct theories from that data (Charmaz, 2006). Therefore, it is of the researcher's understanding that Grounded Theory offers more of a framework compared to Phenomenology, that uses steps and strategies for data analysis. In grounded theory the decisions made to collect data are based on a general sociological perspective rather than a well evidenced literature review (Glaser and Strauss, 1967). Therefore a preliminary literature review before data collection is often not performed. Furthermore, a methodological strategy in Grounded Theory is that after the initial data has been collected, no further data collection can be planned in advance of the speculative theory (Glaser and Strauss, 1967). In Grounded Theory, theory is developed from the starting point of the research project and adapted and advanced with further data collection. The researcher did not want to construct a theory from this research. It was felt that the researcher's interpretation of a provisional reality might be modified by other clinicians or researchers based on their understanding of the phenomena. Moreover, it was necessary in this research project to have written a proposal to the School of Health Sciences at the University of Southampton. Prior to the acceptance for the PhD candidature, the School required the proposal to be supported by critiqued evidence-based research that could justify asking the research questions. Therefore, it was necessary to have performed a preliminary literature review. The researcher also had to apply for NHS Ethical Committee approval to carry out the research. As part of this ethical approval process, a plan of how many participants the researcher aimed to recruit was needed. It would have been difficult to justify to an Ethics Committee the number of participants needed if a Grounded Theory methodology was chosen, because of the restriction in the planning of data collection from the outset of the research project. It is of the researcher's opinion that if the researcher had used Grounded Theory the analysis from the data might have modified the questions that were asked and the subsequent focus of the research in later interviews. Therefore, each individual's experience may have become less unique and more attuned with others' experience in order to generate that theory. The researcher believes that phenomenology allowed for a greater description of individual experiences that might be contrasting to that of other individuals in the research because there was no need to generate a theory.

2.3.5 Postmodernism

Postmodernism as a methodology challenges the idea that the social world can be understood through some form of empirical study (Alvesson, 2002). Postmodernism is a reaction to modernism in that it is against the modernist ideas that the social world should be investigated with intentions of measurement, analysis, logic and progress that can come from studies lacking foundations of knowledge (Alvesson, 2002). It is interpreted by the researcher that postmodernism aims to critique and question "conventional" scientific methodologies which leads either to further philosophical questioning or to developing different ways of doing research. Postmodernists question the idea that research findings can be reported in a way that defines one absolute reality. The researcher shares the scepticism with which Postmodernism researchers view positivist thinking. It is for this reason that the research questions of this research aimed to build on foundations of knowledge in the field of PR research using a methodology which is not common to physiotherapy. However, the scepticism and doubting with which Postmodernists view scientific knowledge was not seen as an appropriate approach to answer the research questions. The main aim of this research is not to critique and challenge the bases and forms of research knowledge due to the lack of knowledge currently available. Therefore this knowledge base of COPD patient experiences of their PR journey needed to be created. This increased understanding will enable clinicians to treat patients with more empathy and therefore improve the quality of patient care.

2.3.6 Discourse Analysis

Within Discourse analysis there are two types of analytic methods. These are Foucaldian discourse analysis (FDA) and discursive psychology (Smith, 2008). Foucaldian discourse analysis investigates different ways the discourse object (i.e. COPD) is constructed in text or conversation (Willig, 2008). Discursive psychology looks at the way individuals use language to manage their part in social interactions (Willig, 2008). Discursive analysis is concerned with what the respondent is doing with their talk. FDA focuses on the implications of the use of discourse for the experience under scrutiny. The use of language and how people talk about their COPD would be interesting. However, the meaning in discourse analysis comes from the type of language and how it is used to describe participant experiences rather than the meaning coming from the experiences themselves. This approach was therefore rejected.

2.3.7 Conversation Analysis

Conversation analysis (CA) has similarities with discourse analysis in terms of the words which are used (particularly in conversation in CA) by participants being important, rather than what is being talking about. The object under study is talk or talk in interaction in conversation analysis. CA is “...the organisation of turn taking; overlapping talk; repair; topic initiation and closing;...” (Drew, 2008) p 134. The researcher was interested in what participants might say in an interview. However, this research study was not of the interviews themselves. Although looking at how the interaction between the participant and interviewer developed may have helped the researcher contextualize data more effectively. CA is concerned with the basic process of ordinary social interaction. The information that was collected would not have been accessible from ordinary social interaction, even though people with COPD will talk to health professionals about their COPD, the depth of questioning that the researcher was interested in would not necessarily occur in the ordinary clinical situation.

2.3.8 Narrative Psychology

Narrative psychology can be described as a method used to investigate "...the active constructing processes through which individual subjects attempt to account for their lives" (Emerson and Frosh, 2004) p 7. The researcher has not aimed to be critical specifically with the way in which individuals construct their stories about their experiences. It is the experiences themselves which were interpreted and discussed. The researcher is interested in the participants stories, not how they have been told.

2.3.9 Content Analysis

Content analysis started off as a method used by the church in the late 1600s to check for non-religious messages being spread through the newspapers (Krippendorff, 1980). The method has since been used in many other areas, such as to assess bias in literature, or the use of symbolic language in inaugural presidential speeches (Krippendorff, 1980). Early content analysis was concerned with mass communications to large numbers of people. However, this method can also be used in sociological and healthcare research. In research, it was originally used with qualitative data as a supplementary technique to cross-validate findings that were obtained from other techniques (Krippendorff, 1980). "Content analysis is a research technique for making replicable and valid references from data to their context." (Krippendorff, 1980) p 21. As a research technique, content analysis is expected to be objective and systematic. It is of the researcher's opinion that using an objective technique to analyse the experiences of people with COPD would have led to a loss of meaning of individual experiences. Moreover, this would have led to a more deductive approach to answer the research question, rather than an inductive, open and subjectively sensitive approach to the research questions. The fact that the researcher was a physiotherapist working in the clinical team where the research was performed undoubtedly affected how the research was performed and analysed. This is seen as a strength of the Clinical Academic PhD candidature and these issues should be addressed, communicated and celebrated. Content analysis as an objective tool, would not have allowed for the type of communication that the researcher felt was needed.

2.4 Phenomenology

The above methodologies and methods were not chosen for this particular research. Upon analysis of the different methodological approaches that could be used for this research, the researcher chose to use a phenomenological methodology. Phenomenological research methodology and the concept of reflexivity will be introduced in the next section. Different types of phenomenology will be described and the researcher provides a discussion regarding complex elements of phenomenological research. These areas include intentionality, bracketing, respondent validation, methodology and method, and quality in phenomenology. The phenomenological discussion then continues with a description of Interpretive Phenomenological Analysis and concludes with a description of other methodological influences. The development of these influences into this research will be explained in the Method chapter.

Phenomenological research methodology aims to describe how phenomena are experienced by those who are being studied (Denscombe, 2003). Phenomenology focuses on exploring people’s perceptions, meanings, attitudes, beliefs, feelings and emotions (Denscombe, 2003). This methodology emphasises the importance of subjectivity, description, and interpretation in the research process. Therefore, reflexivity is used extensively. Reflexivity is the process through which the researcher explores and examines how one’s own thoughts and actions impact on, change or develop one’s research (Finlay, 2002). Introspective and intersubjective reflexivity accounts are used as they employ a descriptive nature and fit within a phenomenological methodology (Finlay, 2002). Through reflexive practice, this research aims to enable healthcare professionals to have an increased connectedness with their patients in PR as they see them and hear them with greater understanding of their lived experiences (Finlay and Molano-Fisher, 2008).

There are different types of phenomenology including transcendental, existential, hermeneutic, linguistic, and applied phenomenology (van Manen, 2002). The researcher has been influenced by reading the works of Heidegger, whose phenomenology is hermeneutic, Merleau-Ponty and Sartre, whose phenomenology is existential, and van Manen and Barritt et al whose phenomenological is applied (Heidegger, 1962, Sartre, 1969, Barritt et al., 1983, Langer, 1989, van Manen, 1990). Transcendental phenomenology would not have been appropriate for this research because it is the study of the essences of one's own consciousness and necessitates that the primary focus of the analysis is of one's own perceptions. A linguistic phenomenology was not chosen as it is seen by phenomenologists, such as Derrida and Foucault, that meaning is linguistic and comes from words rather than lived experience or consciousness (van Manen, 2002). The phenomenology that was used for this research has been labelled as applied interpretive phenomenology. This phenomenology is now justified further.

Phenomenology was a philosophy that was originally pioneered by Edmund Husserl as a science of the ego (Moran, 2005). Martin Heidegger was a student of Husserl, but his philosophy differed from Husserl in that he saw phenomenology as a hermeneutic process whereby the phenomenological descriptions are viewed as being interpretations of the lived experience rather than of the consciousness. According to Merleau-Ponty, the task of phenomenology is to help us to see the primordial bond (the relationship between thought and object and the way they are situated in the world) more clearly and to bring it to our attention (Langer, 1989).

It was necessary that this research could be practically applicable. Both van Manen and Barritt et al believe, that as an interpretive process, phenomenology can be used by professionals to study phenomena as experienced by others (Barritt et al., 1983, van Manen, 1990). These authors come from an educational background and were interested in pedagogy, the study of teaching or process of teaching. However, the same principle of professionalism could be applied to physiotherapy. The aim of this PhD candidature was to increase the researcher's understanding of the participants experience of COPD and PR. Palmer (1969) asserts that understanding is both an epistemological and ontological process. Nevertheless, consensus does not exist in social sciences about the best application of phenomenology (LeVasseur, 2003, Giorgi, 2008). For example, according to Annells (1999), phenomenology can be used across all research paradigms. Furthermore, it is rarely mentioned how to translate the philosophical phenomenological theory into research practice and that is why potential problems may occur when conducting a phenomenological study (Giorgi, 2008). There is also still a lack of clarity in phenomenological methodology (Pringle et al., 2011). In the next section potential problems have been addressed in view of the researcher's understanding of the literature and its effect on this research methodology.

2.4.1 Intentionality

Intentionality is a concept whereby when somebody thinks or acts, they do so towards something. This intentionality is significant for the researcher and those who are being researched. The researcher has many intentions why this research was performed which were introduced in the previous chapter. In order to gain a PhD candidature, this research must be evaluated by individuals who will judge it against their own certain academic standards and those of the institution. The researcher wanted the findings from the research to be applicable to physiotherapy practice, and to the care of COPD individuals who get referred to PR. Participants were involved in the research based on the researcher's intentionality. However, participants' intentionality may not be the same as the researcher's and they may not have focused their intentionality towards physiotherapy practice or PR. Their intentionality for participating may have been very different. It was important for the researcher to keep both his intentionality and that of the participant in focus in order for the researcher to understand each participant’s motivations and reasons for participation in context with the study as a whole during analysis.

In order for the research to have an impact on clinicians who could use the findings from this research it must be easily understood by those clinicians (Annells, 1999). The researcher’s assumption is that this requires the research findings and discussion not to be overladen by philosophical underpinnings and related theoretical analysis. This is a possible limitation to the phenomenological component of the study. However, this could be seen as a strength of the clinical applicability of the study. The participants’ intentionality towards participating in this research must also be taken into account. Their motivations may have been directed towards seeing benefits for other people rather than themselves in participating, or just grateful for help in the past and wanting to give something back (Willis et al., 2011). Participants may have been lonely and keen to have some company.

According to Pringle et al. (2011), the researcher was not fully an insider in the research process because he does not have COPD and was unknown to the research participants prior to commencing the research. However, he was not fully an outsider because of his work as a physiotherapist for four years in the context within which the research was performed. The perceived role of being an insider or outsider may have a significant impact on the way in which the participants conduct themselves in front of the researcher. Because of this, reflections were kept throughout the research process which will be explained further in the methods chapter. Nevertheless, as a research student, the researcher would have been seen as an “outsider” by participants in this study.

2.4.2 Bracketing and the Hermeneutic Circle

Bracketing enables the true essence of phenomena to be illuminated by the suspension of judgments and assumptions of the researcher (LeVasseur, 2003). Bracketing is a concept that is used in transcendental phenomenology to put aside all existential knowledge and opinions so that the phenomena can be studied as how they purely present to us in our consciousness (LeVasseur, 2003). Bracketing is a method used in phenomenological reduction in order to get to the essence of phenomena. This is a fundamental concept in descriptive phenomenology. However, existential and hermeneutic phenomenologists believe that consciousness can not be separated from existence, or what Heidegger calls our “being-in-the-world” (Heidegger, 1962). Therefore, it is understandable why interpretive and existential phenomenologists believe that it is an unachievable task to use bracketing as a way of phenomenological reduction to get to the pure essence of a phenomenon. However, LeVasseur (2003) argues that bracketing can be used in interpretive phenomenology if one limits bracketing to that of the natural attitude or our lack of curiosity about our experiences. In this research, the researcher maintained a curious attitude towards the research participants and phenomena. This enabled the researcher to be attentive to new experiences without taking things for granted which, as a result opened up new meaning possibilities (LeVasseur, 2003). However, in the researcher’s opinion this was not bracketing. The researcher’s presuppositions and experiences form a significant part of development of this research project which necessitates an interpretive approach. Therefore, bracketing could not be achieved.

The researcher’s prior experience and presuppositions were thought of as essentially valuable in the learning experience during this PhD candidature. Rather than bracketing, a hermeneutic circle of inquiry was used. There are many types of the hermeneutic circle including linking parts of a text to the whole, between the interpreter and the object of interpretation, the reader and the author, and between pre-understandings and understandings (Heidegger, 1962, Shinebourne, 2011). Levasseur (2003) asserts that the bracketing of the natural attitude of incuriosity can be used as part of a hermeneutic circle. The problem with this is how those brackets are taken away following the phenomenological analysis in order for the uncurious attitude to be reformulated within the circle and presented as part of the final interpretive account. The researcher believes that an answer to the problem was not sufficiently described by Levasseur (LeVasseur, 2003). The researcher believes that the main aim of bracketing is to reveal the essence of phenomena as it presents itself to the consciousness. This transcendental reduction which suspends experiential knowledge opposes the philosophies of existential and hermeneutic phenomenologists and is somewhat of an idealistic ontological assumption. It appears that the aim of the discussion by Levasseur is to show that bracketing can be used as a method across phenomenological methodologies (LeVasseur, 2003). However, it still remained unclear how bracketing should be employed methodically within a hermeneutic framework.

Hermeneutics can be viewed as the art or science of interpretation (Palmer, 1969). Phenomenology is the study of lived experience as previously described. Heidegger believed that hermeneutics was central to the ability to study lived experience and brought the two concepts together in his existential phenomenological ontology “Being and Time” (Heidegger, 1962). There remains confusion in the existing literature regarding whether bracketing can be used within a hermeneutic context. The researcher believes that this is because hermeneutics and phenomenology have had different aims for a significant period in history. Bracketing was not conceived as being part of the science of interpretation. Likewise, the hermeneutic circle was not conceived as being part of the exploration of lived experience. They are two separate methods but appear to share similarities. A broad, practically applicable explanation of bracketing has been well described as a set of reductions by van Manen (van Manen, 2002). Van Manen appears to develop the understanding of bracketing from its original purpose of eidetic reduction and provides other forms of bracketing which can be compared to some parts of the hermeneutic circle. Table 2 provides a description of various types of bracketing.

2.4.2.1 Bracketing

Eidetic reduction	Bracketing the incidental and particular aspect of a lived experience in pursuit of the invariant meaning and the essence of the phenomena.
Hermeneutic reduction	Bracketing the pre-understandings

	and motives for doing research
Heuristic reduction	Bracketing the taken-for-grantedness of the research phenomena in order to approach phenomena with a sense of wonder.
Methodological reduction	Bracketing all existing investigative methods in order to use a method most appropriate to study the particular phenomenon.
Ontological reduction	Bracketing moral theories and ethics to see what the phenomena is other than our predefined concept of being.
Phenomenological reduction	Bracketing all abstraction, theorizing or generalisation in order to illuminate the lived meaning.

Table 2: Types of bracketing

2.4.2.2 The Hermeneutic circle(s)

The diagram below has been created by the researcher to show different elements of moving in and out of a hermeneutic circle that were applicable to this study. There are various aspects of the hermeneutic circle described by Gadamer (Gadamer, 1989), who draws on its history of development. Different ways in and out of the hermeneutic circle include, linking parts of a text to its whole, linking researcher fore-understanding to new understanding, the relationship between the reader, the text and the author, and an awareness of a distance in time between what has been written and what is interpreted. The arrows in the diagram show that one can move in and out of the hermeneutic circle relating to different stages of the research process.

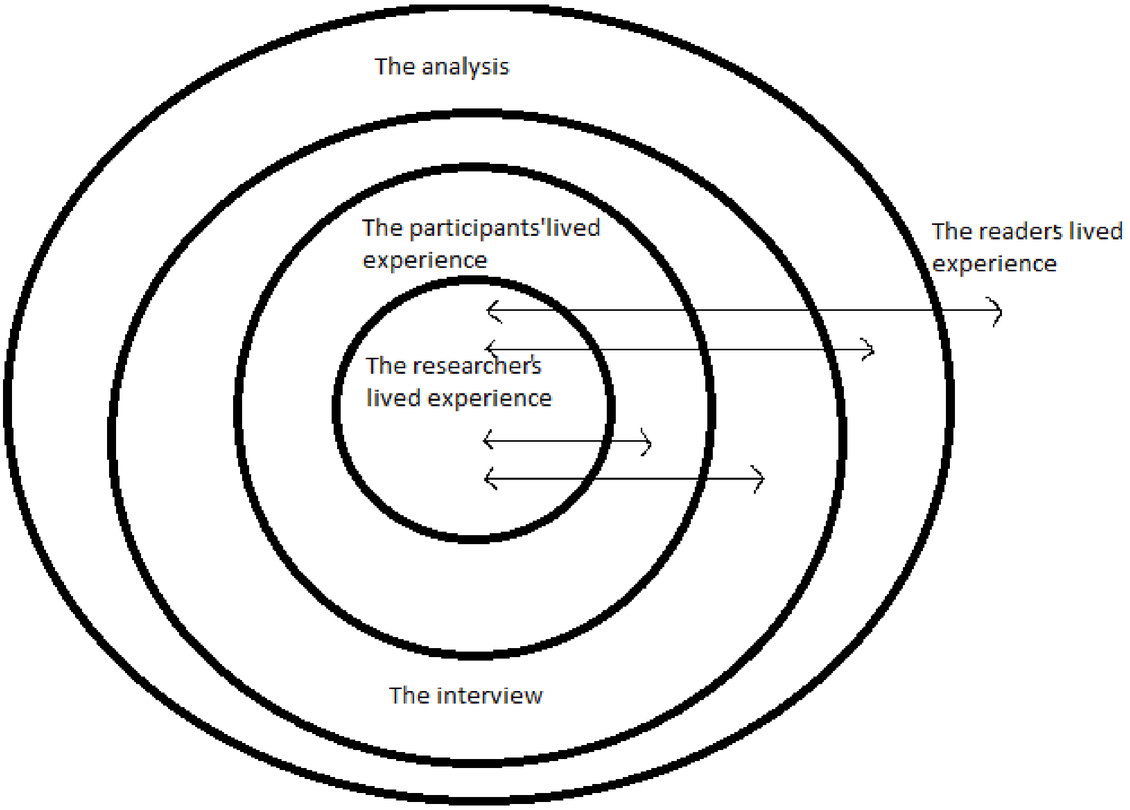


Figure 3: The Hermeneutic Circle(s)

The researcher aimed to use a hermeneutic circle of inquiry to separate clinical interpretations of the research process from the phenomenological interpretations. In this way, data would not be too easily reduced by interpretations from the researcher's own presuppositions. The researcher does not believe that bracketing should be used as way of suspending one's judgements. Rather, because of the clinical application of this PhD candidature, these judgements and presuppositions were used in the interpretation process.

2.4.3 Respondent Validation

Respondent validation has also been described as participant feedback or member checking (Bradbury-Jones et al., 2010). These terms can all be used to describe the process of returning findings from a study to participants in order for them to validate their accuracy (McConnell-Henry et al., 2011). Bradbury-Jones et al (2010) state clearly that the benefits of participant feedback clearly outweigh the disadvantages. Such advantages that were presented include the ability to negotiate meaning between participant and researcher, giving participants the opportunity to correct meanings that may have been misinterpreted and enabling participants to provide additional information. One limitation to their paper is that in all the research they presented, no participants disagreed with any of the findings that were presented to them. Therefore, in the researcher's opinion they did not achieve what they set out to achieve, namely an enriched hermeneutic interpretation based on improving a hermeneutic circle of inquiry. Rather, the authors seemed to be objectively validating the findings from a positivist perspective. Furthermore, much of the justification for using respondant validation came from the work of Lincoln and Guba, based on research methods aligned with descriptive phenomenology, or on the idea that vicarious learning may occur when doing phenomenology (Lincoln and Guba, 1985). The quality criteria to assess rigour in qualitative research provided by Lincoln and Guba may not be appropriate for the assessment of interpretive phenomenology in healthcare (Lincoln and Guba, 1985, de Witt and Ploeg, 2006, Sandelowski, 2006).

McConnell-Henry et al. (2011) are against using respondent validation in phenomenology. According to McConnell-Henry et al. (2011) the aim of phenomenology is to develop an understanding of what it is like to live experiences empathically. In Heidegerrian phenomenology truth is multiple and context specific. Therefore an interpretation can alter depending on the context in which it is viewed (McConnell-Henry et al., 2011). The potential for the 'Halo effect' must be taken into account where participants want to say the 'right' thing in front of the researcher and also overemphasise important aspects of their own experience to ensure it is part of the 'true' interpretation of the phenomenon (McConnell-Henry et al., 2011). There is also an ethical argument not to revisit subjects with participants and leave them at ease with what they have previously said, particularly if the topics are sensitive (McConnell-Henry et al., 2011). Dearnley (2005) states many difficulties with returning transcripts back to participants following their interviews which overall made the authors feel the approach was not worth pursuing in their future work. Corben (1999) also states that the data should be left to stand alone, unchallenged, because that is the nature of the phenomenological method. This is against the idea of participant verification. It is how that phenomenological account is interpreted that has power. Therefore participant verification was not used in this study.

2.4.4 Methodology and Method

The phenomenological methodology that was deemed to be appropriate to use for this study positions itself predominantly within a constructivism paradigm according to the description provided by Annells (1999). Therefore, the researcher was tentative in making generalisations and the illumination of the circumstances under which understanding took place was more important than defining the process of understanding (Todres and Wheeler, 2001, Dowling, 2004). Rather than triangulation or crystalisation, Standing (2009) suggests what is more appropriate in hermeneutic inquiry is bricolage, which was interpreted as being able to use well established techniques but not being bound by a particular method. Bricolage allows the phenomena to determine if new techniques or approaches may be warranted (Standing, 2009). This approach seems to come from the idea that phenomenologists do not prescribe methods but are more philosophical than methodological and may view prescriptive methods as potentially restricting the transmission of new ideas (Barritt et al., 1983). Similarly, Campbell and Scott (2011) state that one of phenomenology’s strengths is its flexibility and the context of research is just as valuable in phenomenology as its process.

2.4.5 Quality in Phenomenology

The findings in phenomenological studies are valid if they are presented in a way which accesses the life-world of the participants in a similar way to that in which Heidegger was able to achieve (Todres and Wheeler, 2001). Time is the central concept to lived experience (Standing, 2009). Using non-scientific language also humanises the phenomenon which is central to a deeper understanding in empathic lived experience (Todres and Wheeler, 2001).

The researcher views bracketing and participant verification as tool options for researchers that help tick boxes that other researchers, less attuned to the nuances of phenomenology use to judge the research quality from a more positivist sphere of influence. In a similar way of thinking de Witt and Ploeg (de Witt and Ploeg, 2006) state that persuasive reason is required over rigour in interpretive phenomenology.

2.4.6 Interpretive Phenomenological Analysis

Another phenomenological approach that has been used extensively in healthcare is Interpretive Phenomenological Analysis (IPA)(Smith, 2008). However, little IPA work has been mainly carried out in preventative health behaviour or health promotion (Smith, 2011). Smith (2008) recommends a sample size of three participants in order to allow for sufficient depth of engagement in the analysis. This was seen as an approach that is more ideographic. Ideographic analysis is focused on studying individuals' experiences without emphasis on comparison of experiences between individuals. However, Barritt et al. (1983) suggest that the less experience of phenomenological research the researcher has, the more material they will need to use in order to understand the phenomena. Furthermore, in order to develop the hermeneutic circle of inquiry a larger number of interpretations of the lived experience of COPD and journeys through PR were justified. A greater ability to question in an open-minded approach would be possible by linking more parts to a whole story and subsequently enabling a development of understanding and critiquing pre-understandings.

In IPA a purposive participant sample is recommended (Smith, 2008). Purposive sampling is a sampling strategy in recruitment that aims to get characteristics in the participant population that are strategically designed to answer the research question (Bryman, 2008). For example, in COPD this might include a sample of COPD individuals who smoke, or those with a certain severity of airflow limitation as defined by diagnostic testing. It was thought that a convenience sampling method would be more appropriate for this research. This was because of the time limitations attached to the Clinical Academic PhD candidature and the researcher’s need to perform practically applicable research. Therefore, the quicker participants could be recruited, who had been referred to a PR programme as part of their normal care in NHS Trusts, the better the recruitment process would be. Other COPD and PR studies have excluded patients with comorbidities and stages of COPD disease severity according to spirometry. This is seen as a limitation to practically applicable research. The convenience sampling in this study did not use any of these exclusion criteria. Therefore, the researcher attempted to explore the lived experiences of a broad range of individuals with COPD who had been referred to PR. Smith (2008) and Corben (1999) both suggest that phenomenology requires a sample that is purposive to optimise the possibility of participants experiencing the particular phenomenon to be studied. Sampling was purposive in this sense because all participants who were approached to enter the study had COPD and were referred to PR. However, unlike IPA, the sampling had the potential to be heterogeneous. The power of the research comes from maximal variation because the research aimed to explore the experience of participants completing and not completing PR. It would not have been possible to predict which recruited participant would complete or not. Therefore purposive sampling for completion or non-completion of PR would not have been appropriate. Furthermore, by using consecutive convenience sampling it was perceived there was a greater possibility that participants may have been on the same rolling programmes together and may have had shared experiences which would sharpen the context within which this research was performed.

Problems exist with previous research in COPD because research has been focused on a homogeneous phenotype of COPD that has not necessarily allowed the full understanding of experience from different COPD patients’ perspectives. A heterogeneous sample of COPD patients is likely to better represent what occurs clinically and therefore was more relevant to this clinically applied methodology. Due to the particularly ideographic nature of IPA and its purposive sampling, IPA was not followed specifically, although some of the phenomenological principles in this research are similar to that of IPA.

2.4.7 Reflexivity and practical applicability

Phenomenology is a reflexive practice. Van Manen (2007) states that the power of phenomenology comes from the pathic reflections from practice. Pathic reflections are those that are "…relational, situational, corporeal, temporal, actional." (van Manen, 2007). Reflections should be pathic because as competent healthcare professionals we act in a pathic manner in order to treat our patients effectively with compassion (van Manen, 2007). Pathic knowledge is the humanised caring attitude (Annells, 1999). Barritt et al. (1983) discuss that one should attempt to look at phenomenological research with fresh eyes, which is similar to an approach with the sense of wonder (van Manen, 2007). By viewing the research with fresh eyes and a sense of wonder, the researcher interprets that they are adopting a caring attitude. In this caring attitude biases are questioned in favour of understanding the patient's experience from their perspective in lay language and experience. Both Barritt et al and van Manen view the purpose of these reflections to further practice, rather than philosophy itself (Barritt et al., 1983, van Manen, 1990). This is because they are using phenomenology to empower their professional practice rather than develop phenomenology as a discipline in its own right. Consequently, Barritt et al. (1983) describe this as performing research with an eye to the consequences for action. Likewise, van Manen (1990) states that the impact of phenomenological research should be for those people who are being cared for by that particular profession. The researcher believes these are similar ideals.

Van Manen (1990) recommends reflecting on the essential themes which characterise the phenomenon whilst maintaining a strong and oriented professional relation to the phenomena. The researcher believes it is difficult to both maintain this sense of wonder and maintain a strong professional relation to the phenomena if the researcher's own professional experience can be related to contrasting perspectives discussed by research participants. However, rather than a limitation, it was the researcher's aim as part of a reflexive approach, to show how the presence and influence of the researcher in this research was a resource to be capitalised upon (Holliday, 2002). Indeed, as part of a clinical academic PhD candidature, the researcher’s role as a clinician is designed to improve the applicability of the research findings.

Van Manen (1990) states that in applied phenomenology it is necessary that a unique method for a unique setting is appropriate in order to gain an understanding of the meaning of the lived experience for those studied. It is also recognised that within qualitative research, methods should be sufficiently flexible to be suitable for the individual nature of the social setting in which the research is being performed (Holliday, 2002). Moreover, Barritt et al. (1983) warn the researcher that they had to make changes to their research practice often without significant preparation due to unforeseen circumstances in the research setting. The research method used for this research was therefore not identical to any prescribed method used by another researcher. However, it has been justified in terms of it answering the research questions, its methodological principles and the unique setting in which this research has been performed.

Phenomenology was chosen because it explores experience in a particular way as justified in this chapter. Therefore the research questions were worded to suit the phenomenological perspective. The participants in this research did not have their experiences observed directly by the researcher as part of the research method. Rather, it has been accepted that what participants described as their experiences are experiences that have actually happened for the participant and are their reality. Questioning the truth of their experiences would be more of a positivist research exploration.

2.5 Conclusion

In order to answer this research question an interprevist epistemological stance was adopted. The ontological position of the researcher is constructionist. The research methodology chosen within this framework was one that can be described as applied interpretive phenomenology. The particular method used for this research will be described and explained in the following chapter.

3. Method

This chapter describes how the researcher carried out the research process. Methodological principles discussed in the previous chapter will be referred to at points to explain how they were adopted for this research.

3.1 Design

This study used a qualitative, multi-centred semi-structured interview design. Twenty five participants were recruited from two separate research sites and were interviewed before they were assessed by a clinician to enter a PR programme. These pre-programme interviews are described as phase one of this two phase study. Fifteen of these participants were interviewed again after the PR programme to which they had been referred had ended, irrespective of whether they participated in that PR programme or not. The 15 interviews that were performed post-programme will be referred to as the second phase of this two phase study. All interviews were conducted by a single researcher.

3.1.1 Research Sites

Two research sites were deemed to be needed to recruit a possible 25 participants within the time frame given for the study. Two research sites also allowed for the exploration of the patient experience in a different context, thereby pursuing a phenomenological variation (Barritt et al., 1983). These research sites have been anonymised as PR programme A and B.

At the time of applying for ethical approval for this research to be carried out with NHS patients, the PR programmes in programme A were run in two venues. The programmes consisted of two hour sessions twice per week for six weeks with the maximum staff to patient ratio being 1:7. The PR programmes worked on a rolling basis to optimise patient numbers in the programme. This means that as soon as a patient finishes their programme, another patient can start on that programme. In this way, if somebody drops out of the programme a new patient can start the programme the next session. New patients were referred on a regular basis to the PR programmes by health care professionals working within a local respiratory centre within a district general hospital, and by local general practitioners (GPs), practice nurses and community nurses.

The PR programmes run by Programme B ran in 4 different facilities. The PR programmes comprised one and a half hour sessions, twice per week for seven weeks. The maximum staff to patient ratio in the programme in one of the centres was 1:6. The other programmes had a maximum physiotherapist to patient ratio of 1:8. All referrals to Programme B come from GPs, practice nurses, district nurses, physiotherapists, occupational therapists, consultants, and community matrons. At the time of receiving ethical and Research Management and Governance approval, Programme B offered block programmes. In the block programme six to eight patients would start and finish a programme at the same time. Other details of the relevant PR programmes can be found in Table 3 below. Table 3 includes some changes which occurred from the time research approval was gained to when participants completed the study.

Pulmonary Rehabilitation Programme A	Pulmonary Rehabilitation Programme B
• PR programmes operated on a rolling basis	• *PR programmes operated on a block basis and changed to rolling basis*
• Physiotherapist and nursing involvement throughout programme	• Physiotherapist led programme
• *6 week programme changed to 10 week programme*	• 7 week programme
• *X 2 weekly 2 hour sessions (6 week programme), X 1 weekly 2 hour session (10 week programme)*	• X 2 1.5 hour sessions
• *Dietitian, Department of Work and Pensions staff and Pharmacist supporting education sessions to sessions performed by physiotherapist and nurse running PR*	• Occupational Therapist, Community Matron, Department of Work and Pensions staff and Dietician involved in supporting education sessions.
• Patients exercise independently per circuit exercise.	• Patients exercised in pairs per circuit exercise.
• Exercises were time controlled by staff	• Exercises were repetition controlled by patients and time controlled by staff
• Walking component	• Walking component
• 1 available maintenance programme.	• 4 available maintenance programmes
• No preliminary education event	• Preliminary education event attended by some patients prior to referral to a programme.

Table 3: PR programme content, structure and development

Changes were made to these clinical programmes that could have not been predicted prior to initiating participant recruitment. These have been highlighted in italic text in Table 3 on the previous page. In programme A the only full-time member of staff left the team and was not replaced. The researcher rotated out of the team for four months of the recruitment process to gain clinical experience of the care of acute exacerbations of COPD when COPD patients are hospitalised. The additional support to PR programme A by external members of staff was also cut because of changing budgets in the relevant department and maternity leave. In Programme B the block programmes were changed to rolling programmes to increase patient throughput in the programmes.This allowed more efficient use of the available spaces on the programmes. The researcher was not made aware in any of the subsequent participant interviews whether they had attended a block or rolling programme. This information was not recorded at the time of patient recruitment and is not information that is kept on patient PR records. Unfortunately, this is a limitation to the contextualisation of the study for participants interviewed in programme B.

3.1.2 Inclusion Criteria

Patients were included in this study if they were over the age of 18 and had been referred to the Southampton City Primary Care Trust and Portsmouth City Teaching Primary Care Trust PR programmes. Patients had to be referrred with a written diagnosis of COPD on their referral form.

It was decided that the COPD diagnosis did not have to be confirmed by spirometry. This was because at the time of gaining approval for this study, it was observed that the majority of referrals coming to the Community COPD Team (where the researcher was working clinically) were not accompanied with spirometry printouts. The inevitable consequence of this decision is that it is possible that some patients labelled as having COPD may have had a different condition.

3.1.3 Exclusion Criteria

Patients who had previously participated in a PR programme were excluded from this study. Patients who had already been seen clinically by the rehabilitation team were also excluded from this study. This was discussed over the telephone with the participants after they had registered their interest in taking part in the study. This was because it was thought by the researcher that the experience of being referred to PR when you have already participated in it would be different to those participants who have not experienced it. The researcher wanted to understand the participant experience before they had been seen clinically for their rehabilitation as there is a limited understanding in the literature of this particular stage of the participant's journey through rehabilitation.

It is common in randomised controlled trials for other exclusion criteria to be used, including the exclusion of patients with significant comorbidities (Rothwell, 2005, Halpin, 2010). One reason for patients with comorbidities to be excluded from controlled trials is because of the researchers' attempt to ensure as homogeneous a sample as possible. Exclusion criteria are also set because certain comorbidities may impact on the efficacy of the drug which is to be trialled in the particular cohort, therefore affecting the trial's internal validity. However, in qualitative research heterogeneous samples may be more appropriate to answer the research question, particularly if the research is directly performed within current clinical practice (Patton, 2002). The presence of comorbidities was seen as a commonly occuring phenomenon in clinical practice with patients who were referred to PR, and these patients were not necessarily excluded from participating in PR clinically. Therefore it was decided to include people into this study who could potentially have had significant comorbidities.

3.2 Procedure

3.2.1 Ethics

NHS Ethical approval for this study was gained from the Southampton Research Ethics Committee B (Ethics number 09/H0504/33) in May 2009. Further details of the ethical approval can be found in the appendices.

3.2.2 Ethical Issues

Patients with more severe COPD are likely to become breathless when talking continuously, due to the airflow limitation experienced when they exhale. People talk only during the exhalation stage of the breathing cycle. In fact, this airflow limitation during exhalation and the disability that derives from it, forms the clinical diagnosis of COPD. Therefore, participants were given as much time as they needed to answer questions without getting breathless. This was discussed when the researcher briefed the participant before the interview and they were encouraged to take their time when answering the questions and reassured that they could rest or take a break should they have felt uncomfortable. During the data collection some participants did get breathless when talking about their experiences. The researcher intervened in these cases and encouraged the participant to take their time and rest, offering to pause or stop the recording. No participant wanted the researcher to stop the recording and all were keen to carry on with the interview.

Participants had the right to withdraw from the interview at any time. It was thought that because the researcher is a qualified physiotherapist working with COPD patients, he would have been sensitive to whether the participants were getting out of breath. Objective physical changes such as the use of pursed-lip breathing, accessory muscle use and the inability to finish sentences would be ways of measuring how out of breath participants were getting.

The aim of the interviews was to explore participants' views and feelings toward PR and their experiences of COPD: this led to participants discussing sensitive and emotional information. Any issues that appeared to cause distress were deliberately not re-addressed in the interview by the researcher. This may have limited the depth of data collection on particular topics that were meaningful to the participants but were deemed too sensitive to pursue during the interview. For example, one participant did not want to continue a discussion about her thoughts on dying. It was felt by the researcher that this was causing the participant much anxiety and significantly affected her lived experience of COPD. However, her choice was respected and the issue was not pursued.

The researcher was working in the same environment as one cohort of the potential participants. The researcher worked clinically as a physiotherapist in Programme A. If the participants were due to see the researcher on a clinical basis, they were not included for research purposes, so that their clinical treatment was not delayed.

There was a very low risk that participants could have been harmed during the interview process. The only potential harm that could have been caused would have been distress. However if the participants did feel that they had been harmed by the interview process the University complaints procedure was in place and details were made available. In the event of the participant becoming overly distressed, the researcher offered to stay with the participant whilst they recovered. It was apparent that two participants did become distressed during the course of the interview as they started to cry and therefore the researcher offered to stop the interview procedure but both participants wished to continue. However, the participants subsequently recovered and agreed to be interviewed a second time following their initial interview.

3.2.3 Research Management and Governance

NHS Research Management and Governance approval was gained from the appropriate NHS Trusts for PR programmes A and B by July 2009. Access to participants was gained through the NHS Research Management and Governance application.

3.2.4 Recruitment Process

Individual potential participants were identified by members of staff in each of the PR programmes. The researcher worked for programme A and therefore, individual referrals for PR were identified by other members of staff in that team. These referrals were then screened by a Band 6 or Band 7 respiratory physiotherapist or nurse to check the appropriateness of the patient referral for PR. If the referral was deemed appropriate an invitation letter, the information sheet and reply slip was sent to the potential participants' home addresses. In Programme B referrals were reviewed by a band 6 physiotherapist. If appropriate, the invitation letter, the information sheet and reply slip were sent to the potential participants' home addresses by the clinical team’s secretary.

A convenience sample was used in order to be representative of the heterogeneity in the COPD patient population (Calverley and Rennard, 2007). It was estimated that interviewing 25 participants would enable 15 participants to be interviewed after their PR programme had ended for the purposes of the second phase of the study, allowing for potential attrition or demise. It was decided to interview 25 people before PR because, based on the available methodological literature, the researcher thought that this would be the maximum number needed to gain sufficient phenomenological variation in participants’ lived experience of COPD (Creswell, 1998, Fraser et al., 2006, Hasson et al., 2008). Fifteen pairs of interviews were deemed an appropriate target because it was felt by the researcher that interviewing more than 15 people over two interviews would have been impractical if the intended depth of the analysis of these interviews was to be maintained. Below is a schematic diagram of the recruitment process (Diagram 1).

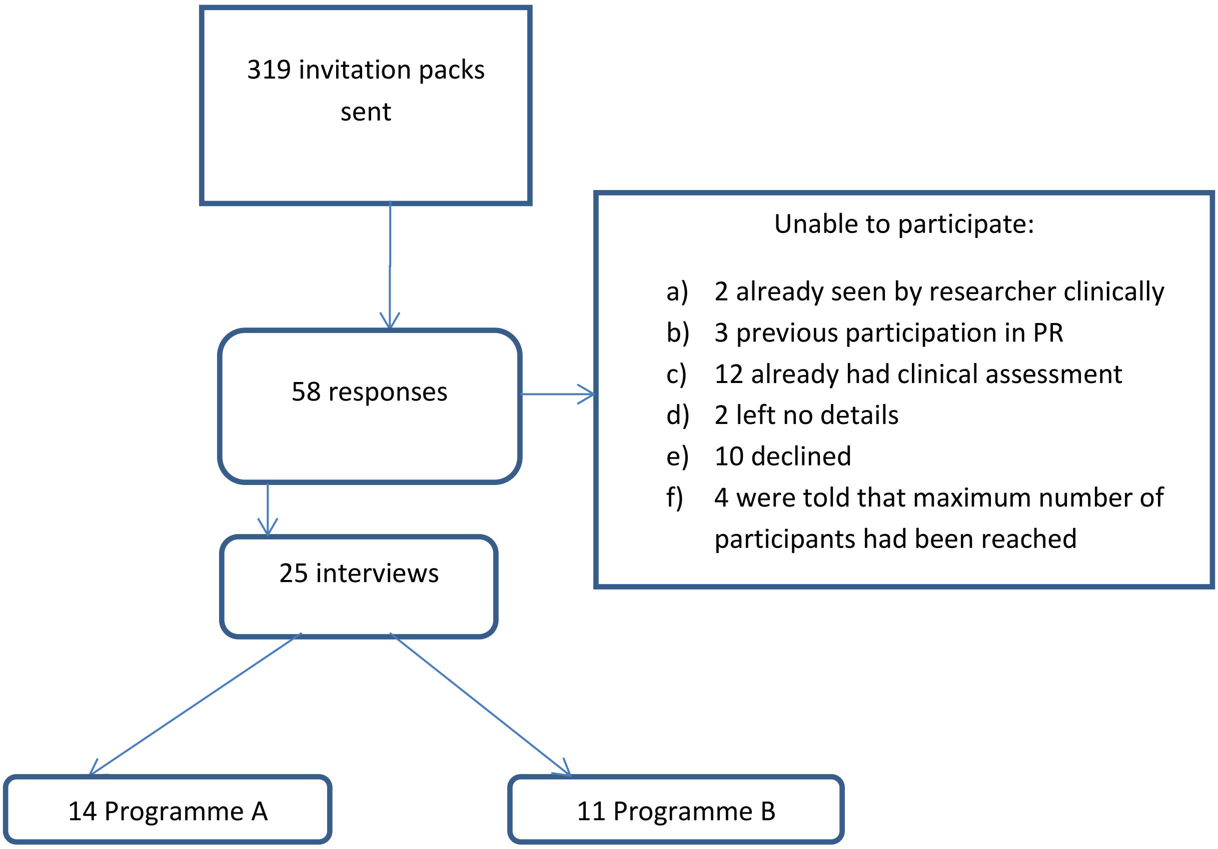


Diagram 1: Participant journey through the interviews

Research and Development approval was gained a month earlier for PR programme A than for programme B. Due to the funding limitations and consequential time restrictions in completing this PhD candidature, recruitment was started as soon as possible. Therefore, participant recruitment started a month earlier in Programme A. It is felt that this is probably the reason why more participants were recruited from Programme A.The recruitment period for both programmes lasted seven months, from July 2009 to February 2010.

3.2.5 Interview Schedule

The interview schedule was developed in four ways. Firstly, questions were developed from reading previous studies related to patient perceptions and experiences of PR which are discussed within the literature review chapter. The phraseology used was then modified after reading the methodological literature to ensure that questions were focused on participants' experiences from their perspective rather than the researcher's perspective. Thirdly, in hindsight, although not a specific stage in the development of the schedule, it is felt that the clinical experience of the researcher influenced some of the questions that were asked. Fourthly, discussions with the supervisory team enabled the supervisors perspectives on COPD patients and qualitative semi-structure interviewing to further develop the schedule. Below is a summary of the questions included in the interview schedule before pilot interviews were performed (Box 1):

Box 1: Summary of questions in interview schedule

Tell me a little bit about yourself.
When did you first notice problems with your breathing?
How often do you see your GP? Respiratory consultant?
What sort of medication are you on at the moment?
How well do you feel your condition is being managed?
What do you know about your breathing?
What thoughts do you have about your ability to cope with your breathing problems?
How does this make you feel?
When did you first hear about pulmonary rehabilitation?
Where did you hear about pulmonary rehabilitation?
What do you know about it?
What did your GP/Consultant/nurse tell you about pulmonary rehabilitation?
What choices were discussed by your GP/consultant/nurse for your pulmonary rehabilitation?
What are your views on pulmonary rehabilitation?
Do you have any concerns?

3.2.6 Pilot Interviews

Two pilot interviews were carried out by the researcher to test the semi-structured interview schedule. The pilot interviews involved: interviewing the research supervisors to increase the researcher's confidence in performing interviews, and to pilot the use of the recording equipment and notepad. In the second pilot interview an individual who had a lung condition (who was known to one of the supervisors) volunteered to be interviewed. This interview provided the researcher with a better understanding as to whether the interview questions were understandable and relevant.

Changes were made to the semi-structured interview schedule following the pilot interview. Certain questions were removed from the initial schedule, which appeared to have come from a clinical rather than research interest, such as how often do you see your GP? Questions were put into themes of COPD and PR. Subthemes were then developed. Other questions were subsequently added to the schedule. Those included:

1) Would you like to know more about your COPD?
2) Tell me a little bit about your social activity
3) Do you know other people with COPD?

The final interview schedule can be found in the appendices (Appendix 13).

3.2.7 Interview Preparation

Participants were given the choice of whether to be interviewed at home or within the University of Southampton. These choices were given to increase the chance of potential participants wanting to be interviewed. Five participants were interviewed at the university and 20 were interviewed in their homes. If the participant chose to be interviewed at the University of Southampton they would have had to pay for their own travel costs to and from the University. Once the researcher received each of the reply slips, every referral that the researcher received was numbered in order of potential participant contact with the researcher. Therefore the first potential participant to contact the researcher was numbered 01 and so on. The personal identifiable information was stored separately from any other data provided by the research participant during the interview, which was stored in a participant case record file. Each file had a corresponding number to the participant contact number.

All potential participants were telephoned on the day and time that they indicated convenient for them as indicated on the reply slip. During the telephone call the researcher would ask:

1) Have you participated in pulmonary rehabilitation before?
2) Have you already been seen at your clinical assessment to enter pulmonary rehabilitation?

After these questions had been answered, the researcher arranged a time and date that would be appropriate for the participant to be interviewed. Participants were given the choice whether they wanted written confirmation of the interview details. For those participants being interviewed at the university, a University of Southampton campus map was sent by post after the telephone call. Within the 24 hours before the interview the participant was telephoned again to confirm they still wished to participate, and to check whether any unforeseen events had occurred since the original telephone call that would prevent the interview being conducted. A lone working policy document was then written and handed into the School of Health Sciences Research office (Appendix 11). Attached to this document was a sealed envelope entitled “Adam Lewis Research Information (date)”. Enclosed was the participant name, home address and telephone number, should anything have gone wrong in the interviews. The dictaphone was then checked for how much battery it had left. Spare batteries were always taken to each interview. A new digital file was used for each interview. It was checked that the mode used on the dictaphone was switched to dictaphone. To each interview, the researcher took a file including:

- A participant information sheet

- A complaints procedure form
- A demographics questionnaire
- Two copies of a pre programme consent form
- Two copies of a post programme interest consent form

Two copies of each consent form were taken in preparation for the participants ticking the boxes by mistake, rather than initialling the boxes on the consent forms (Appendix 6). The post programme interest form was used after the interview to determine whether the participant would agree to be contacted to participate in future research (Appendix 7). Participants were asked to complete a demographic information sheet before taking part in the pre-programme interview. This asked for the participants' age, smoking status, profession of the referrer to PR (e.g. General Practitioner), diagnosing practitioner, time since diagnosis, and living status. These categories were used to analyse the heterogeneity of the sample and to provide further depth to the analysis. These categories were later used to contextualise the data. Participant demographic information can be found in Appendix 18.

3.2.8 Interview procedure

The researcher would read through the semi-structured interview schedule before each interview as a reminder of the questions that may be asked and the interview participants had the opportunity to ask any questions regarding the study. Once all of the questions were answered, participants were asked to read and complete a consent form. The participants were then told the purpose of using a notepad. All participants agreed that the notepad could be used. An example of notes that were taken during a participant interview can be found in Appendix 17. All interviews were recorded using an Olympus DS-30 digital voice recorder. A test recording was taken with both the researcher and the participant making introductions. This was used to test the acoustics of each environment and to check that the equipment was working. The dictaphone was then placed in a position between the researcher and the participant and when the participant was ready, the main recording started. The participant was then reminded of confidentiality and anonymity issues. They were reminded that they could stop the interview at any time. Open ended questions from the interview schedule were then asked such as “how are you feeling today?” or “tell me about a typical day for you?”. Following these questions, others were asked which were thought to be relevant to the dialogue. Prompts were used when necessary such as “can you tell me a bit more about that?” or “how did that make you feel?”. After all relevant questions had been asked, the participant was then asked if they had any questions related to the research that they would like to ask the researcher. The recording was then stopped. The participants were reminded when the recording was approaching an hour. This reminder was used to give the opportunity to each participant to stop the recording.

The interviews lasted between 32 minutes and two hours 21 minutes. It was planned that the interviews would take no longer than an hour and a half; however, the gentleman taking part in the longer interview continued talking and he commented that he did not want to stop the interview at the required time. The researcher felt that the gentleman was grateful to have the company. The dialogue was deemed relevant up to two hours and 21 minutes. At which point the interview stopped. The mean interview time was 68 minutes.

After the interview the digitally recorded files were copied onto a computer in the postgraduate office in building 45, University of Southampton. All files and paperwork were kept in accordance with the ethics and Research Management and Governance approvals.

After each digitally recorded file had been saved these were then transcribed word for word by the researcher into Microsoft Word (Appendix 15). It was felt an important step in the transition between data collection and analysis for the researcher to transcribe the interviews himself, because he felt it brought him back to the experience of the interview. He could remember how things were said, the emphasis put on certain words, the importance of silences or participants describing breathlessness through expressions such as gasps. All these aspects inform the analysis, and the interpretation of the data could have been missed if another individual transcribed the data. Therefore, the researcher was able to remember the feeling or pathic component of the interview which is central to phenomenological analysis (van Manen, 2007).

Below is a diagram of the participants' progress who were interviewed twice through their PR journey (Diagram 2):

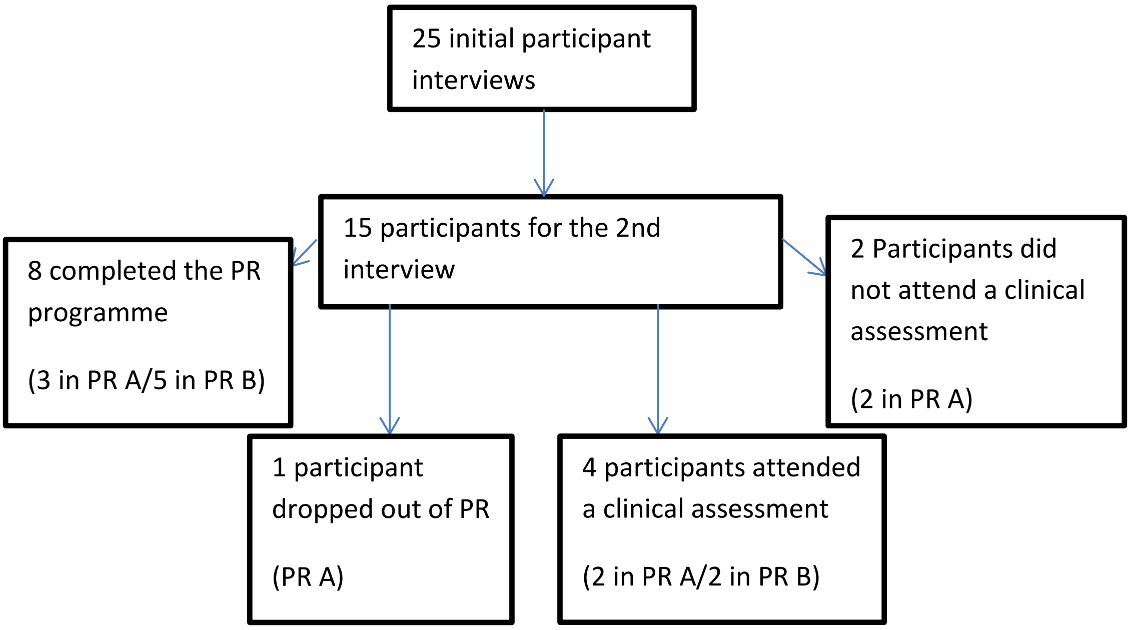


Diagram 2: Participants' journey through PR from referral

The diagram above illustrates that more participants completed PR programme B and more participants dropped out of PR programme A. A limitation to this study is that the people who only completed one interview were not followed up with regard to their uptake or completion of a programme. However, some of those participants declined to be interviewed a second time and it was therefore presumed that their consent had been withdrawn.

3.2.9 Post-programme interview schedule:

The post-programme interview schedule was developed in the same way as the first interview schedule. However, the second interview schedule was not piloted with an individual who had a lung condition because the researcher felt at that time that enough experience had been gained from the pre-programme pilot interview process and the subsequent pre-programme interviews. Box 2 contains some sample interview questions from the post programme interview schedule:

Box 2: Summary of post-programme interview questions

How did you get on with the pulmonary rehabilitation programme?
If you missed any sessions, what made you do so?
What activities have you been doing in your own time?
Please tell me more about your experiences of performing the exercises/walking at home.
What would make it easier for you to attend pulmonary rehabilitation?
What can you remember about the educational talks?
What was it like being in the programme with a group of people?
To make pulmonary rehabilitation more relevant to your COPD as an individual, how would you change the programme?
Do you feel any different as a result of attending pulmonary rehabilitation?
Is there anything else you would like to tell me about your experiences of your COPD?
Is there anything else you would like to tell me about your experiences of pulmonary rehabilitation?

The full post-programme interview schedule can be found in Appendix 14. A potential limitation was a lack of preparation for an interview schedule for participants who would not go on to participate in PR. In these instances the researcher started with open ended questions such as “How have you been since we last saw each other?”. These interviews naturally progressed to be more open-ended. As a result it was felt that they had a strong focus on the participant’s experiences that were meaningful. The researcher felt comfortable in these situations because of the rapport that had been developed with the participants in their previous interviews and the researcher’s increased experience of participant interviews over the course of the study.

3.2.10 Post programme interview preparation

The initial consent form included a question that asked participants whether they were happy for the researcher to have access to their PR records. It was also understood that clinical staff responsible for treating patients on the relevant programmes should not be informed which participants had been recruited to the study. Therefore, patient records were accessed by the researcher telephoning the relevant PR team secretaries who could look at the relevant registers or computer records of participant progress on each programme. When it was clear that a patient had completed a programme, the researcher made a record to contact the participants three weeks later to plan their second interview which was performed between one and three months after PR completion. For those participants who did not complete or start a programme, they were also contacted to be interviewed between one to three months after that choice was made. Those participants who agreed to be interviewed a second time, at a time convenient to them, were then sent a confirmatory letter. Approximately 24 hours prior to the arranged interview time, potential participants were phoned as a reminder and to confirm that they were still able to participate in the post-programme interview.

Participant pre-programme interviews had not all been fully analysed by the time participants were due to be interviewed again. This occurred because of the deliberate time restriction to access participants experiences post programme so that they would be vivid and in depth. Furthermore, the convenience sampling method was consecutive. In the consecutive sampling method each new appropriate referral that a PR team received would receive an invitation pack. The team secretaries were contacted regularly and when each PR team secretary informed the researcher that they were getting to the last 10 to 20 research invitation packs, the researcher would provide them with some more so that consecutive sampling would occur smoothly. The researcher was unable to dedicate sufficient time during this period to analyse each participants pre-programme interview in full which is a potential limitation to the PhD candidature study. Nevertheless, the pre-programme interviews had all been transcribed prior to the post-programme interviews and so had been listened to repeatedly and read at least twice all the way through. From this point, the researcher wrote additional questions to the existing post-programme interview schedule for each participant in his PhD candidature logbook. These questions were based on potential meaningful quotes and experiences read from each participant's pre-programme interview.

Within the 24 hours before the planned post-programme interview the same procedure was followed as for the pre-programme interview. However in the post-programme interview the post-programme consent form and interview schedule was used and the researcher took his PhD candidature logbook to prompt him on questions that were thought pertinent to ask following the participants' initial interviews.

At the end of each participant's second interview, they were informed that it would be the last interview they would participate in for the purposes of this research. They were informed that they had the opportunity to receive a summary of the findings when the research was finished. The participants were informed at the time of the interview that the study would not be finished for a few years. The researcher did not leave the house straight after the interview and answered any further questions that participants had after the dictaphone had been turned off. Participants were thanked for their participation and time in the study before the researcher said goodbye. A copy of the dates of individual interview times can be found in Appendix 19. The table includes details of whether participants were recruited from Programme A or B and whether they were interviewed at home or University. Participants were thanked once again for their participation in the study when they were sent a summary of the findings (Appendix 20) .

3.3 Data Analysis

Diagram 3 provides a summary of steps in the research method used for this applied interpretive phenomenology and the authors who influenced the input of these stages. After the diagram there is further explanation and justification of each of the steps.

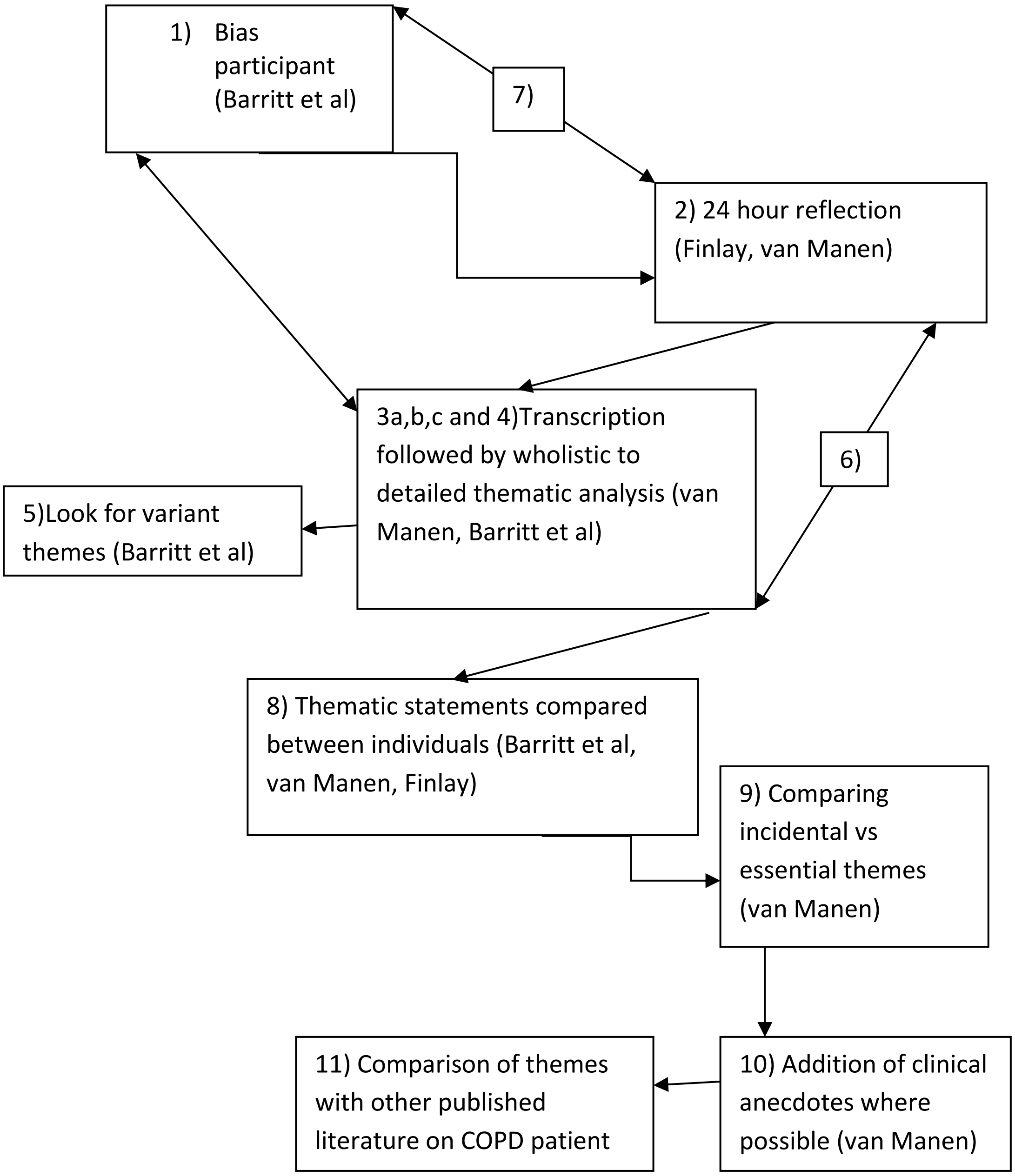


Diagram 3: Data analysis process

Diagram 3 summarises the different stages of data analysis. The numbers in the diagram relate to the different stages of analysis below. The names in the diagram relate to the school of methodology that inspired the research step to be included but are not direct references to one particular paper or book.

The main aim of the following data analysis was to focus on participant experiences using a reflexive approach.

1) Bias participant (Barritt et al., 1983): The first stage of planning the data analysis occurred before the interview data were collected. It was decided that a written account of what was to be expected during the participant interviews was needed (Appendix 12).

Phenomenological analysis traditionally starts from one's own experience in a written account (Barritt et al., 1983).The researcher did not have COPD and therefore this written account would not be a comparison of his experience with that of the participants. However, the researcher thought that writing such an account of his suspected experience of others would enhance a rigorous approach towards the analysis of the data. This is because the researcher's descriptive account revealed biases, or what Gadamer describes as prejudices, towards what he thought a COPD participant would say when describing their lived experience of COPD and PR expectations (Gadamer, 1989). The prejudices could be both positive and negative and were based on his level of clinical expertise at that time. The researcher has labelled this account as his 'bias participant'. By comparing the accounts of individuals with COPD to the suspected experience of this bias participant (as written by the researcher), the researcher would be able to illustrate how during the analytic process he was keeping an open-minded, curious, phenomenological attitude towards the analysis. This meant that he would look deeper into the themes that corresponded to the bias participant account to investigate whether his bias was limiting the analysis. Once the biases in the interpretation were understood this would encourage the sense of wonder and curiosity to develop during the further analysis as discussed in the methodology chapter (van Manen, 1990). This approach enabled the researcher to reflect on his own pre-understandings as a process of the hermeneutic circle. Moreover, the bias participant provided a means to show the development of the researcher's clinical understanding. This development was an essential part of the CAP, as discussed in the first chapter entitled Introduction and Background. The bias participant's account was used when analysing all participant interviews.

Biases were formulated from the researcher's first eight months of clinical experience in PR and his literature review. If these biases reflected participant experiences, then under one interpretation, the level of patient understanding that the researcher had at that time could be commended. On the other hand, another interpretation could be that there were limitations in the method, such as the use of interview prompts that were closed or leading, and this could show poor methodological quality as the sense of wonder would be less transparent. A limitation to this initial step is that only one suspected experience account was created and it may be a stereotyped account of a COPD patient.

2) 24 hour reflection (van Manen, 1990, Finlay, 2008): The second stage of the analysis occurred within the 24 hours immediately after each interview. A written reflection was made about what the researcher thought about the interview. This was based on three principles. Firstly, applied phenomenology is a self-reflective process (van Manen, 1990). By writing the reflection within 24 hours of the interview it allowed the researcher to document the initial analysis before re-listening or re-reading the transcripts. This enabled an analysis of the feel and the mood of the interview. The pathic component of analysis is a central concept to the phenomenology of practice (van Manen, 2007). Secondly, it allowed the reader of the later analysis to judge whether any further analysis has been explored, over and above that of the initial analysis immediately after the interview. This allowed the researcher to display the development of the analysis and the rigour in his method. Thirdly, it allowed the researcher to show how, as part of his applied interpretive phenomenology, he moved between reduction and reflexivity by bracketing pre-understandings whilst at the same time using these to become more critical of the participant experience from a clinical perspective (Finlay, 2008). According to van Manen (1990), the initial analysis should have four elements of existential reflection. These are spatiality, corporeality, temporality and relationality. These concepts come from the existential phenomenological tradition rather than the hermeneutic phenomenological tradition and are all elements of one's lifeworld. It is felt that these four elements enabled greater depth analysis of the general feeling of the interviews and

enlightened the reader to elements of the interview that could not be captured on dictaphone.

3) Transcription followed by thematic analysis: (Barritt et al., 1983, van Manen, 1990). All interviews were transcribed verbatim by the researcher.

Both van Manen and Barritt suggest that the focus of the analysis should be on vivid experiences which fly up from the page and grab the reader (Barritt et al., 1983, van Manen, 1990). These experiences are those that are central to the phenomena. These experiences were chosen in the second stage of a three stage process of thematic analysis (van Manen, 1990). These steps included:

a) The wholistic approach
b) The selective approach
c) The detailed approach.

In stage a, each interview was read as a whole and phrases were used in the analysis to describe the essence of what the fundamental significance or meaning of the interview was.

In stage b, statements were created that were seen as essential to the phenomena being described.

In stage c, elements of the transcript which were focused on dialogue or monologue regarding participant experiences of COPD or expectations about PR were selected. These selections were annotated extensively and analysed in regard to what makes each of these experiences significant for the individual.

Once these specific and insightful elements of each interview were found, more detailed analysis followed:

4) Comparison between the detailed and wholistic statements were made, then these were both be modified as a result of the analysis.

5) Unique variations on the themes were searched for, then the original thematic statements were either further justified, developed or modified as a result of the comparison between the common and unique themes for each participant.

6) The thematic statements were developed further using the reflection taken within 24 hours after the interview had finished.

7) The thematic statements were then used to judge and analyse the bias participant.

8) Thematic statements were then compared between individuals.

9) Incidental and essential themes (van Manen, 1990) were distinguished by comparisons with phenomenological literature from other chronic conditions and research that has explored patient expectations of cardiac rehabilitation. Further modification and development of themes occurred, after the preliminary stages above had been completed.

10) Clinical anecdotes were used where possible to make the meaning of what research participants were saying more explicit. Anecdotes may have a practical significance which enhances the reflective process(van Manen, 1990).

11) A further literature review was performed after the stages above had been completed to search for any research published since the start of data collection related to patient experiences of COPD or PR expectations and perceptions.

3.3.1 Post-programme and subsequent data analysis

The researcher repeated stage one of the method for the post programme interviews. He then moved to further stages as outlined below:

1) comparative analysis of the individual’s pre-programme interview experience to their post-programme interview experience per person, in

order to establish whether any pre-existent themes developed longitudinally or whether other experiences became more meaningful to each individual.

2) A comparison of the longitudinal experiences of completers with other completers, and non-completers with other non-completers.

3) The experience of the completers was then compared to those of the non-completers.

1) Longitudinal comparative analysis of individual experiences:

An example of different stages in the method have been brought together and presented in an analytic summary. A summary like the one below was written for each individual participant interview. Elaine's summary incorporates reflexivity extensively and was therefore chosen as a good example to use. The statements provided are not quotations from the participants. These statements are the researcher's paraphrased summary statements of the important experiential meaning that each interview had after performing a particular stage in the analysis. The following analysis summary is written from the first person perspective for the wholistic and selective statements. It was thought the first person perspective enabled the researcher to think more creatively and make his points clearer during the 24 hour reflections. Writing in the first person enabled the researcher to show when the research made a positive impact on his clinical learning and reasoning. This makes clear to the reader the positive impact the CAP PhD candidature had on the researcher. An example of this is given in the 'comparison with bias participant' part of Elaine's pre-programme analysis summary.

3.3.1.1 Elaine's Pre-Programme analysis summary

Wholistic Statements: COPD means I have to be careful going out in bad weather. I am in control of it at the moment, but it has been masked by a decline in my physical health from arthritis.

PR is on offer, it’s free and its treating the whole person so why not?

Selective Statements: Having COPD means I restrict myself going out in windy weather and I get exhausted more easily than I used to. I am more in control of it than I was a year ago though.

I will give Pulmonary Rehabilitation a go because it’s on offer, accessible and free. I think it will be at the wrong level for me but will go for some information gathering.

Variation: There is a variant experience with this participant in the fact that she actively seeked to maintain and improve her physical activity after hitting a low with coping with her COPD. She sought out a physical job and progressed her physical activity with her job. She had a positive outlook in terms of performing aerobic exercises to improve her health. However, at the same time she still tried to avoid steps or stairs whenever she could because of the breathlessness she gets. She made a comment that the increase in her recent physical activity at work was possible because it was all on level ground. Perhaps it was the close association between her arthritis in her hips and the breathlessness when going up stairs which made her feel more significantly disabled when she thought about getting upstairs.

Post 24 hour reflection: This participant was concerned about being alone and how others perceived her. She had been to a breathing meeting where she compared herself to others and thought that she was at the start of COPD as a result. She was a very positive lady and quite knowledgeable compared to other participants who were spoken to about their COPD. The fact that she saw a positive from her diagnosis when she compared it to cancer is unique compared to other participants; and the fact that she had been out of control of her condition in the past and regained control again is also unique. She was very open about talking about her experiences and how she felt about them. For example, she discussed how annoyed she was that doctors did not diagnose her breathing problems earlier. My interpretation is that she feels annoyed because she believed she had the power to positively change the situation earlier.

Comparison with Bias Participant: A difference between this participant and the bias participant is that this participant was having a worse day than normal for her. I was not expecting to interview people when they were having a worse day than normal or an exacerbation of their COPD. However, I did not include this in my exclusion criteria or whether they had had an exacerbation in the last 4 weeks. This was an oversight at the time of planning recruitment. Upon reflection, this participant was coping with her breathlessness well and was not distressed at any point. My assumption was that people would not invite me into their home should they have felt unwell. It was my perception that this participant was not so much unwell, but just having a worse day than normal. More and more acute exacerbations are being managed in the community. I have treated patients via telehealth for two years, and some COPD patients' symptoms are so variable it would be hard to plan to see them at any 'stable' stage of their COPD. If it was a strict exclusion criterion to exclude patients who had a recent acute exacerbation, fewer participants with more severe COPD would have been eligible, but maybe these participants would have excluded themselves. The advantage of not having the exclusion criterion of recent acute exacerbation, was the potential for seeing patients who were experiencing an acute exacerbation, from whom I have gained a better understanding of what it is like to live with COPD during an exacerbation. I did not actively ask them questions about their current sputum symptoms, which would have given me a better indication of whether they were having an exacerbation, because this would have potentially led them to believe that I was interviewing them as a clinician. Therefore some of the participants could have been experiencing an acute exacerbation without me documenting it as such.

Another difference between the bias and real participant is the fact that the real participant was not so affected on a "typical day" compared to the bias participant. The real participant said that she could do pretty much anything she wanted and was not restricted socially by her COPD. She only had to watch out because of the weather, which had more of an impact on this participant than the bias participant. They had both been diagnosed with emphysema and thought that it was because they had smoked. The real participant knew a lot more than I was expecting about the overall philosophy behind pulmonary rehabilitation being about it treating the whole person. My bias participant did not know as much. The real participant was able to compare herself with others in the area who had COPD, because of her attendance at the breathing meeting, whereas the bias participant was not able to do this. This had an impact on the real participant whereby it gave her some motivation to go to PR to feel better about herself when comparing herself to others on the programme. A similar experience between the two participants is apparent in that they both went to their GP and were then referred to a breathing nurse in their surgery. Another similarity is the perceived benefit of PR's accessibility. I think she thought it would be at a level that was not going to improve her physical abilities. This may show how patient perceptions are affected by going to a breathing meeting.

3.3.1.2 Elaine's post programme summary

Wholistic Statements: I used to think I didn't really have COPD until I recently came over really ill with it. Getting tired is part of COPD and I have to be careful in the wind.

Pulmonary Rehabilitation is great, it means I have confidence in managing my condition better now, I was star of the class, the more exercise you do the better you feel.

Selective statements: I'm not daunted by my COPD anymore. I'm looking at the long term now rather than the short term so I don't panic now. I know I will get tired more because of the demands of having big air balloons in my lungs rather than small broccoli.

PR has given me a positive attitude and that’s half the battle. I really enjoyed the exercises, I was a star pupil. It’s given me reassurance and therefore I’m more confident in being able to cope with the condition.

Post 24 hour reflection: This participant had experienced a chest infection that was so severe she was in bed and genuinely thought that she was going to die. Because of the severity of this chest infection and the improvement she was able to monitor through the rehabilitation, she felt better prepared for her future. The chest infection made her feel like she had COPD whereas previously she thought she was “invincible”. PR was a wake-up call that she was in the same boat as the other people on the programme.

Variation: She commented that the seminar day was ‘rubbish’ in comparison to the pulmonary rehabilitation which was much more ‘professional’. However, as she talked about the breathing meeting more I felt that it was the dynamics of the day and the lack of others’ understanding about using inhalers and respect for the staff running the programme that she found disappointing. She later mentioned that the people who go onto the programme are ‘chalk from cheese’ compared to those at the seminar day, yet she went to both. Could this be because at the time she went to the seminar she had not had her chest infection and felt different compared to the others and felt less affected by her COPD? Therefore, at that time she was a bit of an outsider. After she went to PR she felt exactly the same as the others and she got on with the people on the programme. Perhaps it is the difference between feeling part of a group or an outsider.

Comparison to Bias Participant: The real participant is different to the bias participant because she is still working and this affected her ability to go to the maintenance programme. The maintenance programme is something that was not available for all patients when I wrote the bias participant. Therefore, I did not think that I was going to hear particularly focused wishes to attend a programme. I thought maybe that participants would take things more on a day to day basis and not look too far into the future, but the real participant stated that she was now looking in the longer term rather than the shorter term. The real participant got a prolonged chest infection at the beginning of the programme. I was not expecting participants to continue with the rehabilitation if they had a persistent chest infection over the course of months. Another difference between the participants was the experience of the initial assessment. I was expecting participants to feel that they were disabled at the initial assessment. The real participant felt that she was better than expected. I was also not expecting the real participant's annoyance about the quality of her Primary Care.

These summaries show how this participant developed a positive attitude over the course of PR but she still found it difficult going out in windy weather. The impact of an exacerbation is highlighted as one of the fundamental experiences which may have changed this participant's perceptions of coping with COPD. The 24 hour reflections and comparisons with the bias participant show examples of researcher reflexivity whereby participants impacted on research methodological thought and how the research impacted on the way the researcher thought about clinical practice.

Table four illustrates a summary of the process of thematic development in the second stage highlighted above. The themes of the participant experiences were compared longitudinally for completers and non-completers. The themes that have been highlighted in bold were seen as the most meaningful for the participants. These were meaningful in the way that they seemed strongly associated with the lived experience of COPD and PR, linked to different phenomenological domains such as relationality and corporeality and those with potential importance for professional action. Furthermore, the themes were also shared experiences between participants. Themes written in bold text have been developed further in the findings chapter. Quotes have been provided which have come directly from participant interview transcripts.

Pre programme working themes	Post programme working themes
Being in the dark "*I don't know what it means or what its causes*"	Still in the dark "*See I don't know how they diagnose it"*
Experience of panic *"a lot of it might have been panic"*	Experience of Panic (out of control is panic) "*I worry and I panic"*
Comparing oneself to others positively *"I'm a lot fitter than he is"*	**Comparing oneself to others positively** **"***seventy seven years of age and I beat them all,"*
Dying "you're coming to the end, death you know"	Dying "I don't care how I go"
Experience of frustration "*things you can't do because of it and it's very frustrating"*	Experience of frustration "*I get so frustrated that I can't do it"*
Perceptions of disease process *"the bottom part of my right lung is clogged"*	Perceptions of disease process "COPD *its squashed just the bottom of my lungs"*
PR for better breathing *"breathe better, oh Christ anything to be able to"*	**Breathing properly** *"I breathe much deeper now"*
PR as physiotherapy *"some sort of physio thing, exercises"*	The Physio Factor *"he obviously knows his job and runs it dynamically"*

I don't have COPD "*I just got a complete disbelief"*	Poor primary care **(anger with care)** "*it's not satisfactory whatsoever really"*
COPD as Asthma "*they were treating me for asthma"*	Not coping "*wake up during the night and I need my inhalers"*
Being in Limbo *"it's been like limbo type of thing for over a year"*	**I don't want to do PR** *"come on what can they do? Nothing"*
Smoking only part of getting COPD "*perhaps its in the family along the line"*	**Benefits regardless of PR participation** "Yeah, I feel a lot better"
Affected by the weather *"it's worse when it's hot or wet"*	**My COPD is getting worse** "*panicky cos I think its worsened"*
Living with comorbidities *"my legs get stiff, the hips down to the legs"*	**Comorbidities** "*it clashed with um my foot dressing days"*
Being a shadow of yourself/self-degrading *"I'm slowly fading away"*	PR as a wake-up call "*brilliant because it was a wake-up call"*
Loss of freedom "*I lost my freedom"*	Star Pupil *"star pupil for squats and things like that"*
What is PR? "*I honestly don't know what it involves*"	Have a laugh *"good banter down there and good fun"*

PR is a waiting game “*now I wait a couple of months*”	Positive attitude “*Think positive up here*”
PR as gentle exercise *“she said no its gentle exercise round”*	Being young with COPD on a programme “*isolated from the rest of the group because we’re not pensioners*”
PR as “give it a go” “*so I said yeah why not, its there innit, take it*”	Experience of a maintenance programme “*I can have a bit more a laugh.*”
Recovery from Breathlessness *“would take me two hours to do it on a bad day um because I have a job to breathe”*	
Relationship strain *“the sex is finished”*	
Conflicting care *“the hospital told me to go away and never come back”*	

Table 4: Participant themes

Table 4 above shows how some of the themes were recurrent in the pre-programme interviews and post-programme interviews. These themes, presented at the top of the table, such as comparing oneself to others positively have been included in final themes presented in the following Findings chapter. Some themes which have been presented as bold in the pre-programme analysis but not in the post-progamme analysis were viewed by the researcher as becoming less meaningful in the longitudinal experiences of participants. Dying is an important example of this. Before PR, living with COPD and the associated breathlessness was bringing participants closer to their death. In their post-programme interview many participants did not discuss their perceptions of dying, and those who discussed the issue mainly felt that they were able to push the closeness of death away from them following PR. This type of discussion will be explained further in the findings chapters.

Data analysis was initially performed using NVivo 8 software (Appendix 16). The researcher then was unable to use the programme for a number of months and had a series of changes in desktop equipment with subsequent delays in re-installing software. The researcher then switched to working predominantly from home and could not install NVivo on his laptop at home or remote desktop into a hot desk at university. Therefore the data analysis became paper based. The researcher believes that this made the data analysis more efficient. Multiple documents were being used at the same time over a number of days. This enabled patterns to emerge between data sets (transcripts, selective statements, statement summaries, bias participant) that may not have emerged if the work had to be shut down on computer at the end of each day at the university. Moreover, on reflection when comparing the amount of free nodes that were created on the NVivo software compared to the home-based analysis, far too many codes were created that were not necessarily distinct from one another but were created because of ease. In the researcher’s opinion, the individual’s interview experiences were not as easily comparable using NVivo compared with performing the analysis at home.

3.4 Conclusion

This chapter documents the method of data collection and analysis. The method has been linked with methodological principles described in the previous chapter. The steps of data analysis have been presented in a structured and listed way for ease of interpretation. However, in practice this did not always happen and the researcher was free to move back and forth between stages, which is important due to the method embracing a reflective research process (Finlay, 1999).The next chapters detail findings from both stages of the study.

4. Findings: Pre-programme Analysis

In this chapter findings will be presented to answer the research question:

What are the experiences, expectations and perceptions of patients with Chronic Obstructive Pulmonary Disease (COPD) who get referred to a Pulmonary Rehabilitation (PR) programme but have not yet started it?

The next chapter answers the questions:

What are the experiences and perceptions of patients with COPD who have been referred to a programme after that programme has ended?

And:

What are the experiences and perceptions of patients with COPD who have been referred to a programme but do not complete or start that programme?

4.1 Pre-programme experience introduction

The researcher feels that the main experience of living with COPD in Primary Care is one of uncertainty. This uncertainty has been described below temporally in the past, present and future lived experience of COPD. Uncertainty is then described in corporeal and relational dimensions of the participant’s lived experience of COPD. Uncertainty in the past is described as a theme of ‘being in the dark’. In the present, uncertainty is described as ‘being in limbo’. Being in the future includes the themes of having a ‘give it a go’ attitude to trying PR and participants’ future thoughts about dying. A theme which seems to cross the different temporal aspects of COPD is the experience of panic. This theme has been included in the experience of the present because participants discussed their experience of panic in a way that suggested they were reliving their experience. Furthermore, they discussed their experience of panic vividly, with immediacy.

4.1.1 The use of quotes

The quotes below were chosen to illustrate themes for three reasons. The quote is thought to have depth of meaning for the individual who originally said the quote. Secondly, the quote has relevance to many of the other participants that were interviewed. Thirdly, the quotes help illustrate a particular aspect of the COPD lived experience from either a temporal, corporeal or relational phenomenological perspective. The interpretations provide further analysis that aimed to be reflective and practically applicable to the researcher’s experience of working with these participants and working clinically in a PR programme. Although interviews were transcribed verbatim, in order for the importance of each individual’s experience to be kept in focus within each quote parts of the original transcript have been removed for ease of reading, such as when the researcher said “mmm” or “okay”. The sacrifice associated with this style of presentation is that a feeling of dialogue is lost. However, the researcher felt it more important that the participants’ experience, rather than a faithful description of the process of the interview, comes to the fore in this chapter. A key to the interview transcripts is provided as the first Appendix. Sections have been highlighted in bold text which significantly impacted the consequent interpretation and helped link participants’ experience of their COPD and expectations, perceptions and experiences of PR. Each quote is placed within a box for clarity in separating quotes from text, and is followed by a pseudonym to protect the identity of the participants while maintaining their human character.

4.1.2 Terminology

When other studies are referred to, the terminology “their study” will be used. When the analysis of this study is referred to the terminology “this study” will be used. Furthermore, the terminology “participants” refers to those who participated in this study. The word “patients” is used for patients included in other studies. When participant quotes are referred to, they will be indicated by being enclosed in double quotation marks such as “floating”. Terminology used that has been included as a result of findings from the pre-programme and post-programme analysis such as ‘being-in-limbo’, will be enclosed in single quotation marks. Participant language was used in analytic terminology because it best reflected participants’ perceptions and lived experiences. When participant quotes are used in the analytic terminology they are referenced by single quotation marks. When terminology has been created by other authors, single quotation marks are also used, but the text is in italics as used in Heidegger’s ‘*being-in-the-world’.*

Each aspect of the temporal experience of COPD will be summarised with a paragraph written in the second person with the aim to be evocative to readers and make them feel like they are experiencing COPD in a similar way to the participants in this study (van Manen, 1990). It was thought by the researcher that if this summary was written in the first person it would disassociate feeling from the text as the reader may associate the paragraph with the voice of the researcher rather than that of the participant. The summaries will include statements that may not be directly attributed to quotes used in the findings chapter of the thesis but are taken from experiences of other participants, who may not have been quoted, with a link directly to that particular theme. Consequently, it is intended that the reader will gain a broader insight into the lived experience of COPD from the participants’ perspectives.

4.1.3 Participant demographics

Participants completed a demographics form during their initial interview process (Appendix 18). Participants were aged between 42 and 90 years old. They had a mean length of time since diagnosis of 35 months. There were six smokers and two ‘never smokers’. The other 17 participants were ex-smokers. Nine participants lived alone and 21 participants were referred to PR from Primary

Care via their GP or practice nurse. Seven participants did not know who diagnosed their COPD.

4.2 The participant experience prior to PR clinical assessment

4.2.1 The Temporal Experience

The temporal lived experience of COPD as described above can be shown as a diagrammatic representation. This will provide the reader with a means to understand how different aspects of the participants lived experience are related:

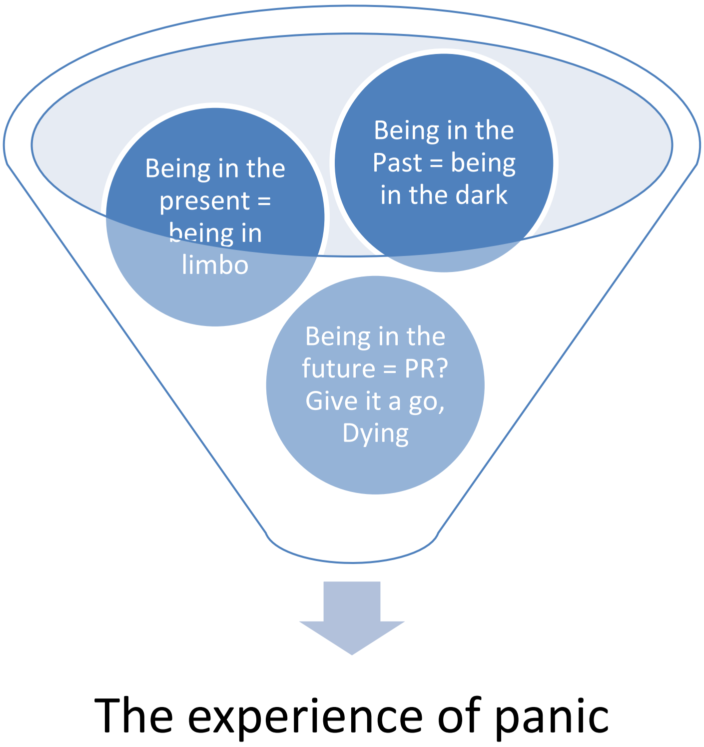


Diagram 4: The funnel of uncertainty

Diagram 4 shows different temporal aspects of COPD enveloped in a funnel of uncertainty which leads to the experience of panic.

4.2.1.1 Being in the past - Being in the dark

The main theme of the experience of living with COPD, by those participants who acknowledged they had the condition, was ‘being in the dark’. Many participants did not know much, if anything about their COPD. However, they did acknowledge that they were receiving treatment for their condition. This treatment did not seem to represent NHS treatment that had been delivered with a central ethos of care for the participant, but rather more of a managerial, interventionist approach to treatment. Combined with a lack of knowledge, the uncertainty impacts upon the participant experience due to the confusion COPD causes them and because of the disease’s gradual onset and the fact that they may have been given previous diagnoses of other respiratory conditions. Participants who were more reflective about their past experience of breathlessness described how this lack of knowledge could be scary and lead to feelings of panic. This panic could be controlled through relaxation and breathing techniques. The following quotes illustrate participants’ lack of knowledge about their condition.

A: okay, so what do you know about your chronic obstructive pulmonary disease?

P: I don’t know nothing about that no. ***I don’t know what it means or what its…causes it you know, mm,…see they, the doctors they don’t tell you actually what’s wrong with you****. They’re all, they don’t tell you, explain the pills. They don’t turn around and say, well this pill do’s this, and all that…they don’t turn round and say how’s the pill do? They don’t say anything like that. All they do is just write you up a prescription you know…just tick them off, then go down to the chemist, pick them up, next day, twenty four hours, and carry on again.*

Fred

P: I don't know a lot about it at all, I really don't. ***I know I had it, emphysemia explained to me****, and I have had the asbestos side of it,* ***but the COPD nobody has****. The doctor said oh you've got COPD. Great, but they haven't got time to explain it to you.*

Joe

P: I don't know what that means… Nothing at all… ***Always thought about my lung, not that tubes that go, so I know absolutely nothing……she never uh, nobody's ever gone into the tubes to my lung…****and I got a like an engineering logical brain that I could understand that, you know, but uh no I don't know nothing about it. All I know that I got asbestosis, there's like a lump of leather on my lungs, so it's reduced the capacity of my lungs. But other than that I know nothing else, I know nothing about tubes at all. Its only since seeing this nurse a couple of months ago… and she taught me how to use my inhaler properly, but nothing at all, I know absolutely nothing.*

Keith

Fred, Joe and Keith are all participants who have been treated for a lung condition. Fred has been treated by his doctor in a way that he seemed to be a passive respondent of his healthcare rather than becoming more of an active contributor to the way in which his condition was being managed. Fred had been effectively managed from his doctor's perspective. Joe acknowledged that he has had emphysema explained to him, which is part of COPD. Nevertheless the explanation given to Joe did not appear to make it clear to him what his COPD was. Likewise, Keith had been previously told about the disability in his lungs but during the interview he felt that COPD was a disease of the tubes to the lungs and therefore a different condition completely. Leonard felt that he had some knowledge of his COPD but this did not stop his uncertainty about the reason for his experience of breathlessness:

P: I have not got a clue, I've got no idea at all why it comes on and why it doesn't you know…I can't describe it, it's just that your chest closes in and the, the thing I have got is uh, that caused this last bad bout, I've got bronchitis, and my, the bottom part of my right lung is clogged… this COPD it, it, it's a, it's a gradual process. It come, it must come on gradually until it reaches…a certain point where you notice something different. And like me, it was a, a lot of wheezing and uh, I don't, ***I don't suppose really and truly there's, the, there's anyway that you can diagnose it before and the patient itself****. It, it, it doesn't, you don't realise it. I mean it, it wasn't me anyway, but my wife was tell, telling me that I was…I didn't even notice it (myself). Didn't even bother me, not at all. And uh it, it, it's such a gradual process that uh it, you can't say you know, like, like you've got an ache in your leg. You can't say well I did, now I have, because you, you, you can't tell when it starts, when it even, when it gets really bad. You (can't), you, you don't even notice it yourself… Because it's so gradual it, it, it's something that you just live with. And then you notice it, and you say to yourself, well it is bad.* ***And then by that time of course it's too late. You've got COPD.*** *There's the, there's nothing anyone can do about it then because its uh, there's no cure I don't suppose. I , I think for this type of thing…prevention would be a lot better if you, if you could diagnose it earlier. To prevent it would be better but uh, I can't see how they could diagnose it.* **(***laughs***)** *Catch 22 isn't it. It's a crazy situation.*

Leonard

Leonard described the experience of breathlessness as one of restriction. He mentioned that he has got bronchitis which he felt was an acute condition for him. The gradual onset of COPD and diagnosing it is very difficult because he could not tell when his lungs were getting worse. He compared the damage to his lungs to feeling an ache in his leg, which he found difficult to know how it started. The researcher believes Leonard found the slow onset of the disease an important area to target in disease recognition. The slow onset of the condition is the 'being in the dark' of uncertainty. Earlier recognition of symptoms and diagnosis of COPD is a major point for improvement in clinical practice. Therefore, this participant experience is a useful description of how living with uncertainty can make earlier diagnoses challenging for clinicians.

The quotes thus far have shown that the uncertainty due to a lack of knowledge and confusion has been a negative experience for those participants. However, some participants viewed this uncertainty as a positive way of dealing with their condition:

> *A: okay, um and what do you know about uh your chronic obstructive pulmonary disease?*
>
> *P: Not very much, and* ***I don't know that I want to… cos that'll freak me out even worse****… yeah, but then I do want to, but then I don't want to. So, um yeah. I don't know, I don't know, I think what you don't know, you can't worry about can you…Yeah, um, I just wanna know that I can help myself.*
>
> *Sue*

Sue was uncomfortable thinking about her COPD because she experienced elements of hopelessness and helplessness, guilt, fear and defeatism. These all caused her frustration which made her feel tense and seemed to affect her breathing. Because of these feelings it is possible that she did not want to know more about her COPD as it may have scared her further.

4.2.1.2 Summary

You feel that you have been in the dark in terms of knowing what your COPD is. Not enough information has been given to you by your GP. Perhaps your GP has not had enough time to give you a proper explanation of what COPD is and what causes your breathlessness. COPD has been cloaked from your attention, concealed from your lived experience even though on reflection you understand you have been getting symptoms. Nevertheless, it remains cloaked due to the disease's gradual onset. 'Being in the dark' about COPD means that you have panicked more. Perhaps you still have not been told you have COPD and perhaps you feel that being kept in the dark has helped you cope with the condition as it was protecting you from knowing too much and "freaking out". You have been told that you have emphysema or asthma as well and therefore this is likely to be very confusing.

4.2.2 Being in the present – Being in Limbo (and the experience of panic)

The experience of living with COPD in the present was one of 'being in limbo'. 'The experience of panic' has also been presented in the present experience for the reasons previously stated. The researcher believes that both the experience of panic and being in limbo related to the uncertainty which these participants experience. For many 'the experience of panic' may be associated with 'being in the dark' about their condition and participants questioning their own ability to cope with a condition they knew little about. Participants felt that relaxation is thought to be the key to coping with panicking. 'Being in limbo' means that participants are left waiting or floating in the healthcare system.

4.2.2.1 Experience of panic

For some participants the experience of panic felt like they were having a heart attack. The experience of panic seemed to be a manifestation of the experience of uncertainty.

P: The first time it really happened was um, probably two years ago and um, I called an ambulance because I thought I was having some sort of, I didn't know what I was having…and ***they came up and said I was having a panic attack****…*

and I couldn't understand it, cos I had, just had my hair done. I had just put a very large cheque in the bank which I was thrilled skinny with… ***I was full of the joys of spring and suddenly I was like a fish when it's out of water****….But you get pains in your chest and things as well so* ***it's really quite scary****. I suppose it's your lungs are doing something… and uh, it happened a couple of times and, and they kept saying you're having panic attacks I was saying what? (I've), I've got no (reason), you know I wasn't stressed about anything …I kept thinking what on earth is up with my chest? What on earth's that? Anyway, I drove back home and I was mooching around and I was going* **(***gasps***)***, and I couldn't get my breath and I had to call an ambulance, I really had to call an ambulance….Because* ***I thought Christ, it's like I'm drowning.*** *And it was like I was drowning, and it, that is really the very first time that I thought there's something wrong here… and they turned up and they said oh you're having a panic attack dear…they took me up to QA the third time, and* ***I actually had thought I was having a heart attack****,…*

Elaine

P: I'd, I'd not realised how, how bad I was. I mean I'd been breathless but not you know uh, and I realised after giving up smoking you've gotta give it time. It was a steep hill, I've got to admit it. Do you know St Catherines Hill, no? It's very steep. It's like that, literally like that… with steps, but its steep and like I said, I did the first four, five steps and I, whoff, I saw the top and I, ***my heart really was pumping. And it terrified me because I thought, am I having a heart attack?*** *Um, and because I, I work in the community and I work with palliative patients and I've been to people whose got, I've seen the effect of tobacco at the end of it…then I thought gosh you know is my lung collapsing?...****A little knowledge is a dangerous thing*** *if you know what I mean. And uh, because of the pain as well and, uh the tightness in my chest, I thought that's not normal.*

Pauline

These participants felt out of control of their symptoms and panicking was a very scary experience. Elaine's experience of panic was one that was unexpected and came 'out of the blue' which was confusing. Pauline had clinical knowledge of respiratory disability and therefore questioned why she was experiencing her symptoms. This uncertainty fuelled her panic. In PR or during an initial assessment with patients, it may be important to discuss the differences between what a heart attack feels like and the symptoms participants get from their panic or breathlessness with their COPD. Perhaps the experience of a heart attack and breathlessness resulting from COPD are actually very similar experiences from the participants' perspective.

Nigel related the fear during panic to his thoughts about dying which many other participants have discussed when confronting their experience of panic.

P:…sometimes you, if ***you get into a panic, you get to the stage is my next breath gonna be the last one?*** *You start panicking about something…Earlier on this year I should have gone to Bulgaria for a holiday and I worked myself up in such a state about the flying that I was panicking every day about going on this plane. And then in the end one day, (name) and myself were going down to see the nurse and I said (name) I don't want to go to Bulgaria. She said why? I said I don't want to go. I said it's me I don't want to go. She said well not a thing, we don't go. Hour later I was brilliant. That has gone off, over and off my head then. But prior to that I was thinking about it all the time, thinking you know, I get on that plane, am I gonna be, breathe properly? Am I gonna be alright?...****it's like (you're) being scared stiff****. Alright you're down, down town. Half the old yobs, yobs down the road are gonna beat (the) hell out of you, it's that type of scared…. you know, you just, you know Christ do I run? What, it's that type of,* ***actually more like you're being petrified than scared****…. if I put it, that's the best way I can explain it…it can be anything. I went through a phase that I couldn't go upstairs to bed. I couldn't go up to bed! As soon as I got up to bed, got undressed to get into bed, I had to come down, and I had to take (name)* *upstairs to bed with me, cos I was petrified of it. Why I don't know, I can't tell you why, but I was. And I had to make her come to bed with me because I was so scared of going to sleep,* ***thinking that I'm going to go to bed and not going to wake up. You know am I going to be here in the morning?****…*

Nigel

Nigel described how restricting and isolating his panic affected him. He thinks that the experience of panic is worse than feeling scared. He felt ''petrified''. This was an interesting word to use as to petrify means to turn to stone. It is not clear whether Nigel meant that he felt he turned to stone in the experience of feeling petrified. However, it seems that his experience of being petrified rendered him motionless in confusion of not knowing what to do in a situation. The other participants have also described a similar feeling which may be related to the experience of panic and being petrified. These other participants also felt unable to do anything and stiffened up when they panicked. Leonard describes how the scary experience of panic was one that was born out of fear; fear of the unknown which is uncertain.

P:*I went to shave and uh, I got so breathless I couldn't stand up. I had to sit down. Called the doctor because well I, I just couldn't breathe and we got out onto the emergency doctor, the out of hours doctor and he said is he turning blue? Well I wasn't obviously so she said no he's just breathless. So (she), he said has he got a breathe, a puffer? She said yeah, he said tell him to take ten puffs now and believe it or not within an half hour the doctor was here and uh he said, no he said uh it, its frightening he said but believe it or not he said, you're getting enough air into your lungs. You, he said it, it's you know, you're, you're getting enough in there, he said but uh. And he gave me steroids and antibiotics but that one, it, it,* ***it feels as though your chest is being crushed you, you, you can't, you (just), you just can't breathe. It's as simple as that and it is, it, it's a bit scary. I'm, I'm not so scared now because I know it'll, it'll pass but…It, it really, it, it really is a scary experience*** *…**fear is, is the worst***

***thing**, when, when, when you have a, a real bad, bad bout is the the fear….that is the worst thing at all. and uh it, it's, it's okay to tell, say to someone yeah you're fine. But uh yeah, it, it's the actual fear that you're not gonna be able to breathe at all. That's, that is uh obviously frightening but uh, but the rest you, you can live with…I did not think I was going to breathe. It, it was, I, I'd, I didn't think that I, I was gonna recover from it. That was what it was more than anything else. I, I didn't uh, I didn't think there was any way that I could recover from it because it was so severe. **But uh you, you, it, it, it's so bad you, you can't move, you, you literally can't move.** You, you can't walk, you can't think straight even. It uh, I couldn't even tell my wife that I wanted a doctor, that that was how bad it was. Obviously she knew, but uh I (couldn't) I couldn't, I couldn't tell her because I couldn't speak…**the fear is only fear because its unknown.** And I did, I did. I'd never experienced it before and if I'd (have) known what I know now, it wouldn't have been so frightening.*

Leonard

Leonard described how even if he had been told by somebody else that he was going to be fine, his fear remained more disabling than the breathlessness. The initial experience of being out of control of one's own breathlessness was the scariest for these participants. Once they recovered from their breathlessness, this fear was no longer as scary. Anne illustrates this point. She had received a lot of treatment for her COPD and was well known to her local respiratory centre in the district hospital where she had been taught breathing control strategies.

P: I think I used to have a lot of them when I first had it,… because I didn't know what it was, I didn't know how to handle it. And when I went up the hospital I said to them about having these attacks and he said what do you do? I said well I just try to breathe, and breathe hard, he said no, no, no! You make it worse, and that's when they taught me to breathe through (my) stomach. And he said well if you feel one coming on just start breathing through your stomach gently… he said and gradually you'll feel it go over, and it's true, it does. …the point is, it's, *it's just that freedom (of) choice… and* ***once you get over the scaredness of it, you get the freedom of it, of your breathing.***

Anne

The breathing technique which she seems to have described is diaphragmatic breathing. This participant was on Long Term Oxygen Therapy (LTOT). Therefore one could assume that she had previously been diagnosed with severe COPD. The freedom that participants got through their increased control of breathing seemed to allow them to do things again and to no longer be petrified. Joe elaborates how learning how to control his breathing and relax probably saved his life.

A: yeah how, how, how, how do you feel that she was able to help?

P: I think that she, she taught me if (you're) like that, you have to relax. That's the big thing, she said when you get a panic attack, you panic (and) your whole body stiffens up and then all of a sudden it just relaxes….she said if you think about it you will slow down, slowly take deeper breath, deeper and deeper, and eventually it will come through that you'll be breathing normally…and to me well I think ***she was a hero, she probably, she, she might have saved my life in one respect…by uh, a silly little thing by relaxing and that is the big thing*** *...And that's the same sort of principles she worked on, if you slow down, slow down, slow down, she said then, as you as your body slows down, your breathing starts picking up.*

Joe

Joe described his experience of going to see a clinician who ran a workshop for people who panicked. The fact that he had been told that his body suddenly relaxes relates to another experience of breathlessness where he told me that he suddenly wet himself when he lost control of his body during an episode of panic which was similar to the other participants' feelings of being petrified.

4.2.2.2 Being in limbo

The experience of 'being in limbo' means that participants fear they might be deteriorating whilst they are waiting for treatment. Participants are not always told sufficient detail regarding the progress of their treatment or the process of referral to rehabilitation. It appears that the delay while waiting for rehabilitation can spoil the prospect of having fun and gaining improvement from participating in a programme.

> *P:…if somebody said do more exercise… that is good for your breathing, but when you say walk go walking, well that would really annoy me cos uh I, I would think somebody would be off their head to say go for a mile walk. I can't walk fifty yards you know um…but whether I should persevere, walk fifty yards, hang on. Then well I don't know. But I really was looking forward to (these) breathing exercises because I actually thought; I'll be getting somewhere then. And then I'll be perhaps up the gym again in that room doing all the, making me sweat with these balls and things, but* ***at the moment I'm in limbo****. I'm not doing anything. That really annoys me, I mean I haven't been up that gym, two or three months ago… but at the moment I'm doing nothing so I'm just, let myself what, what's the word, just (disintegrate), not disintegrate,* ***but instead of exercising getting myself up to a level, I'm deteriorating.***
>
> *Keith*

Keith was used to doing exercises in circuit classes in the past and has been told to try PR before entering the circuit classes again in the future. As a result he felt that waiting to start rehabilitation was causing him to deteriorate in his health condition.

*P:… **it's been like limbo** type of thing for over a year, so I don't know what they're doing **(**laughs**)**. You're the first person whose actually contacted me so I just don't know what actually is happening. I've got an appointment on Thursday with the nurse at my surgery but then that's the nurse I saw last year in May or June… So I don't know what's, what (is) in between… they haven't made up their mind of what was wrong with me. Um, I started to go to the surgery in uh, in May, June, because I was very breathless. Uh had a chest x-ray which said it wasn't cancer, even though the bottom of my lungs, she said was squashed a little bit. So she referred me to the nurse um who did some peak flow test and they decided I had asthma. So they put me on a couple of inhalers which was a waste of time. So I went to France, I'm French born. I went to France in October and because the health service in France is a little bit more together than the English one. My brother had made me an appointment to see a pulmonary consultant and I saw her and she's the one who diagnosed COPD and gave me an infomag, information sheets to give to my doctor. And as well, what treatment I needed which has been ignored because it's too expensive…And that's when the nurse said oh good you've got COPD I can now refer you to the rehab team… So I went to the surgery for other things and I saw her. She still had not done it so I reminded her…Then January came, nothing (happened) again and I thought you're pissing me off now, you know… um so I saw my doctor and I just said she's done nothing. I haven't heard from anybody, uh and then I saw her about six weeks ago and she said oh you're gonna hear very soon. I referred you, that's it. I'd…it's that referral that I've been waiting for the rehabilitation team… I've been waiting for that referral because I feel they're a specialist, if I had heart trouble, my doctor would refer me to a heart specialist…If I had bladder trouble, kidney trouble, I'd be referred to specialist immediately. I've got COPD and **there I am floating**…and you just wonder, if **the longer you're floating with no treatment, no advice, no nothing, are you, are you making things worse like, are things getting worse? Have I lost something in that one year?***

Pauline

Pauline believed that she had been left floating in the NHS system because she is a smoker and was therefore given low priority. It is felt that she resented this and did not feel well looked after by the NHS. She understood that COPD is a condition that progresses. Therefore she was worried that without intervention for her COPD, her lung health would deteriorate. The quote from Jane shows a similar experience of not being informed about COPD, even though it seems clinicians had been given this opportunity.

P: So I think when they get these this information back they should call the patient in. My son uh, he, he's so angry about it, he can't believe that they never called me in, and even the asthma nurse uh this January, when I see her, this is the time after she said I don't know how they are gonna treat this. She, she, she started reading it out and she said yeah it says here ***not yet discussed with patient****. And that's in, in the medical notes. That from April, and it says it was not discussed with me…I think that's crazy in it,…*

Jane

Some participants were frustrated with the time they had to wait for PR. This seemed to be more frustrating for those participants who were keen on participating and had heard of the potential benefits PR could provide for them.

P:…now I wait a couple of months, you know it's, that annoys me. I'd rather go up there and give (them) a kick up the behind and shake them up you know because… in my, in my life you wouldn't get away with it you know…I hate lackadaisical you know. And when they make a cock up with the prescription or something like that you know I, it annoys me…

A: How do you feel um, about your referral to pulmonary rehabilitation?

P: I feel good, but I'm, I'm, ***the shines gone off it because it's so bloody slow waiting.*** *You know I mean, I mean this is a couple of months ago. Never heard* *another word about it. I'm not seeing the respiratory nurse anymore. I'm just left, left uh dangling.*

Keith

P: Well I'm very pleased that I'm, I'm getting it. I'm going with open arms and hope that it does something for me but, I'm only too pleased to try anything to make me a little bit stronger so I can walk go walking out, walk a bit more, can actually lift something with my arms, and this give me a bit of strength. I'll be thrilled to bits so that ***I will I'll only be able to tell in time.***

Norman

P: Sooner the better, sooner they send for me the better…It can't come quick enough as far as I'm concerned…um mate (name) lent me his dvd…um, well if the people on there talking like they been on it, and it's done them the world of good, hope to Christ it does me the world of good, cos the sooner I can get there the quicker (and) the happier I'll be. Might not work, don't know but it is a chance that it could work. And if it works, well, all well and good…I would like to go on it, well tomorrow if I had my way, if they sent me a letter tomorrow, I'd be there… um, ***but I've got to wait, there's a waiting list to do it apparently.***

Nigel

From the last two quotes it seems as though participants understood there would be a waiting time from being referred to starting PR. However, it seems that participants were left waiting too long after their initial referral to enter a PR programme. This appeared to be a greater frustration for participants in PR programme A compared to those in PR programme B. This frustration may be interpreted by the language the participants use such as “floating” and “dangling” At the time of recruitment, the PR programme B team was better resourced than the PR programme A team and could offer patients the choice of attending more classes. Unfortunately, since performing this research the NHS budgets have become more restricted than they were in 2009. Therefore, with arguably fewer resources or growth in staff numbers, patient waiting times may rise further. This may take more of the “shine” off the prospect of PR for COPD patients participating in a programme in the future. There could possibly be a case for not informing patients that they are on the waiting list for PR until nearer the time that they can be accommodated within a programme, to lessen their frustration. However, this would present its own ethical issues about keeping patients fully informed.

4.2.2.3 Summary

The most significant experience of living with COPD is panic. You panic because you think your lungs are going to stop working, fighting for breath when you feel out of control. You panic when you lose your reassuring inhalers. When you panic during breathlessness it feels like you are having a heart attack. Panic can make you change the way you are breathing to a way that you know is wrong. Panicking feels scary and frightening. In fact you are petrified because you’re fearful. You are fearful of the unknown because you have been kept in the dark. Panic makes you feel the need for reassurance. Unfortunately you can still panic if you are very knowledgeable about the disease because you have seen how people die with COPD and this scares you. Panic exhausts you and brings you closer to death as it increases your focus on your breathlessness. Panicking restricts what you plan to do in the future. However, you can overcome the associated feelings of panic if you have been lucky enough to have been told how to relax and use breath control strategies.

You have been told you will be getting some further care for your COPD in the future but have been kept waiting in limbo and this makes you feel that you have been left to disintegrate. You are very frustrated as you are floating in the system of the NHS as a smoker. This is wasting valuable time and you feel ignored. You feel this can be part and parcel of being treated in the NHS but nevertheless makes things uncertain for you. You feel like you are being cared for in a lazy fashion. Being kept in limbo has tarnished the prospect of PR for you.

4.2.3 Being in the future

Participants thought about their future with regard to the more immediate possibility of going to PR. Furthermore, the participants thought about their death and how they were going to die.

4.2.3.1 PR as "give it a go"

Participants viewed PR as something that was offered to them, it was free, it might have helped them or somebody else and so participants wanted to try it to see what it was like.

*P: Yeah and they'll probably tell me what, whether I am doing the right thing, they'll say is there anything else that needs to be done. If they say well we think you should try this**, I'll say right lets go for it**…Oh I'll go for it, I'll go for it yeah. Yeah I want to find out. See **by them helping me, they are helping other people**… and people who are, I mean people who are stubborn should learn. Because I always, my dad always said you'll learn more through your life by your mistakes, and I have.*

Dave

*P:…course I go every year to see (name) at my doctors and that's when she said put in for this these courses sort of thing you know. So I said yeah why not, its there innit, take it (laughs)…and **anything to help. If it don't help me, it may***

***help someone else** you know so …She asked and I said yes (laughs). So I'll give it, anything like this if it helps me, well someone else, **go for it**, that's what I say.*

Tony

Both these participants had an altruistic motive for going to PR. Dave wanted to go to find out. I feel that this meant he understood there was going to be an assessment of his current management of his condition before entering a programme and he felt like he was going to be judged. He commented that stubborn people should learn and at another point in the interview he commented about how he went about managing his condition, doing things which he knew might be wrong. This may have been related to the fact that he was a current smoker. He felt that he would be able to help others by learning more about COPD so that he could tell others more about it. Tony discussed a lot about his army background. Tony seemed to be altruistic in his motives to attend PR, but with uncertainty. He was uncertain of what to expect from the experience. This uncertainty may be similar to his experience of volunteering to be in the army.

*P: **I'll give anything a go** you know. I'm not in the least bit (bothered), I don't see the point. It's on offer, **it's on offer, it's free**… if it was on offer and I had to pay **I might give it a go** just to you know see if it really suited. No, I think the more that I think is, I think that um I, I think this is what the health service are here for… You know really, because it's, it's treating the whole person. That sounds a bit touchy feely doesn't it but it's community care… You know, and if you got people sitting, and apart from anything else for a lot of people there's gonna, there's a lot of people there that (are) probably sitting at home and don't see a lot of people. This is of course, I'm absolutely look, inundated with people myself. But you know (laughs), no but it's, it's a social thing and you can talk to like people if you feel like it… or look at people there and think well at least I'm not that bad. Which is what, which is what I should be doing… you might get ideas that you haven't thought of.*

Elaine

Elaine summarised the philosophy of PR from a rare perspective that was not solely based on exercise. Elaine believed in the theory behind PR, that it is what community care should be, treating people holistically. She also discussed the potential social benefits of attending PR. Nevertheless, she was not convinced by the prospect of attending like other participants. This can be analysed by the fact she says “see if it is really suited” and “I might give it a go”. Richard echoes these sentiments below.

P: I oh, there’s a certain amount of disbelief when I got the letter. Um, my attitude towards anything is that um, ***if something’s offered to me which I think might do me some good, I’ll go and do it, which is free, I’ll go and try it****… If it doesn’t work, then I’ll pack it in. It’s only six weeks course, so I mean, and um, um dependant on the days which it’s (going to) take place uh is dependant. A lot will depend on whether I can attend you know. I mean I’ll have to, that’s something I’ve got to discuss tomorrow (coughs).*

Richard

P: they just said it’d do me good so I go, no problem…anything that I think (will) do me good, I’ll do it…I don’t, I don’t worry about things like that you, if, if, they say do it, I’ll do it. Exercise, I’ll exercise. I don’t like it so much when they say sit down and (stop), don’t move but, if its anything that I can do actively… then that’s fine… ***I’m open to anything, any, anything that’ll help me or anyone else.***

Leonard

Participants may have attributed little value in PR but it may also be the case that they were ambivalent about the potential benefits. This may be because participants did not know what to expect from attending a programme even if they knew how many classes and for how many weeks they would be attending. Therefore they were open-minded at the prospect of gaining some improvement but prepared to quit if they did not think the programme was for them. However, Anne thought differently.

P: But if I don't give it a try, I don't know whether I can do any better than what I'm doing now and that's why I'd like, to give it a try, and see if it makes me feel more whole of a person than I am… I ***can't make it any worse****… than what it is so I can only improve it…cos that all comes under pulmonary, um and I think that* ***even if I get a slight improvement, it's going to be a big help to me.***

Anne

Like other participants above, Anne was uncertain of the potential benefits of PR. However, she felt so severely disabled by her COPD that she thought it could not get any worse. Therefore the slightest improvement in her ability to manage her COPD would have been perceived very beneficial for her. She valued the importance of PR.

4.2.3.2 Dying

Participants perceived they were being brought closer to feeling like they were dying when they became breathless. Participants revealed these perceptions after probing questions about describing experiences of breathlessness and how participants felt during these episodes. Participants also thought about dying in the future and got scared about their quality of life before they die.

P:…when you go and see people with, at their last stage of COPD, they are very blue. Because the oxygen's not getting (into) their bodies, so all their extremes *are blue, and their feet are blue, their lips, all they're,* ***they're all blue. They (are) very thin, they (are) not drinking, they are very frightened****. They're wide (eye'd)* ***their eyes are almost pops out, and I look at them and its awful****. Absolutely awful! And I think to myself, that person must know (that) he's going to die because he* **(***pants***)***… Nothing's going in. That's why they're blue. The oxygen's not getting in. And they are on oxygen, but not going through. And I think how is, is all along as well now,* ***how will the end come?*** *And normally you go in and we've had some people, we found them on the floor and they're dead.* ***They're dead in the chair, but you can see there'd been some kind of struggle because they've tried to either remove the mask or the table with the telephone.*** *They tried to reach for the phone and it's all gone flying… do you know what I mean, so, so there'd been a struggle at that last minute…so* ***that's the fear of that, that you're all alone and you're dying*** *and there is nobody to um see if your, if your lungs collapse through it. You go to a hospital and what they will do, they will put uh, the syringe driver in, or they will uh put you in an induced sleep and then they put you on the life support machine and then they consult your family and say this is it. This is the end. Then the life support machine is switched off while you're sedated, heavily sedated, so you are passing away severeless…you with me? But when you're at home it's a different matter…****that death can be quite shitty really.***

Pauline

The researcher had not previously experienced how people manage end-stage COPD independently in their own homes at the point in time this research was performed. This participant's experience made him appreciate how much more of a reality dying was for her than for him. The researcher appreciated that it must have` been very difficult for Pauline to continue to work with end-stage patients who had respiratory conditions.

Panic about the quality of life before dying also affected Sue who worked as a cleaner in a local hospital and therefore in close proximity to sick patients.

P:…the reason being I think is ***because I've heard so much about um either swine flu****, and people dying with um underlying problems, and then of course then I start thinking oh god, you know,* ***I'm gonna die. And how I'm gonna die. And that's what freaks me out,*** *gets me a bit tearful. Um cos, its self,* **(***coughs***)** *self-inflicted so um, you know I wish I could go back and never start smoking. But of course I had to, because I had to be big I am. You know sort of like when you're young, um. So I think that had made me more tense and more aware of my breathing. And um sort of like noticing that um walking sort of makes me a bit more breathless and I'm not sure if that's because of the stress I'm feeling. Because I'm freaking myself out… Or because um you know its the illness you know…like sitting here now, my shoulders are sort of like tense and everything's tense about me …****it's not, not the thought of dying, dying. Cos everyone dies. It's you know you, you, quality of life before you die…that freaks me out you know.***

Sue

There were some participants who were not scared or frightened about the prospect of dying. These participants still thought about the prospect of their own death in relation to how it may be associated with their experience of living with COPD.

P: That, that's it. I (don't), I'm hoping I won't be wheelchair bound. I'm hoping that if this works, I will still be able to keep going. ***That is my great fear actually, is I won't be able to keep going it will get worse and worse… And I wouldn't cope, then I think I would go to Switzerland****…I know It's giving up and all that but I'd* ***hate to be a burden****…and become a burden on him and on like in general you know and* ***people would pity you****. Couldn't stand that, couldn't stand that.*

Jill

For Jill it was the thought of being a burden in the future and being pitied that would make her want to die. Therefore, she looked at death without fear, but rather as an opportunity to escape her disability.

P: and I know it's going to get worse. I know it could probably kill me in the end. I'm aware of that…I accept it, **I'm not afraid of dying.**

Dave

Dave had accepted the fact that his disease might be the cause of his death. He had accepted the fact that he had COPD and that it was a progressive condition. As a result it is felt that he was more positive about what could be achieved in the present and he was keen on improving his quality of life whilst he could.

4.2.3.3 Summary

You are going to give PR a go because you may have the opportunity to help other people. Ultimately, PR is free, it has been recommended and your COPD cannot get any worse so why not try it? You are open-minded. You think it is a good idea because you think it is about treating the whole person. It will be a challenge for you but even if you gain a little benefit you will feel as though you would have made big improvements to your health. You will just have to wait and see.

You have thought about dying in the future and see it as inevitable. Part of you accepts it. However, you do not want to be a burden to those around you and if that happens, you would rather die. You are worried about your poor quality of life before you die, how it is going to happen and how you will not be able to get hold of your breath.

4.2.4 Corporeality

Amongst these participants, there was a great deal of uncertainty with regard to their perception of how their COPD affected their lungs.

4.2.4.1 Perception of disease

Participants felt that they could explain what they thought was happening to their bodies as a result of having COPD. The perceptions were contrasting between participants. Participants show very strong beliefs about their COPD pathology. However, there remains a degree of uncertainty with regard to: how acute infection in the lungs potentially affects diagnosis, the relationship between bronchitis and COPD, damage to the ‘hairs’ in the lungs, the confusion of living with comorbid lung conditions, and whether COPD is a lung disease or a disease of the ‘tubes’ to the lungs.

A: Mm and how do you, how do you think having this cold at the time of doing the test affected it?

P: …if you’ve got bronchial, if you’ve got bronchial disease you can’t fully expand. You (can’t) lungs to do the test properly…cos that’s correct isn’t it…So when, when you blow into this tube and the amount of air you can expand is restricted by the amount of fluid that you’ve got in your lung at the time…So therefore, if ***I’ve got a heavy bronchial cold and they do a lung test and they tell me my lungs are ten years older than they should be you know, why should I pay a lot of attention to it?***

Richard

P: It well, the, the, ***this is because I've had bronchitis****. I think more than the uh, (obstructive disorder), disorder. It, I, I think the, the bronchitis…it fills your lungs...the only reason I've been really bad is because of the bronchitis is,* ***the bronchitis is exacerbated the uh COPD****, and uh, I don't think that it (wouldn't have) been anywhere near as bad if I hadn't have had the bronchitis…and uh as I say, if the rehab can give me a little bit of. There again it might in actual fact uh help me when I do get really breathless to do maybe a little bit of the exercise to relieve the breathlessness.*

Leonard

The two gentlemen above believe that a bronchial cold or bronchitis are separate from COPD. Richard believed that he did not have COPD because his bronchial cold negatively affected his ability to perform spirometry. Furthermore, at other points in the interview he indicated that he did not feel significantly disabled with his breathlessness as he could walk for miles, played golf and felt better physically abled in comparison to other people his age. These factors strengthened his view of not having COPD. Leonard believed that having bronchitis had exacerbated his COPD because the bronchitis filled up his lungs. It was not clear at the time of interviewing Leonard what he thought was filling up his lungs, but it was assumed by the researcher that he was talking about mucous. Indeed he was prescribed antibiotics and steroids for his recent bronchitis. The bronchitis is probably what a clinician would describe as an infective exacerbation or chest infection. Dave described the pathophysiology of getting a chest infection which is very common for people with COPD.

P:..the reason for that is I got this lung here, my left lung …and this lower lung here on the right are ***not functioning because they are worn out, the hairs inside the lungs****. It's like a, it's like a, a, a, bull a sweeper a carpet sweeper…***the hairs get soft***… and they go soft, and they wear out. So what it,* *when I got this bacteria in your body, something gets inside it, and attacks the bacteria, comp, causes you to uh* **(***three short breaths in***)** *like this…and you gotta bring up that phlegm if you can* ***so's the lung is really collapsing****. Right, well I have known that for a long time and I know also that I have got spots on the lung which I have had for fifty years.*

Dave

To Dave, it was the inefficiency of the 'hairs' in the lungs which allowed something to get into the bacteria in the lungs and caused a shortness of breath. Presumably Dave was referring to the cilia lining the bronchial epithelium, which many clinicians describe to patients as 'hair-like' structures. In addition to this, he believed his lung collapsed as he forcefully cleared phlegm from his lungs. The role the bacteria played in the pathophysiology of a chest infection was not clear for Dave because at one point in the interview he described the negative effects of the bacteria entering the body but he also described the bacteria already being in his body. The pathophysiology of a COPD chest infection is very different for Joe.

P: Well, they, they reckon that it's cos of the fluid in ***the bottom of me lung. It's stale fluid****. It never goes away, and same as the nurse was saying. If a germ gets into you then it,* ***it causes, it's like a piece of meat going off****, you know. It's alright for so long, but then once you know,* ***it starts rotting away*** *and that's what they reckon that causes that there…where you get an infection, in to inside of your lung, and it gets in that matter that's left in the bottom and it's like a breeding ground for germs, so, but I, I don't know I, I would have thought with the amount of coughing I do sometimes it would come out but it doesn't it just stays in the bottom…****Everything in the bottom half of the lung has gone****. You just got the, case in there…I don't think the asbestos, the pleural plaque has got any worse but I think the rest of it has taken over now you know it's, cos she said eventually…****it will destroy the muscles in your lungs.*** *Well if it destroys that, that's… it'll destroy your, slowly destroy the inside muscles… which allow you,*

you know to breathe. So she said then you'll get a sh, ***shorter breathing span*** *you know…for the emphysemia.*

Joe

The way in which he perceives his lung disability is incredibly bleak. Joe interprets his lungs rotting away with muscles that get destroyed. Therefore, he viewed his body as significantly deteriorating and it is felt that this reflected his overall way in which he felt disabled with COPD during this interview. The next two gentlemen believed in contrasting ideas. Peter believed that COPD was not a pathology of the lungs but one of the "tubes" to the lungs. Keith believed that COPD was a pathology of the lungs rather than of the "tubes" to his lungs.

P: It's a blockage of your airways, um down to your lungs. Uh, ***everybody looks up and says yes it's a lung disease. No it's not a lung disease****, it's the airways down to your lungs, and what it is, it's a, a, a, its mucous that blocks your airways.*

Peter

P: ***I don't know where the water actually goes in the lungs, or in the cavity*** *and ever since then. Then he sent me to the heart people when I got back, and that's it. Its, that's when it got worse, nothing to do with my che, well this lump of leather or whatever growth whatever, nothing to do with my tubes. Just the water wherever it was…yeah it's like, I, it amazes me the way that you think…I know tubes should be (empty), uh open for people to (breathe). But if you were trying to fill a balloon, and the balloon was half stapled together,* ***don't matter how good your juice is, you're never going to blow the balloon up are you.***

Keith

Peter describes more of an obstructive disability to his COPD whereas Keith's view is that his lungs are restricted with their ability to expand. Both of these views are equally plausible because COPD is a term covering several underlying pathologies from airway obstruction to destruction of the alveolar walls i.e. both the 'tubes' and the 'lungs'. Nevertheless, with such varying perceptions of what their disease is, it may be important clinically to ask patients how they feel their COPD affects their lungs and how this relates to their perceived disability of their condition. For example Richard did not feel disabled because he viewed his bronchial cold as temporary whereas the perceived catastrophic picture that Joe described may be related to how disabled he feels and his perceived poor ability to cope with his COPD.

4.2.4.2 Summary

You feel that you have had a bronchial or chesty cold which is not actually COPD. You feel that you have had bronchitis which has exacerbated your COPD. You view your COPD as a restrictive rather than obstructive condition whereby you could not expand your lungs, or they are like a balloon that had been stapled smaller. In COPD, airways are like broccolli that are coated in mucous. The lungs are seen as worn out or weakened as the hairs in the lungs are soft and therefore cannot stop the bacteria from coming in. These hairs get clogged up like a cobweb. This makes you feel breathless as it can make you feel like your lung is collapsing. You generally see your lungs as a dirty environment, perhaps having stale fluid in the bottom of your lungs which germs get into, creating an environment like rotting meat. COPD destroys your muscles around your lungs. COPD could be a blockage to the airways to the lungs and not a disease of the lungs themselves.

4.2.5 Relationality

The participants who were interviewed compared their level of disability and their perceived ability to perform PR to other people of similar ages or those in the same social setting.

4.2.5.1 Comparing oneself to others positively

The overarching experience of uncertainty continues with the way in which participants viewed themselves as disabled with their COPD but nevertheless not as severely disabled as others with the condition. The first two participants both attended a COPD education seminar in the city where Programme B was run. This is where they registered their interest to be referred to PR.

> *P: um I thought I, I looked better than some of them (laughs). Um but mind you* ***when it came to it, I was as bad as them****. Cos I also couldn't walk. They gave tea and that and he had to go and collect the tea I couldn't get up. And start walking up and queuing up and I suddenly thought well I may look better but I'm not I'm just as bad as they are.* ***It's just some people look worse than others.***
>
> *Jill*

> *P: You know you don't, you adapt. You, you think I mean I think I've been to a couple of these do's where you meet people. We, we all get together and* ***I'm looking at them and think oh I'm not like you. But then when I'm out in the wind I think well I'm more than like them than I am like you****…this other I went to, this um this meeting the (people), the women there were very WI I would say* **(***laughs***)***…but bless their hearts you know…and in the* ***main they were dealing with people who were sort of feeling so, considerably later stages than me*** *and sitting around and saying to each other, oh my doctor says he don't know*

how I look so well! ***And I'm looking thinking you look dead mate, you look dead!***

Elaine

These participants originally perceived that they could not compare themselves to others at the education event. However, on reflection of symptomatic experiences that certainty was questioned and they felt like they experienced COPD in the way the others did at the education event. Elaine and Jill explain a point that has been noted from the researcher's clinical experience. Namely that looks can be deceiving with COPD, because it may not look as if people are disabled by their condition. Importantly, this is felt by the person with COPD and not just from those who do not understand the condition. Edward discusses how he thinks he saw a PR class finishing in his surgery and viewed his potential peers as "old dodderers". He viewed this positively as it made him feel that he would easily be able to do the exercises at rehabilitation and give him an ego boost.

P: I was in there as I say and I think I saw them, a, a group coming in that looks as if they're, (they) ***they looked like old dodderers actually****… if that's what I'm going to cope with I, I think all they'll do is sit down and, and do this sort of thing. I don't think they'll be doing the exercises that I would expect. Like well, we'll jump and down and touch your toes and all that. Um you know the old, the ones we used to do at school. And because (of) that I'm certain has helped me a lot. Because when you, when (you're) doing exercise of that sort and I'm doing that largely because I can't walk, well I can but uh…not the sort of walking I'm talking about…* ***they're a bit more decrepit than I think they'll be, that'll be an make me feel big headed****…which I suppose is a good thing in a way. But uh I want to go and see what it is, and what they do.*

Edward

Edward described his peers as old. He was in his late eighties. His perceived physical ability for his age was good, regardless of having COPD. Likewise, Richard, Sheila and Nigel all compared their ability to their age or the ages of others.

P: well, I. It was to me. I mean ridiculous you know I mean. I, I'm (coughs) eighty at the moment. I still got a bit of a (problem), I'm still a bit bronchial. Um, ***I'm eighty and uh you know fairly active****, I don't find that my breathing restricts me. You know (what) I mean? I, uh* ***a friend of mine could hardly walk fifty yards*** *you (know). You understand what I mean? And I mean whereas I can walk nearly three miles and I mean I there's, not there's* ***not all that many eighty year olds that will walk three miles****.*

Richard

Richard's good physical ability for his age made him feel that he was not restricted with his breathing, particularly because he could walk a far greater distance than one of his friends.

P: But then I look at myself and think gosh you know ***I'm quite fit at seventy five****. I look at other people and they're ancient, or dead… no I think having seen so many chesty people all my life as, as a nurse, that I think that* ***mines probably very easily controlled and acceptable.***

Sheila

Sheila felt, that for her age, her COPD was controllable and acceptable in comparison to other "chesty" people she has seen. She was coping well with her condition. However, at another point in the interview she described how she would ask to be assessed at home for PR as she predominantly lived on the middle floor of a three story town house. She felt that the only way the assessing clinician would understand her disability would have been to see how she copes at home. For many other participants they did not feel so severely disabled by their COPD. When participants compare their condition to that of others it may be the case that they are comparing their best abilities to those of others. This may lead to uncertainty with regard to how they perceive their disability.

P: ***(name)'s worse than me… Oh I'm thousand times better than (name)****…hope to Christ I don't end up like that, but knowing I probably will. That's, I don't want to end up like (name)…but I probably will…* ***and (name)s younger than me****… well I think it will (progress), progress to that stage…I know it ain't gonna get better, it can only get worse… I'll go and I'll sit there and do what they want me to do, even if it bloody half kills me. I'll do what they want me to do…Cos I know, (name) said something with, he feels (knackered) after some of his exercises...*

Nigel

Unlike Richard and Sheila, Nigel compared his COPD with someone younger than him, who was a friend of his. Because his friend had previously completed PR and continued to do exercises at home, this gave Nigel the encouragement that he would not encounter any difficulties when he attended a programme. Unfortunately Brigitte did not feel that her COPD was less severe than others.

P: I know I'm ***eighty*** *and when you think, going oh well you know about time to kick the bucket kind of thing. But the way, the* ***way I see some people at eighty who hasn't had a bad breathing or whatever, heart…I say my god, I was like that, why can't I still be like that?***

Brigitte

Brigitte discussed other cardiac and obesity comorbidities which may have also had a significant impact on her breathlessness. By Brigitte comparing her ability to cope with other people her age, this may have led to very depressing thoughts that she was close to dying.

4.2.5.2 Summary

You look better than other people you have seen with COPD, but practically you can feel the same and especially if the weather is bad. You feel that you will do better than other people at PR because they are “old dodderers”. You understand that there will be a mixture of abilities of other people at PR but you feel you will do better because in general you feel quite fit for your age and compared to other people’s COPD you feel that yours is quite controllable at the moment. If your friend with COPD can do the exercises at PR, then you feel you will be able to especially as his is worse than yours.

4.2.6 Conclusion

The findings above have described the lived experience of participants with COPD who have been referred to PR. Their experience is one of uncertainty, temporally, Corporeally and relationally. Temporally this uncertainty manifests itself in the participants’ experience of panic. Uncertainty can be seen Corporeally in the confusion with which some participants describe their COPD. Furthermore, as participants compare themselves to others, many feel that their condition is less severe than that of their peers. However, these comparisons may often be made without knowledge of how disabling COPD is for the other individual because the disability is often concealed behind how the individual looks for their age.

Uncertainty may cause an individual to experience COPD in a way that is more disabling than maybe necessary. For instance, the panic which causes participants to feel petrified could be reduced if participants knew why they were getting breathless and to what the symptoms they were experiencing were attributed. Furthermore, they may have a better understanding of the treatment and diagnosis process. Being kept in limbo caused unnecessary frustration for these individuals. A lack of knowledge with regard to PR seems to lead COPD individuals on a journey through PR which does not hold much value and is relatively free of commitment. Through uncertainty, participants are fearful about the quality of life they will have just before they die. Some participants viewed the pathophysiology of their disease in a way that potentially disabled them further. Finally participants questioned the importance of interventions that are offered to them if they felt their COPD was not as severe as others who have the condition.

The next part of the findings will develop the theme of uncertainty for those participants who completed, dropped-out or failed to start the programme

5. Findings: Post-programme Analysis

The post programme analysis will aim to answer research question two and three of this study. The analysis of the experience of those participants who completed a PR programme is presented first. Subsequently the analysis of the experience of those who did not complete a PR programme is presented. The analytic summary completes the chapter.

Figure 4 provides a representation of the themes of analysis from the participants' pre-programme experience to their post-programme experience.

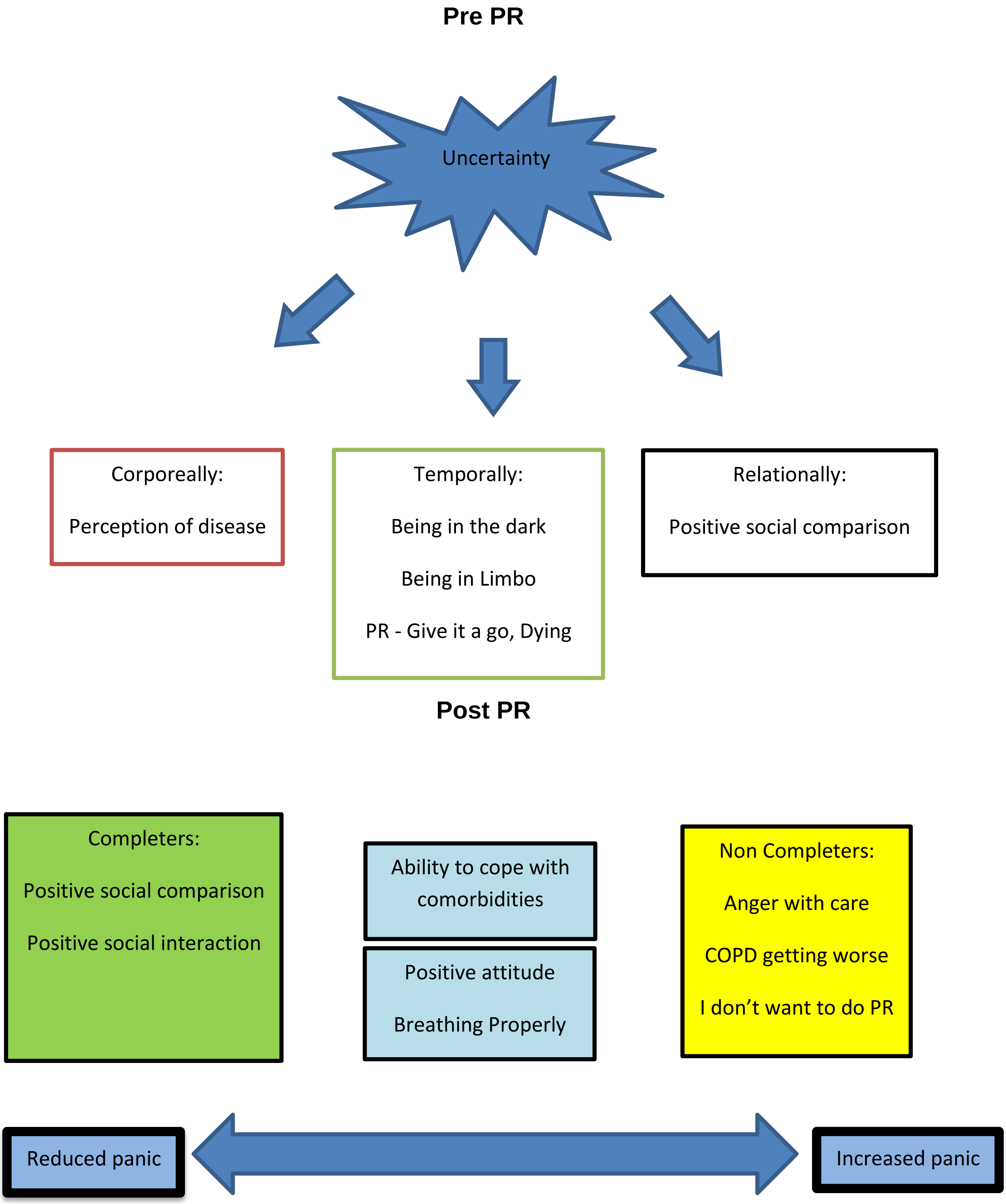


Figure 4: Pre and Post-programme analytic themes

The main finding from the post programme analysis is that the experience of uncertainty is reduced in those participants who complete a programme. Therefore, their experience appeared to reduce their levels of panic which can be seen on the left hand side of the diagram. Those who do not complete PR seemed to have a level of continuing uncertainty and many continued to experience panic. However, some participants who did not complete a PR programme also seemed to gain significant benefits in their ability to cope with COPD if they received other interventions targeted towards their breathlessness rather than completing a PR programme. For example, some of these participants gained a positive attitude towards their future without continued participation in a programme. Those who completed a PR programme appeared to be able to cope with their comorbidities more than those who did not complete PR.

5.1 The experience of completing PR

Themes have been categorised into those which are relational, corporeal and temporal in order to relate to the phenomenological lived experience of participants.

5.1.1 Relationality

5.1.1.1 Positive social comparison

The positive comparison of one’s ability compared to others started before these participants attended PR. Participants who went onto a COPD education seminar before PR had the opportunity to compare their abilities with other people at the seminar and may have thought they would be able to do better than others on the PR programme. These participants also thought that they did not want to let themselves get to a more severe stage of COPD and were therefore encouraged to do rehabilitation.

*P:…one thing I did find extremely interesting was going to a meeting where we were all to greater or lesser degrees on some sort of ventilator…and being shown how to use them…and thinking to myself, surely to God you've spent goodness knows how much on prescriptions for these things. Surely to God you are, you find out how to use it before you got it…And people were doing all sorts of things with them…**I'm sure there are a lot of people that are maybe put off by the state of the other people that are at the meetings…because it's a bit like looking at your future…and the future's neither bright nor orange**…I think because that main meeting was awful. I do you know. Isn't it dreadful. That was awful, but they did have biscuits and teas so it wasn't too bad* **(***laughs***)***. Um I went to the rehab expecting it to be on the same sort of the same standard as that big meeting and it wasn't. It was far more professional. That meeting, every time any, uh the women at the front held up, and some people will be taking this inhaler, sort of fifty old blokes were oh I'm taking that one, I've got that, you know. Oh sit down, shut up. Listen to the woman. And, and finding out that half of these people aren't using the things correctly.*

A: How would you compare the difference between the people who you met at that breathing meeting and the people who you were with on the rehabilitation?

P: Oh crikey chalk and cheese. I would um, ***I would say as a blanket thing the people that staggered in all being helped by what have you, uh were drowning not waving. Whereas the people at rehab are waving not drowning.***

Elaine

For some of these participants the COPD education seminar seemed to act as a wake-up call in the same way that others described PR. The quotation from Elaine above suggests a fundamental difference to those patients who accept the offer of PR and those who do not. It is as if all patients have fallen out of a boat at sea after being diagnosed with COPD. Elaine's quote above states that "people at rehab are waving not drowning". It may be that Elaine perceived those people waving wanted to be helped and those drowning did not, or they have given up.

Many of those participants who completed the programme thought that they had a more successful experience than other people on the programme. When participants compared themselves with others on the programme, their age was important in determining whether they believed they had a successful PR experience. This was true for both the younger and older participants. The younger participants perhaps thought that they had greater potential to do more exercise compared with older participants. They seemed to view older people's age combined with other comorbidities as more disabling than the COPD itself. Some of the participants also showed a competitive nature when comparing their ability with others:

> *P: They pairs you into twos which is fair enough. So you're like, you're encouraged each other. Well I'm, me and (name) can match each other going like, uh, like sit to stand, um, and uh leg lunges and things like that. We are more matched than say me and (name), who I was, who, who, who I partnered before. And, but* ***she's eighty one*** *so …it's obvious who I'm gonna (win),* ***it's not a, it's not a competition but I'm gonna win anyway.*** *And you gotta write how many you've done. Well, all with me and (name) would always win because we're so, you know* ***they got forty years on some of us.***
>
> *Jane*

> *P:* ***I was top of the class****…seventy seven years of age and I beat them all. They were all younger than me…they'd never seen anybody at my age, achieve so much. She'd never, in two years, she'd never seen anybody achieve it.*
>
> *Dave*

Other participants perceived they gained a more positive experience during PR because they put more effort in compared to others on the programme. For some of these participants putting in more effort did not mean that they felt more disabled through increased breathlessness. Other participants did not feel the benefits of exercise unless they were sufficiently exerting themselves to get significantly out of breath.

*P: … **these others I mean you, you pass em about four or five times** like, you know. Because they're, they're so bloody slow, and me I, I'm just, walk round and it doesn't bother me at all…let me put it this way, fifty per cent of those people are what I call lazy people*

Leonard

*P:**…they're not exerting themselves and that's what they wanted us at as**, say (name) bit faster, legs up (name) legs up you know, (name) slow down cos I was going fast you know that sort of thing but they like to see exert yourself to recover and see how you how you are*

Tony

Tony's perception was that the staff on the programme wanted to see patients exert themselves in order to judge how well individuals recovered from their breathlessness. It is possible that he perceived he was better able to exert himself during exercise compared to others on the programme because he needed no encouragement to work harder and was told to slow down. However, this may have shown a limited ability for him to pace himself during activity.

Some of these participants attended PR as a result of attending the education seminar. These participants also completed the PR programme. Therefore, it appeared that the attendance to the education seminar was linked to continued attendance to the PR programme. However, the education seminar was not always experienced beneficially at the time they attended. The importance of the seminar could be in its potential for people to compare their condition with others. After seeing other people with COPD at the education seminar, participants may have believed that they had a better ability to carry out PR, or they may have looked into their future in comparison to others and this encouraged them to do PR to delay further worsening in their condition.

5.1.1.2 Positive social interaction

Participants enjoyed their experience of PR because they were able to have a laugh and a joke. For some participants this laughter was shared among other patients. Others gained more of a positive social interaction with staff on the programme and valued the staff's charisma and "driving force" because it enhanced participant's motivation and perception of freedom. It appears that when participants could have banter with the staff on the programme they seemed to work harder to thank and reward the staff. Part of having a laugh was being in a group activity which in itself was therapeutic for participants.

*P:…**We could have a laugh.** I mean some people were really very poorly. **Some people were really very old**… Some people to get up on a stepper was a hell of a to do. They got two sticks…But we'd sort of say oh well, oh so and so (is) gonna do sixty a minute now aren't you! And she'd laugh and do her five or whatever. It was you know, but no, it was jolly good. **I think group, group activities are very therapeutic.***

Elaine

*P: So I've gotta make an appointment to go there you see, so I'll go up there and disrupt the whole class again. **Have a laugh. You have a good laugh there and***

make them relax, enjoy it. *Some people are too serious… and we used to have a laugh and jokes with the girls. (Wind) there, and wind everybody up with our jokes…****we all had a laugh taking the mickey out of each other.*** *I would say look at it (name), you're not going straight up. (Name) tell him off. You carry on with your own. Yes dear… yeah, they were a lovely crowd I enjoyed the company. I enjoyed going up there I looked forward to it you know.*

Dave

Dave was having a laugh with the clinicians on the programme rather than with other patients on the programme. Dave was "taking the mickey" out of other patients in order to wind the staff up. However, not all participants who completed a PR programme perceived the staff on the programme as effective at stimulating positive social interaction. This was because a more serious atmosphere was created or it was perceived the staff used a more dictatorial style of communicating with patients.

*…****we had someone new, different last week and it didn't work****…We had the strict hour one fifteen to two fifteen, and then we were all out. Well with (name) we stand around talking and you know, um but it didn't work with that one…it was um very regimented… where with (name) we have a laugh and a giggle and you know* ***he makes it feel worthwhile****… he makes us feel good …I had (name) straight off, he assessed me and he said from the start oh yes we can help you. Before I even did the walk. He said he could help me, where maybe the person who uh, she got a funny name (name), always get it wrong, um, had it. Maybe she was feeling a bit on off that day.*

Jill

…she's only a tiny little lady but she um, ***she takes no prisoners****. She's quite a, she talks everybody actually as if, if they're about five years old.*

Sue

The participants above describe situations in which they found the PR programme enjoyable. An important part of the enjoyable experience appears to be the personality of the clinician running the programme. In a PR programme which was perceived as good fun, the clinician initiated or allowed banter between participants and also allowed participants to joke with the clinician. This possibly enhanced social cohesion within the group. This positive social interaction was reduced when staffing changed throughout the programme or patients got spoken down to. The possibility that participants were being spoken down to was interpreted from Sue's perception that everyone was talked to as if they were about five years old. This is a potential major difference between the two programmes in this study whereby participants perceived one of the programmes as fun and the other programme less so.

5.1.2 Temporality

5.1.2.1 Positive Attitude

Participants recognised a positive attitude in themselves once they completed PR. This positive attitude relates to how they view their ability to cope with their condition and their outlook towards the future. This positive attitude resulted from feeling more relaxed and calm about having COPD. Other participants were more positive about their condition because they felt more in control of their condition so they were coping better and regained confidence.

P: ***I feel more positive about the condition.*** *Is made a difference you know, um. Cos I think you know, your psychological mind is just as important as your physical really…because I'm not where I was before Christmas. Where you know I was sort of sat here with my phone doing, oh I breathed in for ten seconds and I* *breathed out for five…I mean* ***I was like somebody possessed. I was like freaking out twenty four seven.*** *Where you know I'm, I'm, I am* ***more relaxed about it so***

Sue

It is the change in the "psychological mind" which led to a positive attitude through being relaxed and calm, as Elaine reinforces. For Elaine it was the reassurance provided by the clinical team that was fundamental in enabling a positive attitude.

P: ***I'm a lot calmer about it (****laughs****)****. Um, I know that I can phone somebody. Cos they said you know if you're ever up, you know bothered, give a ring…,* ***it's given me much more of a positive attitude****…gave me a much more positive attitude. Which I think when you've got any sort of condition, is half the battle,…Surprise was that it also eased up my arthritis at the same time.*

Elaine

P:…Because I know that really it's that word again, I can cope with everything now… it's given me back the confidence. Whereas before I felt very oh, it was talking over. I was ill before. Now I don't classify myself as being ill... I wasn't coping. I wasn't doing anything I was letting that rule me…I think I am winning now. Um this was what I said at the beginning. ***I let it take over me. Now I'm taking over it.***

Jill

Jill states "it's that word again." The word she was referring to was "cope". Being able to cope meant that Jill felt that she was winning her fight against COPD. For many of these participants this positive attitude meant that they did not think about dying so intensely and were able to push their death further into their future:

P:…*before I went I really did feel* ***death was knocking on my door****…Now I don't um because…my lungs, my body is gonna deteriorate as I get older. Everyone's is you know… so my lungs are not very, very, very good now. Um and obviously as I get older my lungs won't be as good, my heart won't be as good, my walking won't be…So I'm not just focusing on lungs, lungs, lungs, lungs, lungs, lungs.*

Sue

In order to gain a positive attitude, participants needed to become confident in their ability to control their condition, or gain a feeling of starting to win a battle against their COPD. This enabled participants to feel calmer and more relaxed with living with COPD. The reassurance, support and fun provided by the PR teams created the atmosphere within which this positive attitude could be nurtured. Other participants described how their positive attitude was strengthened when they had experience of attending a continuing exercise maintenance programme provided by the same staff, or they were looking forward to attending such a maintenance programme.

5.1.3 Corporeality

5.1.3.1 Breathing properly

Participants benefitted from PR if they learnt to breathe properly. Participants could track their own improvements in their breathlessness and understand how their breathlessness affected them in the past, whilst learning strategies to control their breathlessness in the future. PR provided these participants with tools, such as the Borg dyspnoea scale, that enabled them to track their breathing progress more easily.

P: *I'd be paired with (name), or with (name), or, or ,(name) and* ***everyone's Borg was coming down so they was definitely breathing easier as the weeks went on*** *… So it's, you can see it for your own eyes. You don't need (name) to tell you.* ***You can definitely breathe easier****… You do your two minute exercises and then you write on your, you write your Borg or whatever it is, so how many you done, and then what was your breathing level. And that's how (name) after your eight, seven weeks he knows if you've improved. So running on the spot, when you first started it, if at the end of it you couldn't breathe and it was a level four, couldn't breathe. And then after seven weeks it was a level one. You've improved.*

Jane

Breathing control strategies such as pursed-lip breathing were seen as very effective in enabling participants to control their breathing. The panic that patients experienced before PR was reduced once they learnt to control their breathing.

P:…instead of getting into a panic about it, just, just stand relax and sort of like you'd breathe instead of going **(***gasps***)***. Cos* ***you can't breathe properly which you just sort of go, and you do this sort of like purse, which brings your breathing back****… a lot quicker. And little, little things like that, that you wouldn't have known. Um, and you would have got into more of a panic. Because um, you couldn't breathe you know um.* ***Trying to learn how to relax…um it doesn't freak me out as much.***

Sue

P:…and if I do feel a bit panicky, what for some reason, deep breathing, and then I'm alright. ***It's all in the mind I think half of it****…****if they get you breathing properly that's half the battle, well three quarters of the battle I think****. Well it was with me…I wasn't breathing properly and you're panicking you know. And, and (name) said, what's wrong with your inhaler?...But now, sit down, relax, do me breathing, away you go. Back to normal…Cos I'm not going to get any better you know. But I can control it a lot better now within myself you know. Whereas before you know,* **(***gasps***)** *breathing like that you know. Said deep breaths, control, relax…well at first time I was a bit worried (to) get out of bloody, you know. well wait. Until I, well done the exercise, a, uh, one of the exercises fast, and they was a like, sat down breathing you know. And I was going* **(***gasps***)** *sort of thing. You know and had to say breathe, you know you,* ***how to breathe properly you know…and after a while I was alright****. Next exercise I got a bit tired, cos of first time I been round for yonks. So I sat down, done me breathing and I was happy. Cos I knew I could recover properly you know.* ***Whereas before I was, I, I suppose I panicked.*** *You know like that (pressing) in* **(***gasps***)***, oh panic a bit you know and. But now I don't panic.* ***Cos I know if I'm out of breath sort of thing, sit down, relax and do breathing properly.***

Tony

Participants who completed the PR programme got significant benefit from learning to breathe properly. This seemed to work in combination with participants learning to relax. The importance of learning to breathe properly enabled participants to gain control of their symptoms of panicking. Furthermore, participants more readily associated their breathlessness with panicking in past experiences in comparison to their current experiences of breathlessness. The themes of positive attitude and breathing properly appear to be very closely related in terms of reducing the feeling of panic.

One theme that was shared between completers and non-completers was the ability, or lacking ability to cope with comorbidities. This related to differences in the way groups of completers and non-completers perceived the way they coped with comorbidities.

5.1.4 The ability to cope with comorbidities

COPD participants who completed the programme did not appear as disabled by their comorbidities in comparison to those who did not complete PR. Those who coped with their comorbidities were used to self-management of their comorbidity or had hobbies which meant that the COPD was not significantly noticeable.

P: I was a gym freak. I was an absolute gym freak. But what you've got to understand is um, I didn't notice what was happening with my breathing. Because I have developed osteoarthritis rather rapidly…so I was a gym freak…and it was anything that was happening was a bit overshadowed by the fact that I was in the gym.

Elaine

In the above quote, Elaine is possibly discussing two separate points. Firstly, she felt that she was more focused on the pain and limitation from her arthritis compared to her breathing. The osteoarthritis appeared to limit her being able to do the same activities that she would have done in the past when using the gym. Secondly, she felt that because she was going to the gym frequently she was used to getting breathless and therefore did not notice her deterioration of breathlessness as easily.

P: It's when you sees the diabetic nurse and that they, they do listen but they, they says the same thing. My doctor told me to go out and have a load more insulin cos she said my, my insulin doses were baby doses yeah. But if the more insulin you have you aren't half gonna have to eat more so I don't. I'd be on my *sixth slice of bread which is obviously a carb before twelve o'clock in the day time. Now you carry that on you're gonna end up the size of a house yeah…it's dangerous. So what I done on every rehab day is I lowered the insulin. Otherwise like you, I'd just be eating too much and always going into a turn so it wasn't worth it. like a few times (name) joined uh rehab. I had to uh have, I had to have bloody raw sugar the first time cos I felt myself going too funny too quickly. Um, and then after that, shored it up with biscuits after rehab um. Or on a bad day I'd have to have bloody stuff before going in to do the exercise do you know what I mean. So in the end I just lowered the insulin and I thought, you know just deal with it like that…So that's how I, I'll coped with that.*

Jane

Unfortunately other participants who did not complete a PR programme were less able to cope with their comorbidities. These participants found that each comorbidity negatively affected the other.

*P:…it might sound silly. Well yeah you can do this, you can do that but when you got (a) dodgy hip as well, its uh. If I was quite able to walk then it wouldn't be so bad…I'd be slower, but…**it's all a combination, now it's a very hard**.*

Peter

*P:…so probably if I can get that sorted, but then, if its arthritis it never goes away again. It's one of those things that stays with you for the rest of your life so, I just don't know. It's, **it's one thing fighting against another all the time**. It's very, It's very hard to walk and be able to breathe properly at the same time,…*

Joe

From the analysis above it appears that some participants were disabled by their comorbidities, to an extent whereby they felt they were not fully coping with them, or they were restricting their ability to cope with COPD. These participants did not complete a PR programme. Those who were independently continuing to perform activities regardless of living with comorbidities did complete PR. By the time patients get COPD, many may have other comorbidities that may be due to the systemic inflammatory nature of the condition and lifestyle factors such as smoking that contribute to other comorbidities.

5.2 The experience of not completing a PR Programme

The experience of not completing a PR programme had fewer similarities among participants than those who completed a programme. Some of these participants' post-programme experiences appear closely related to what they had previously discussed in their initial interviews. Therefore, it could be interpreted that these participants are looking more comfortably into their past rather than their future. The majority of the participants who did not complete a PR programme seemed to remain living with uncertainty in regard to living with their COPD. There are a few variant cases which will be described below.

5.2.1 Relationality

5.2.1.1 Anger with care

In contrast to those participants who completed their PR programme, it appeared that the participants who did not complete a programme had received a standard of care that led to increasing feelings of anger, disappointment and frustration. Participants had been given information that led them to believe nothing could be done to help them further. Participants were kept waiting for future interventions without understanding why they were waiting for so long. Others perceived their care only improving once they had been hospitalised because of their COPD.

P:…panicky, very panicky. Cos I think it's worsened…At my doctors they don't really, I haven't heard anything from the clinic whatsoever. Um, and when I went on Friday I did mention it you know. Uh but apparently ***they haven't sent the appropriate paper. It has been going on since last November and it's not satisfactory whatsoever*** *really. I do, I'm very disappointed that it's taken that long for a referral you know…and I said* ***there is obviously no communication between one team and another*** *…you know so I'm not happy with it at all. But I will push. I will go back on Monday and I will see what's happening about it. I, I* *will be a pain in the arse now…Because I think I could have valuable advice from them about uh, you know like when I'm under stress or if I'm not sleeping or. The, the, there is things that they do for other people, exercise, and I've heard so much about (it) I want to be part of that. And it's my right, simple.*

Pauline

Pauline appeared to have had enough and was very frustrated. Her anger that she expressed during her first interview was still evident in the second and caused her a great deal of stress. This can be interpreted in the statement that she will be a "pain in the arse now". She felt as if it was her right to go to PR. She had not heard from the PR team and she felt that her referral process was taking far too long which ended in a feeling of disappointment.

Some of the participants received information which led to confusion about whether they believed they had COPD or not. This is illustrated in Phyllis's quote below. However, in contrast to other participants who did not complete PR, these participants did not seem to be angry or frustrated. Their reduced level of anger compared to other participants perhaps occurred because they felt less disabled by their COPD:

*P:…**the first one doctor tells me I've got uh, um emphysema. The next one tells me I haven't. And that's how it goes**. So my daughter says to me, we're never gonna know. So we just go carry on. But um, I mean I've always had a slight sort of chest infection there really you know, but uh as I say, its, it's one of those things.*

Phyllis

P: I can't understand what's happening though because I went to (name), to the rehabilitation place and I went under all these tests like stand up, sit down for two minutes while you're on a stop watch and everything and they're monitoring you all the time and she turned round to me and she said what are you doing here? ***I said well my doctor and the nurses have all said I've got COPD and that I'm to start a course here. She said, well we can't find anything wrong with you so I don't know what's happening.*** *I've got to go back on (the) twenty fourth of this month and they're going to do further tests, but I've not had to use an inhaler. I've had no trouble with breathing or anything so…See I don't know how they diagnose it in the first place so I'm none the wiser…See* ***I don't know what you know the symptoms are or anything*** *so I can't say oh I haven't got it. But as far as I'm concerned you know, it's nowhere near as bad as my friend and she's only in her forties…and he said, oh you've got chest infection when he listened in. He said, I'll put you on a course of antibiotics. So took the course of antibiotics and I suppose I should have really gone back to him and told him I wasn't feeling any better. But I didn't. I just left it. And the following Tuesday I had to go and see a nurse for my test. But if I'd gone in to see him on the Friday when I'd ran out of tablets and started another lot, it might (have) been different.*

Katherine

Katherine perceived her condition had improved since her first interview because she no longer needed to use her inhaler and she did not feel breathless. Katherine and Phyllis may both perceive their COPD as temporary chest infections.

These participants explain experiences where they have either felt let down by their GPs or practice nurses, or feel confused or still in the dark in regard to the care they received for their COPD. Many of these participants remain 'in the dark' and are kept 'being in limbo'. This frustrated many participants, but this did not seem as concerning for those who perceived their symptoms as temporary. It appears that being 'in the dark' and 'being in limbo' are two temporal aspects of the experience of uncertainty which manifest into the experience of panic as previously discussed in the last chapter.

5.2.2 Relationality/Corporeality

5.2.2.1 I don't want to do PR

Participants interviewed a second time who did not complete a programme discussed the fact that they did not want to go to PR. Participants lacked motivation, did not want to exercise in a group, felt unable to leave their home or thought that they would waste clinician's time because they believed they did not require any help. Some participants believed the most beneficial way to learn how to live with COPD was to learn from previous personal experiences:

> *P:… it's alright having um group meetings. I think well because you can talk about peoples own experiences um…**I personally think if you learn from your own experiences then what you do to overcome the problems you get with it**... until they actually do a full analysis on me um, which again is gonna take time, um, they can't really tell me which way I'm gonna go…**they can't actually diagnose what's actually caused it**. It's because in the past I've worked with acid chemicals so breathing in that does not help. Cos back in my teen days when I was working for a firm, they didn't have the masks or anything, you had a set of rubber gloves and that's it……well hopefully it will start soon. But I've got really, **at the moment I'm getting myself back into my routines,** even though it's a different place of getting myself into a routine.*
>
> Peter

Peter's perceived impending investigation may relate to the floating in the system that was described in the pre-programme analysis where it was attributed negatively as an experience which led to participant uncertainty. This uncertainty and Peter's subsequent delay in pursuing PR gave him more time to get settled into his old routines in a new home. This uncertainty seemed beneficial for Peter in the post programme interview. Joe believed that he was too severely disabled to put more pressure on his body at PR.

> *P:…the woman up there, she was concerned because I wasn't doing enough walking. That's what she was concerned with. But then the one she, she had it all on paper. One of them there was walking round and round the chair for half an hour. I couldn't do that, you know. I (could), I can walk five minutes and I have to stop. You know I have to find something to lean again I have to stop… and I thought well as I was bad* ***I didn't really wanna go and put any more pressure on my body than there was already****…I think you got to do some walking you know. You got to whether you want to or not and okay if they say alright you go round the chairs two or three times you could probably do it, but* ***when you're talking a half an hour at one go, that's an awful lot of time for a person that has (a) job to breathe****.*
>
> *Joe*

Participants who did not want to participate in PR seemed content in their decision. Furthermore, participants continued to think of other people who may be referred to a programme that could have gained more benefit or would have been more likely to complete the programme. Participants did not want to do PR because they perceived themselves as being either too disabled or not disabled enough by their COPD.

5.2.3 Corporeality

5.2.3.1 Getting the benefits without completing PR.

Some participants who did not complete a PR programme appeared to gain similar benefits in experience to those who had completed the programme. These non-completers seemed to be able to gain a positive attitude and better control over their COPD, panicking less and breathing better. Peter describes how he gained many benefits from learning to accept that he was disabled with COPD.

P:…you gotta learn to you know take it easy, do it steadily. Especially when you're getting out. Because if you, you know, slip or anything, you hurt yourself. Um if you take it nice and easy you're not getting too out of breath…and you control, ***you're in control of what you're doing****…. they always say try and keep calm, try and keep calm. Well that to me is the way I stay calm. If I don't put my body under stress, and it starts making you panic, then I,* ***I won't end up panicking,*** *and trying to use the inhaler more and more and more. And then become reliant on it, which I don't want to do. I want to use it as minimal as possible so that I'm still using my lungs myself… but if you can't do it, accept it. It's the* ***biggest thing of all. Accept it****. Get on, deal with it and then you'll find in a few weeks it's just a part of normal life again. You know you can do, oh I can't do that. Don't feel down about it. Get up, do it to what you can do you know...I know this is going to sound funny, um but because I'm lighter it's easier for me to get round. I know I've got problems with me hip but that's nothing to do with COPD…But because I'm lighter, it's easier getting round and* ***I'm not so struggling with me uh breathing****.*

Peter

Some of those participants who have not completed a programme have also been able to push death further into the future in a similar way to those who completed a programme:

*P:…****I'm gonna die and no matter what they were saying to me that's the only thing that stuck in my head****. Cos I thought you need your lungs to breathe* *you know… The future is not so bleak for me now. Whereas before it was you know oh you won't, can't do this, can't do that… now I can look forward to the future and think well yeah good you know. I can do this so we'll have a go at it and see what happens.*

Sandy

Non-completers have described improvements that have been described by participants who have completed a PR programme. These improvements seemed to have resulted from a reduction in their experience of panicking which led to participants having more control of their breathing, having a more positive outlook towards the future, starting to do more exercise and increasing the amount of time they spend socially with others. All of these participants had some significant clinical interaction in regard to their COPD. This was not always provided by the PR teams but also through being admitted to hospital.

5.2.3.2 The COPD is worse.

In regard to living with their COPD, many participants felt that little had changed and they were indeed getting progressively worse. They still panicked, were frustrated, angry and continued to experience uncertainty.

P:…Not too bad. I had a bit of a scare and (name) was here and she put on a, um, a couple of the tablets and mask and I uh you know, half an hour later I'm okay. But it was a bit of a scare this morning. But that's why it's all on the chair… I got out of the chair there bit too quick, which gave me a shortage of breath, got to the sink there and I just couldn't move. So fortunately she was coming back…called her in and she just broke um two of the vials. Put them in the mask, gave me the mask and turned the machine on for me. Sat here ten minutes and as is now sort of thing like that. But it was a bit, bloody thing. Um, yeah so that was it this morning. Happens now and again… just probably um, ***panicky a bit***

maybe**…when you're out of breath you know, come on you're out of breath and of course you can't move.* ***You're gasping for air. You have to stop you have to use the inhaler, or like this morning the nebuliser…and it can be quite frightening.

John

P:..And I'm gasping for breath you know I end up, if I'm not careful, I end up swallowing half the bloody shampoo, because it's going down (my) face. I'm washing it off and because I been there doing you know, and it's got to the stage my missus comes in and washes me hair for me now. I can't do it no more…Well ***when you can't do things like that then you get frustrated, you get angry, you get frustrated and oh, dear I do, I get so angry.***

Joe

***I worry and I panic** and I feel oh, if that's gonna be my life with an oxygen mask.*

Pauline

These participants appeared to be getting more worried and were still experiencing further panic. They did not appear to be able to gain control of their breathing in some circumstances or rely on other people and often got frustrated. These participants also remained in the dark with regard to what PR was. In the previous theme participants seemed to be able to cope better with their experience of panicking following various interventions. However, these participants could still feel that their COPD was worsening. Those who have not had any significant self-management intervention from clinicians were still floating in the system and have experienced greater panic as a result. The experience of panic was shown to be a result of the temporal experience of uncertainty as shown in the pre-programme analysis. This seems to have been true for many participants who had not completed a PR programme.

5.4 Summary

The post programme analysis has detailed themes relevant to those participants who had completed a PR programme and those who had not completed or started a PR programme. The experiences in the post programme analysis were more varied than those in the pre programme analysis. However, the experience of uncertainty is still present in the ‘Anger with care’, ‘I don’t want to do PR’ and ‘the COPD is getting worse’ themes of the non-completers. Unless these non-completing participants received other multidisciplinary clinical interventions in the time between pre and post programme interviews, their experience of panic was still disabling for them. For completing participants, the experience of panic was significantly reduced when participants learnt to breathe properly and developed a positive attitude alongside a supportive clinician who enabled participants to have a laugh in PR. It appeared that as their experience of panic was reduced, they did not feel as uncertain over their symptoms anymore.

6. Discussion

6.1 Introduction

This discussion reviews the purpose of the study, and phenomenological terminology and discussion is embedded throughout this chapter. This highlights how phenomenological methodology was used throughout the thesis, not only for the purposes of being able to use a rigorous research method and analysing data, but also highlighting how phenomenology was used as a way of thinking with philosophical grounding. Therefore, discussion points are explored with relevant phenomenological literature that was influential in the development of the thesis methodology. Phenomenological concepts that have been used as part of the discussion can also be referred to in the glossary of terms at the end of the thesis. Findings from the pre-programme and post-programme interviews are discussed integrally and the points of discussion led the researcher to provide recommendations which could develop clinical practice and stimulate further research in COPD and PR. These are provided at the end of the chapter. Findings are contextualised with published literature which relates to clinical practice. Some of this literature is related to studies which have included COPD patients. However, other studies have included patients with other conditions in order to contextualise whether the discussion points are essential to COPD or incidental and occur across other chronic illnesses. This represents a stage of the methodology influenced by van Manen (van Manen, 1990). As previously discussed, reflexivity is an important aspect of applied phenomenology. Therefore, a reflection of the researcher’s role in the research is provided and written in the first person because it is a description of his personal experience.

6.2 Purpose of the study

The aim of this PhD candidature was to increase the understanding of patient experiences of their own COPD and PR, from the point after which they had been referred to a PR programme, to when that programme had ended. The increased understanding of the patient experience may enable clinicians to treat patients with more empathy in order to improve the quality of patient care. Furthermore, it is likely that this increased understanding will help clinicians to develop new approaches to PR programmes, or to stimulate debate about how COPD patients are referred or assessed to enter PR programmes. In order to achieve this aim three research questions were created:

1) What are the experiences and expectations of patients with Chronic Obstructive Pulmonary Disease (COPD) who have been referred to a pulmonary rehabilitation (PR) programme, but have not yet started it?

2) What are the experiences and perceptions of patients with COPD who have been referred to a programme after that programme has ended?

3) What are the experiences and perceptions of patients with COPD who have been referred to a programme but do not complete or start that programme?

6.3 Discussion points

The questions above have been answered separately in the findings chapters. The discussion points have been presented thematically in order to incorporate the findings from both pre- and post-programme interviews.

6.3.1 Uncertainty in COPD

6.3.1.1 Introduction

The experience of uncertainty occurred throughout the lived experience of COPD derived from the pre-programme analysis and began with participants' lack of knowledge with regard to how their COPD was diagnosed. This lived experience of uncertainty is similar to COPD patients who were directionless in the longitudinal study of severe COPD patients in Scotland (Pinnock et al., 2011). The patients in their study found it impossible to identify a beginning in their COPD story, and relates well to participants' experience of 'being-in-the-dark' in this study. Chan (2004) also describes the experience of uncertainty for COPD patients in their past, prior to having PR. Small and Graydon (1993) state that COPD patients who have been hospitalised experience uncertainty with regard to their future, and some patients experienced the constant threat of death. Patients in their study believed they had the resources to cope with experiencing uncertainty through developing a positive attitude, hope, acceptance and making positive comparisons with other people. This study indicates that the experience of uncertainty is reduced for participants after completing a PR programme.

6.3.1.2 The uncertainty of "floating"

For participants in this study who were angry or disappointed with their COPD care, they seemed to remain "floating" in the NHS with an uncertain future. '*Floating*' has been characterised as a positive effect of PR against the sinking nature of living with chronic lung disease (Toms and Harrison, 2002). These two concepts of floating are different. The "floating" in this study also relates to the participant uncertainty with 'Being-in-Limbo' about their care in the present. The experience of "floating" in the study by Toms and Harrison (2002) is a positive but more temporary phenomenon of coping with COPD which can be lost months after patients finish PR. The experience of "floating" from this study is more similar to that of the concept of '*stagnation*' described by Williams et al (2011).

‘*Stagnation’* relates to the patient perception of no movement of their condition after being told by clinicians that their COPD would not improve (Williams et al., 2011). The term “floating” may be more appropriate than ‘*stagnation*’ to describe the uncertainty experienced by people with COPD as it is more closely associated with ambiguity and unpredictability, which are central to the concept of uncertainty (McCormick, 2002). “Floating” may imply a lack of stability, whereas stagnation is better related to a lack of movement. The experience of “floating” seems associated with anger and disappointment for the participants in this study. This means that participants may have expected better care from the NHS and felt that they were waiting too long for consultations, treatment or therapy. Prompt and regular communication with patients in Primary Care may reduce this experience of “floating”.

6.3.1.3 Uncertainty in the future and dying

The COPD participants in this study felt they needed to be told they have a future with COPD. This became clear following PR, where it appeared that clinicians could reduce the burden of patients thinking that their death was closer to them than previously thought. Closeness as a concept forms part of the spatial lived experience of participants. This closeness is not related to measurable distances, but what is held close to the participants in their circumspective concern (Heidegger, 1962). When something is brought closer in spatiality it is thought that one has a tighter grip on it (Romdenh-Romluc, 2011). Furthermore, Merleau-Ponty describes what is close to experience as depth of perception (Romdenh-Romluc, 2011). Therefore, what is close in experience is what one perceives in circumspective concern, on which they have a ‘*tight grip’*. This research suggests that following PR, participants are able to loosen their grip in perception of their own death. This may be exemplified by the fact that participants discussed their attitudes towards their own death to far greater an extent in the pre-programme interviews compared to the post-programme interviews. This difference in disclosure has been described as pushing the ‘closeness of death’ further from immediate experience.

6.3.1.4 Hope in uncertainty

The lack of hope given at the point of diagnosis was a finding in the pre-programme analysis of this study and many participants gained a positive attitude with hope for the future following PR. Patients have stated feeling increased levels of vulnerability at the time of diagnosis which came from the perception of being told they have an incurable disease (Halding and Heggdal, 2011). The perception of an incurable disease does not give patients hope for the future. However, patients perceived strengthened hope following PR (Norweg et al., 2008, Halding and Heggdal, 2011). Moreover, COPD patients with higher levels of hope have been shown to have higher levels of self-care and optimism (Alberto and Joyner, 2008). The findings from this study highlight the development of hope longitudinally. This study illustrates that the perception of strengthened hope may be due to patients being able to push the ‘closeness of death’ into the future following PR and is linked to the previous discussion point. The relationship between hope and ‘the closeness of death’ for COPD patients is a new finding in PR research. The relationship between hope, perceived longevity of life and the role PR has in changing these perceptions could be explored further as they may significantly affect COPD patients’ ability to cope with their disability.

Hope was described as temporally changeable through participation in PR. Hope may be an experience in which time is extended. With hope, participants may see a future, but their future without hope is non-existent. Without hope, everything becomes more pertinent in the present, the future becomes closed-off, and the lived experience of the disability of COPD perhaps becomes more authentic. Authenticity and inauthenticity are terminological words used by Heidegger to describe modes of being (Heidegger, 1962). In authenticity one understands one’s own power in choosing one’s own potential in survival and eventual death. In inauthenticity, we ‘*fall’* into the preoccupations of what society, termed as the ‘*they*’, deem important or necessary (Heidegger, 1962) . Inauthenticity may enable participants to remove the negativity associated with uncertainty and create space to develop a positive attitude by focusing on more immediate day-to-day concerns. In this mode of being, participants turn away from their understanding that they are going to die. They can then fall back into their everyday '*being-in-the-world'* (Heidegger, 1962). It appears that some of those participants who have accepted that they have COPD and have understood its progressive nature have been in a mode of authentic rather than inauthentic being. Sometimes in the circumstances that participants were living in the authentic mode of being, PR may have been seen as superfluous for those participants' future motives. Consequently, they did not go on to complete a PR programme.

6.3.1.5 The changing nature of uncertainty

Many participants who experienced 'Anger with care' also experienced panic and uncertainty. Feelings of anger and panic have been described by other patients with COPD (Bulley et al., 2009). However, participants in this study who seemed less concerned about a lack of clear diagnosis seemed less angry and frustrated living with COPD. These participants perceived their COPD more like an acute chest infection, rather than a chronic disease. Therefore, COPD may have presented as a temporary phenomenon, which they felt was less concerning. This may relate to COPD patients experiencing their COPD as '*a health problem that is not an illness'*, because of possible causes from a patient's lifestyle or normal processes such as aging (Habraken et al., 2008, Pinnock et al., 2011). Howard et al. (2009) state that those who are more angry about their condition, and think COPD is a condition that has long term affects, experienced increased severity of panic attacks. Therefore, combining the experience of participants in this study with other research findings (Howard et al., 2009, Pinnock et al., 2011), it is possible that those COPD patients who view their illness as a temporary condition which can be overcome, may consider COPD less disabling and do not panic as much. These participants may have low levels of anger towards living with the condition.

Fischer et al. (2010) state that patients who have been diagnosed more recently perceive a greater life expectancy after PR, but all patients, regardless of time since diagnosis, believed that COPD affected them in a more cyclical nature following PR. Fischer et al. (2010) suggest that the perception of COPD being cyclical in nature may reflect a more positive outlook without being significantly disabled by symptoms. This research reinforces the impact that illness perceptions have on the ability of patients to manage their COPD. The experience following a PR programme seems to improve these illness perceptions. Furthermore, this research is meaningful because it shows how ‘anger with care’ may be associated with the participant perception of having a more disabling disease. This anger could be targeted to reduce patients’ experience of panic.

6.3.1.6 Time since diagnosis

One of the differences between this study and the study performed by Pinnock and colleagues is the length of time since participants were diagnosed with COPD or the duration with which they experienced symptoms (Pinnock et al., 2011). In this study the average time since diagnosis was approximately three years (35 months). The average duration of symptoms in the study by Pinnock et al. (2011) was 18 years. It is possible that patients have a greater acceptance of their condition the longer they live with COPD. For example, chronic heart failure patients who have been diagnosed for more than three years have higher levels of acceptance (Buetow et al., 2001). For those patients recently diagnosed with COPD, the experience of anger with care, panic and uncertainty may have a greater impact on their ability to cope with COPD as an illness compared with those diagnosed for longer periods.

COPD patients who have been diagnosed for five years or more have been reported to differ from those diagnosed in the last four years (Fischer et al., 2010). However, in their study Fischer et al found that those who had been diagnosed for five years or more had a greater belief that their symptoms were due to COPD, perceived greater consequences, perceived that their COPD would disable them for longer and were less optimistic about disease controllability (Fischer et al., 2010). This seems to contradict findings that patients who have been diagnosed longer are more accepting of their condition.

6.3.1.7 Acceptance

Coping can be viewed as a style, or process of cognition and behaviour, used in response to stressful or threatening encounters (Lazarus, 1993). The researcher believes that living with a chronic illness could be viewed as both stressful and threatening and because this was a longitudinal study, coping is viewed as a process rather than a style (Lazarus, 1993). An individual's coping style is more constant, whereas coping as a process allows for a change in coping over time in accordance with the context of each situation(Lazarus, 1993). Coping is the management of taxing demands which threaten to exceed a person's resources (Lazarus, 1993). Acceptance is a way of coping with loss and is the last stage of the Kübler-Ross's Five Stages of Loss (Kubler-Ross, 1969). Furthermore, accepting responsibility is a key domain of the Ways of Coping Questionnaire (Lazarus, 1993). This study suggests that uncertainty is experienced across all lengths of time since diagnosis. However, the acceptance of COPD as a permanent illness, which has been shown to occur in those who have been diagnosed for longer periods of time, may restrict the amount of perceived available improvement possible from PR. It may be the case that it is too late to refer patients to PR by the time patients accept they have COPD. This is plausible because acceptance means that people actively acknowledge events without attempts to change the frequency or form of those events, particularly if that action may cause more harm (Biglan et al., 2008). This is potentially pertinent for those participants in this study with COPD who perceived negative associations with breathlessness.

The mean length of time from diagnosis was approximately two years (25 months) for completers and four years (47 months) for non-completers in this study. These findings may warrant further research because this suggests that those who are referred soon after diagnosis may show greater improvements in their ability to live with COPD yet it is not clear at what point in time after diagnosis these improvements would be significant. Patients who are referred soon after diagnosis may be more likely to complete a programme than those referred after being diagnosed for longer periods of time, potentially due to increased levels of disease acceptance in non-completers.

A minority of participants seemed to benefit from the experience of uncertainty in this study. It prevented them from “freaking out” about the damage that had been caused to their lungs and the progression of the disease. Severe COPD patients have stated that they would rather not know information about their condition (Pinnock et al., 2011). This has been described as passive fortitude which is experienced either as acceptance of the disease or giving up on improvement (Chan, 2004). Pinnock et al. (2011) suggest that this passive acceptance should not necessarily be viewed negatively as weary resignation with COPD, but acceptance that may allow patients to stop fighting against their condition. The frustration associated with living with COPD has been stated to deplete patients’ resources to manage their condition (Toms and Harrison, 2002). Furthermore, Bussing et al. (2008) state that for patients coping with other chronic diseases such as depression and alcohol addiction, acceptance should not be associated with fatalistic resignation but viewed rather as a complex and active process of dealing with the disease. Not wanting to know information has therefore been conceptualised as passive fortitude and an active process. It seems that some participants in this study wish to remain “in the dark” about their condition or the future care they were to receive. This could be their way of coping with COPD but it is unclear how best to manage these patients who seem comfortably naïve.

6.3.1.8 Acceptance, Avoidance or Disavowal

There are some similarities in the lived experience of heart failure and COPD patients (Gysels and Higginson, 2011). Buetow et al. (2001) describe four ways of coping with Chronic Heart Failure which may be applicable to participants in this study. These are avoidance, disavowal, denial and acceptance. These will be considered in relation to this study. To remain ‘in the dark’ may be a strategy of avoidance rather than the acceptance described by other authors above. Avoidance coping occurs when a patient deliberately avoids information, particularly if it is unfavourable. Avoidance is different from denial in that patients respond to the experience of the chronic illness in avoidance (Buetow et al., 2001). According to Buetow et al. (2001) acceptance is the acknowledgement of the validity of diagnosis without attempts of positive reconstruction. This seemed to be experienced by a number of non-completers in this study. In disavowal the threat of the chronic illness is understood, but people dissociate the awareness of their reality from its impact on them (Buetow et al., 2001). In this instance patients would positively reconstruct meaning or significance of the condition which can be linked with gaining a positive attitude (Buetow et al., 2001). Many participants who went on to complete the programme may have been in disavowal. Avoidance may give way to disavowal, particularly in younger patients whereby hope occurs through disavowal and helps the process (Buetow et al., 2001). This may be similar to the longitudinal development of hope shown by COPD participants in this study.

A potential limitation to the description of coping styles above is that people seemed to require at least a basic understanding of the seriousness of the condition they were living with (Buetow et al., 2001). Due to the broad lived experience of uncertainty experienced by participants in this study and their lack of knowledge, it is not clear whether they were able to benefit from using these coping styles effectively. Being “in the dark” may be more of a passive process when such uncertainty remains.

Sartre (1969) states that individuals can only wish not to see certain aspects of their being if they are first acquainted with the aspect that they do not want to see. In this respect many of the participants in this study may be in the being of discovering COPD in order to enable them subsequently to cover it up as part of their being again. It is the discovering which may be uncertain as the participants were unaware of what was to be discovered. Disavowal, rather than denial may be the discovery-covering.

6.3.1.9 Summary

This research has provided valuable information regarding COPD patient illness perceptions soon after they had been diagnosed with the condition. Examples have been given of participants coping with their condition by viewing it as temporary and those who are not coping with their condition because of panic, anger and uncertainty. The concepts of “floating” and ‘closeness of death’ have been explored and contribute to the experience of uncertainty. However, uncertainty seemed to benefit some participants as it prevented them from “freaking out” about their COPD. Uncertainty could be changed to acceptance following education provided to the patient, which leads them to perceive COPD as a health problem which is cyclical in nature. Further research is needed in regard to disease acceptance in COPD. It remains unclear whether those who have been diagnosed for longer have more negative illness perceptions compared to those who have been more recently diagnosed.

6.3.2 The Non-completers experience

6.3.2.1 Introduction

In this study participants were divided into two groups in order to answer the research questions: Those who completed a programme and those who did not. The latter category also includes those who did not attend an assessment to determine eligibility to enter the PR programme. Seven out of the 15 participants who participated in the post-programme interviews were non-completers. The discussion points of their longitudinal experiences are provided below.

6.3.2.2 Reasons for non-completion

Participants in this study have given many reasons for not wanting to participate in PR. Participants lacked motivation, did not want to exercise in a group, felt unable to leave their home, felt like they required no further support or believed they could learn from their own experiences. These participants did not want to do PR and seemed content in their decision. Similar barriers to patient participation have been previously explored by other authors (Rodgers et al., 2007, Taylor et al., 2007, Harris et al., 2008b). Participant choice of non-attendance and subsequent drop out has also been reported in cardiac rehabilitation (Sharp and Freeman, 2009). Fischer et al (2007) described some of the participants in their study who were interviewed but did not go on to complete a programme as "*sceptic*". Sceptic patients are those who have little involvement in the decision of referral to a programme, anticipate few benefits, have few treatment goals and are severely functionally disabled. Some of the non-completers in this study may not have been given the adequate support that was needed to make an informed choice about whether to perform PR as was clear from the anger with care and pre-programme experiences. Because some of these participants also perceived a lack of benefit from attending a programme these could be regarded as sceptic patients.

6.3.2.3 'Being in the dark'

Completers and non-completers of PR in this study seemed to be kept 'being-in-the-dark' in regard to what PR was in the pre-programme interviews. The negative influence of a referring practitioner and lack of knowledge regarding PR has previously been highlighted as affecting the patient's experience before commencing PR (Arnold et al., 2006, Fischer et al., 2007, Taylor et al., 2007, Bulley et al., 2009, Keating et al., 2011b). It could be said that those patients were also kept ‘being-in-the-dark’. This study highlighted the negative influence of participants’ doctors and nurses in the way in which participants were kept ‘being-in-the-dark’ in the past and kept ‘being-in-limbo’ at the time of their pre-programme interview. Those who did not complete a PR programme also showed significant anger with their care in their post-programme interview. Other research has indicated that a significant predictor of non-adherence is a dissatisfaction of disease-specific social support or dissatisfaction with the organisation of care (Young et al., 1999, Fischer et al., 2009). Therefore, a combination of the negative influence of a referring practitioner combined with patient anger or dissatisfaction with care could lead to poor patient adherence to PR. The main finding from the largest qualitative study of non-attenders and non-completers in PR indicated that transport was the main problem for patients attending and completing a PR programme (Keating et al., 2011b). Transport was not a significant problem for the majority of participants in this study. This could be because this research studied participants experiences of a community-based PR programme compared to the majority of other research which has investigated hospital-based PR programmes. Furthermore, patient transport could always be provided to patients in PR programme A should it have been needed.

6.3.2.4 Non-Completers still benefit

Some participants who did not complete a PR programme recognised similar improvements to those who completed a PR programme such as gaining a positive attitude and gaining better perceived control over their COPD. This is a significant new finding from this study and has not been discussed in other longitudinal qualitative studies. As a result of gaining similar benefits to those who completed a PR programme it could be the case that these participants have less of a desire to gain further support from a specialist PR team. Any COPD care that non-completers received, that was separate from PR, may have offered the reassurance they felt they needed when they experienced panic in the pre-programme interviews.

6.3.2.5 COPD perceived as worsening

Non-completers experienced their COPD as worsening. This may imply that even though many of the non-completers perceived that they were coping, this coping was unrelated to their perceptions of disease severity. Many of these participants remained “floating” with uncertainty. As a result they continued to experience frustration, anger and panic. Even if perceived benefits could be attained for patients who do not complete a PR programme as described in the last discussion point, these benefits may not necessarily relate to improvements in objective outcomes seen after patients complete PR. It has been stated that successful PR completion can lead to a reduction in hospital lengths of stay and admissions, associated with the improved quality of life (British Thoracic Society and Primary Care Respiratory Society United Kingdom, 2011, Department of Health, 2012). These outcomes may not occur with a different structure of care.

6.3.2.6 Ability to cope with comorbidities

COPD participants differed in their ability to cope with their comorbidities which may relate to their potential for functional improvement in PR. The non-completers were less able to cope with the interaction of their comorbidities than completers. Other research exploring patient experiences of PR have excluded patients with significant comorbidities (Toms and Harrison, 2002, Bulley et al., 2009, Williams et al., 2010). Therefore, this research furthers knowledge of the importance of living with COPD and comorbidities. Comorbidities are common in COPD but it remains unclear how they affect PR outcomes (Garrod et al., 2011). Investigating the impact of comorbidities is important in COPD as they are predictive of mortality and on average COPD patients have six comorbidities (Divo et al., 2012). Keating et al. (2011b) state that the burden of comorbidities affected the decision to attend PR for non-attenders. This research would also suggest that it is how individuals cope with their comorbidities, rather than the number or type of comorbidities, that affects PR participation. Keating et al. (2011b) state that it is the pain experienced from the comorbidities which most disables COPD patients. This PhD candidature research would suggest that it is the participant's perception that the comorbidities and COPD negatively impact on each another which makes activity more difficult.

6.3.2.7 Summary

Gaining an understanding of non-completers of an intervention in research is challenging (Baker and Edwards, 2012). This study has therefore provided valuable data. Many reasons for non-completion or adherence to a PR programme have previously been stated. However, it is thought that this study provides a deeper understanding of the non-completer experience from their perspective. These participants may still gain perceived benefits to coping with their condition with a different structure of care that does not involve PR. However, they may continue to perceive their disease severity as worsening. Furthermore, this research has provided a rare qualitative insight into the perceived interaction of comorbidities in COPD patient lives and how that interaction may affect their perceived ability to perform PR.

6.3.3 Social comparison and interaction

6.3.3.1 Introduction

Social comparison occurs when a person determines the accuracy of their perceived abilities and opinions with the abilities or opinions of others (Festinger, 1954). When one judges their perceived ability to perform a task rather than in the judgement of opinions, one's perceived self-efficacy becomes important. Self-efficacy is one's perceived ability to be able to successfully do something with the skills one has in a particular situation (Bandura, 1997). PR is a group situation and it appears that a comparison of the participant’s abilities with others occurred as it was discussed in this study’s interviews. One is likely to change the evaluation of one’s own ability if it is in comparison with those whose ability is different from one’s own (Festinger, 1954). It seems that when participants compared their abilities more favourably in comparison with others, the experience of uncertainty and panic for these individuals was reduced. Before going to PR, participants used their own experiences of exercise and walking to judge their physical abilities. PR then enabled participants to compare their abilities to others with COPD on the programme.

6.3.3.2 Self-Efficacy improvements through exercise

The findings from this study suggest that the perception of doing more than others on a PR programme may be sufficient for participants to gain a sense of achievement. When exercise capacity is a comparative phenomenon with others on the programme (who are perceived as more severely disabled, older or lazy), the perceived cost needed to gain improvement may become reduced in comparison to pre-programme expectations. Consequently, getting benefit from PR may be perceived as easier than previously expected and self-efficacy to exercise may be improved. This is a potential reason why exercising in a group is perceived as beneficial for COPD patients. Exercising in a group has been stated to be beneficial in other studies (Arnold et al., 2006, Fischer et al., 2007, Keating et al., 2011b). Furthermore, self-efficacy scores have improved following PR in COPD patients (Vincent et al., 2011). However, self-efficacy has also been shown to have an insignificant relationship with physical activity for COPD patients (DePew and Benzo, 2012). Therefore, this study further highlights the importance of being in a group because of the potential improved self-efficacy gained from comparison with others on the programme rather than from physical activity improvements alone.

6.3.3.3 Downward contrast seems beneficial

Drawing on Festinger's theory (1954), Dibb and Yardley (2006) state that there are four types of social comparison: upward, downward, lateral, and comparison for information. When one compares upward, one looks at those people who have better abilities. Downward comparison occurs with those who are worse off and in lateral comparison one compares with those with similar abilities. Comparison for information occurs when there is a lack of affect in the comparison (Dibb and Yardley, 2006). Downward comparison has been shown to reduce over the course of a 3 week PR programme (Petersen et al., 2011). This means that at the start of the PR programme the patients compared themselves with those more disabled than them. At the end of the programme they reduced their degree of comparison with those patients who were more disabled, which could be interpreted as becoming less pessimistic. Petersen et al. (2011) state that the degree of comparison reduces over time if social situations are not expected to offer new situations for self-evaluation. Toms and Harrison (2002) state a contradictory finding that patients in their study used negative comparisons prior to PR and positive comparisons following PR. This may show that the programme offered by Toms and Harrison was more effective in changing participants social comparison preference compared to the study performed by Petersen et al., or that the participants baseline degree of social comparison was different (Toms and Harrison, 2002, Petersen et al., 2011). The study by Toms and Harrison (2002) relates well to social comparison theory. The patients in their study could have had unstable subjective perceptions of their own abilities prior to PR because of a lack of availability to compare their abilities with others. Following PR they may have changed this comparison to downward contrast because of the recognition of difference in abilities with others (Festinger, 1954).

The research in this thesis indicates that downward comparison occurs before and after PR. Downward comparison was strengthened in contrast rather than in assimilation for completers of the programme. This means that participants thought their abilities were more improved compared to the ability of others, rather than perceiving their abilities as similar to others following PR. These findings seem to contradict social comparison theory which indicates that the existence of a discrepancy in a group will lead group members to attempt to reduce this discrepancy and reduce levels of comparison with those who are different (Festinger, 1954). The results from this study may contradict social comparison theory because of a wish not to be labelled as a member of a group of people who have COPD or because participants perceived little power in choosing the group to which they would become a member. However, these are the researcher's ideas and are speculative as they did not emerge from the analysis. Festinger (1954) states that if a person has no other comparison outside of the group or that the ability is highly relevant to the group, then comparison is somewhat forced. It is possible that those who completed a PR programme found the abilities which they wanted to improve were specifically related to being a member of the PR group, therefore forcing further comparison. PR programmes are likely to be successful if they can reduce the downward assimilation of COPD patients through the course of the programme (Petersen et al., 2011). Completers in this study developed downward contrast which is opposite to downward assimilation and so the programmes could possibly be judged as successful. However, downward contrast was not measured objectively as was performed by Petersen et al. (2011). This is a potential limitation to the discussion of the findings from this study.

Downward contrast was also used by the majority of non-completers in this study. Downward contrast is commonly used in chronic illnesses when a threat is perceived, soon after diagnosis or during an active stage of the illness (Dibb and Yardley, 2006). Therefore, it may have been predicted prior to performing the interviews that all participants would have engaged in downward contrast. However, there are two main differences in the use of downward contrast used by completers and non-completers in this study. Firstly it appeared that the non-completers who used social comparison were doing so as an information gathering exercise, to gain reassurance for example, rather than always being able to specifically compare themselves with others in the dimensions of coping and disease severity. This perceived need for further information from others who have COPD may be associated with the experience of uncertainty in ‘being-in-the-dark’. Indeed, according to Forsyth (2000), people seek information when they are in a situation that is ambiguous and has no reference points. It is very possible that the non-completers of this study found themselves in an ambiguous situation with no reference points in their experience of uncertainty. Furthermore, information gathering could be achieved in a single event, whereas a comparison of abilities may require a longer period of engagement, in a PR programme for example. Therefore, a single consultation with the participants’ practice nurse may have been sufficient to gain the information needed for the non-completers.

Secondly, when downward contrast was used for social comparison by non-completers it seemed to have a predominantly negative affect. Completers were able to use comparison with positive affect. These findings are important because it indicates that those who enter into downward contrast with negative affect and for information gathering purposes only may not go on to complete a PR programme. Moreover, clinicians could investigate the type of affect in downward comparison in pre-programme assessments and work with the patient on changing their thoughts regarding social comparison. This finding also indicates that those wishing to compare with others’ abilities rather than gathering information only, may perform better on a PR programme.

6.3.3.4 Social comparison and age

In this study older and younger participants perceive benefits from PR in regard to their age. Howard et al. (2009) found that the younger COPD participants in their study had significantly higher levels of anxiety and depression than the older participants, and for the same degree of disease severity COPD had a greater impact on younger patients’ lives. Furthermore, Rodgers et al. (2007) state that younger patients may feel out of place at PR. The age of patients could be discussed at diagnosis in comparison with the spectrum of ages that people get diagnosed with COPD. Positive comparisons could be made for younger and older patients as this was experienced by participants in this study. The chronicity of COPD may have a different meaning for those diagnosed in their forties to those in their eighties. Referrers to PR could discuss the potential benefits of age comparison at PR. This may encourage participants who feel they are too old or too young for PR to attend a programme.

6.3.3.5 COPD education seminar

The opportunity to meet others with COPD and compare one’s ability with others positively could also be a mechanism of success of the COPD education seminar. PR and the COPD education seminar have similar benefits by both encouraging COPD patients to be with others who have the condition. However, there is potentially less patient effort required for reward in attending an education seminar compared to PR. This could encourage more COPD patients to attend a seminar and consequently PR may be seen as beneficial for these individuals. Moreover, following the COPD education seminar, participants then perceived that they were not as severely disabled as they originally thought.

Having, doing and being are all categories of human reality according to Sartre (Sartre, 1969). In the researcher’s opinion, to suffer COPD is to be and one suffers COPD because predominantly one does not consider the suffering or put value on that suffering in uncertainty. One has to wrench oneself away from oneself and one’s world in order to make the suffering a motive for action (Sartre, 1969). It is possible that in COPD, in order to become motivated for action, participants’ spatiality must be restricted for them before positing that the disability itself is the restriction of spatiality. This may be an appropriate explanation of what is meant by an ‘interiorised’ COPD patient prior to PR. It seems that this ‘interiorisation’ was necessary for some of the participants in order to realise the motives for ‘externalisation’.

The education seminar prior to PR may trigger uncertainty in a positive way by enabling patients to hear others’ stories of living with COPD. This ‘externalising’ process at the education seminar may have encouraged them to start a PR programme. Participants who perceived themselves as being too disabled to gain benefit from PR or not sufficiently disabled to warrant further support, could gain hope of similar benefits by attending a COPD education seminar. Furthermore, these patients may not feel as if they are ‘waiting in limbo’ to such a great extent. Graves et al. (2010) state the benefits of a preliminary group opt-in session (GOIS) prior to an initial assessment to PR entry in a controlled study. The GOIS session lasted 1.5 hours and was delivered by two clinicians. The patients who had an initial assessment following a GOIS were less likely to drop-out following their initial assessment and improved graduation rates from PR compared to those who did not attend a GOIS. The COPD education seminar in the study ran in a similar format to a GOIS. This research explores the experiences of those who attend such a session and provides a possible explanation of its success to support the findings by Graves et al. (2010). Keating et al. (2011b) suggest that COPD patients could be better provided with information about the benefits of PR from peer support and education delivered by patients who have completed a PR programme. Therefore, it is recommended that a patient who has previously completed a PR programme be given an integral education role as part of a GOIS prior to an initial assessment to attend PR.

Heidegger describes that ‘*being-with-others’* is essential for existential Dasein’s ‘*being-in-the-world*’, even in the being alone (Heidegger, 1962). The importance of social comparison can now be brought to light from a phenomenological perspective. In PR, participants in this study brought close the experience of others with COPD in their concern of ‘*being-with-others’*. With this concern, participants began comparing their abilities with others who had COPD, rather than others in society of their own age. At this initial point of comparison, the authenticity of living with COPD was possibly signified. With this signification, the participants gradually entered into a more downward contrasting social comparison, potentially in order to '*flee in the face of authenticity'*. The duration of the PR course in this study seemed sufficient to enable this. The education seminar may have also acted as a stimulus for people to understand the authenticity of COPD in order to want to '*flee in the face'* of it and were therefore more likely to want to do PR. Those participants who did not know anyone else with COPD prior to the programme were potentially less able to realise the potential benefits of understanding the authenticity of COPD. In PR, participants may "become *authentically* bound together." P159 (Heidegger, 1962). Participants may have been showing their '*being-with-others'* in the character of '*distantiality*' in downward contrast by the constant care about the distance between them and others in their difference, trying to maintain priority over the others (Heidegger, 1962). Pulmonary Rehabilitation was an experience whereby participants who attended the programme were able to move from 'being-for-the-they-other' to the 'being-for-the-COPD-other' which potentially reduced their experience of uncertainty, vulnerability and panic.

Sartre (1969) discusses the body as '*I am for others'* where the other is the subject for whom I am the object (Sartre, 1969). In this circumstance the individual's body becomes '*alienated*' as a '*being-a-tool-among-tools'* for the other person, accompanied by a collapse of the individual's world flowing towards the other's world (Sartre, 1969). This alienation could form part of the uncertainty as people perceive their body as an object viewed by others. In order to be in control of the situation and alleviate oneself from this danger the individual may view the other as object (Sartre, 1969). This possibly occurred for the participants who completed a programme who participated in the education seminar. Romdenh-Romluc (2011) states that Merleau-Ponty believed there is a commonality in the way we perceive things in the world because of our bodies having a similar form and function. After the education seminar, participants may have a tighter grip of their COPD by being enlightened with commonality in form and function with others. Once they performed bodily action they seemed to be able to compare their abilities with others more easily. This finding is important because it potentially indicates that an education seminar promotes social comparison which has been previously discussed as important for both completers and non-completers for information gathering and comparison of abilities.

6.3.3.6 Summary

Social comparison is an existential mode of ‘*being-in-the-world’*. Various comparisons can be made with others who have COPD including exercise capacity, age, coping and the severity of the condition. Downward contrast appeared to strengthen through the participants PR journey. Furthermore, initiating downward contrast may be one of the possible benefits and mechanisms of success of the education seminar.

6.3.4 Gaining a positive attitude and breathing properly

6.3.4.1 Introduction

Non-completers and completers of a PR programme gained a positive attitude between pre- and post-programme interviews. In this research, participants described living with COPD as fighting a battle against their breathlessness. Furthermore, participants described gaining control of their breathing and gaining a positive attitude as winning half or three quarters of the battle. Breathlessness has been described as fighting a battle by other researchers (Fraser et al., 2006, Williams et al., 2011). Nevertheless, this study suggests that being able to develop a positive attitude, hope and a fighting spirit towards COPD is associated with winning the battle against breathlessness which appears to be facilitated by PR. Therefore, PR may act as catalyst enabling for people to move from avoidance to a disavowal coping strategy, particularly in those more recently diagnosed.

6.3.4.2 Relaxation the key to a positive attitude

This research suggests that feeling calm and relaxed as a result of doing PR enabled participants to gain a positive attitude. Relaxation was provided as part of the education sessions within the PR programmes in this study. However, those participants who were angry or frustrated in their pre-programme interviews did not discuss having a positive attitude towards their COPD. This seemed particularly apparent in the participants whose quotes have been included in the ‘Anger with care’ theme. It also appears that those participants who became calm and relaxed did not discuss further feelings of anger and frustration. Gullick and Stainton (2008) state that the feelings of anger and frustration come from a loss of effectiveness and increasing reliance on others. In this study, participants felt calmer when they were confident they were in control of their panicking and breathlessness, which possibly meant they felt they had gained more independence following PR. However, Gullick and Stainton (2008) state that anger and frustration are normal for people living with severe emphysema because they can no longer rely on a body that has become unpredictable and clinicians should provide a caring response to this behaviour. It is of the researcher’s opinion that these emotions should only be seen as normal if the participants live with uncertainty as described in this study. These emotions should be understood by health care professionals with the aim of changing them rather than accepting them as normal.

6.3.4.3 Breathing properly and panicking less

Participants in this study who completed PR felt they learned to breathe properly following PR, which was associated with reduced perceptions of panic. Williams et al. (2010) state that the most significant change after PR that impacted on patients’ activity was a change in perception of breathlessness related to a loss of fear and improved confidence. The importance of learning how to breathe properly has also been described as improving self-confidence and control over COPD (Camp et al., 2000, Chan, 2004, Halding and Heggdal, 2011).

Many participants in this study did not realise they were not breathing properly until they became ill. Breathing suddenly then became more of a conscious corporeal experience when they experienced illness. The experience of breathlessness becoming a conscious phenomenon has been described previously in patients with severe COPD (Gullick and Stainton, 2008). The revealing of breathlessness during PR from its previous concealment may become clear once patients are shown how to breathe normally or shown ways in which they were breathing prior to having COPD. A clearer comparison of ways of breathing then becomes possible. It is proposed that PR assists COPD patients of all severities to become increasingly corporeally conscious about their breathing. It has been discussed that the lack of being able to breathe properly in breathlessness only becomes a conscious corporeal experience when it is revealed from its concealedness in illness. This relates well to the dealings of equipment which are '*ready-to-hand*' and are met as unusable (Heidegger, 1962). The lungs are discovered as something not adaptable to the purpose asked of them. In the unusability of the lungs, they may then become conspicuous. They become '*un-readiness-to-hand*' (Heidegger, 1962). The participants in this study may have been viewing their breathlessness as obtrusive and their lungs as obstinate in a way that was existentially corporeal:

"The more urgently we need what is missing, and the more authentically it is encountered in its un-readiness-to-hand, all the more obtrusive does that which is ready-to-hand become…something un-ready-to-hand which is *not* missing at all and *not* unusable, but which stands in the way of our concern…Anything which is unready-to-hand in this way is disturbing to us, and enables us to see the *obstinacy* of that with which we must concern ourselves…" (Heidegger, 1962) p 103.

Breathlessness could be the ‘*what is missing’* and the lungs are what is ‘*not missing’* if described phenomenologically. This quote relates to the participants understanding that their lungs were “worn out” (Dave) or “rotting” (Joe) or those who could not “blow up” their “balloons” no matter how good their “juice” was (Keith). It is the researcher’s opinion that these participants viewed their lungs as equipment that was ‘*obstinate*’ because they were experiencing breathlessness. Heidegger continues to provide an adequate explanation of what has been described as the concealment from the conscious corporeal experience of breathing; Heidegger states that what has been missing has been previously so obvious in everyday experience, that no notice has been taken of it (Heidegger, 1962). Consequently, the environment in which one is concerned is viewed in a new light. The normal ability for the lungs to enable one to breathe, discloses a new environment in which the participant with COPD previously became vulnerable and got involved in their battle against breathlessness. Furthermore, according to Sartre our body is an instrument and end of actions (Sartre, 1969). As an instrument it is a tool (Sartre, 1969). But the COPD lung is a tool which has become maladaptive. Sartre states that the body becomes invisible as it is lived and not known in normal lived experience (Sartre, 1969). The example Sartre gives is that one experiences the brake of the car, not the foot, in the change of speed of the car. This is the primary position of instrumentality and the body is normally surpassed (Sartre, 1969). Sartre states this is also true in disability where one projects one’s own body towards projects, with the disability being a necessary obstacle for being (Sartre, 1969). This reinforces the idea of the lungs being obstinate for participants in this study.

A potential problem with COPD for participants may be the ‘*taken-for-grantedness’* of breathing normally as a motor skill. After all, breathing is not learned, it is given. This relates to Merleau-Ponty’s discussion on motor skills as practical knowledge (Romdenh-Romluc, 2011). If participants have not learned how to breathe properly, it may have been difficult to describe their experiences of breathing, and even more difficult when this breathing becomes difficult. This further embeds the experience of uncertainty. Once participants learnt to “breathe properly” they could look at their lungs like an external part of their body, such as a hand, in its instrumentality. In this circumstance, the depth of the COPD changed and moved slightly further away in the depth of perception for participants. Thus when COPD is seen as slightly remote from one’s immediate sense of self, the participants would be able to have a ‘*maximum grip*’ for perceiving it (Romdenh-Romluc, 2011). The best possible perception is when one has ‘*maximum grip*’ of it according to Merleau-Ponty (Romdenh-Romluc, 2011). When the participants have learned to “breathe properly” it stands that they have acquired a new motor skill. Merleau-Ponty believes that one can only execute an acquired motor skill if one has learned to perceive opportunities to exercise it (Romdenh-Romluc, 2011). In this way the positive attitude and the ability to breathe better may be linked, as previous situations that would have caused participants to panic are then seen as opportunities to exercise the new motor skill. Participants in this study talked about pursed-lip breathing in this way.

There was a close association between breathlessness and panicking with these individuals. This was also recognised by Williams et al. (2010). Participants thought an important part of the experience of learning to breathe properly was being shown how to deal with panic. Participants described their panic as “sheer panic” as if the sensation came on suddenly, or “blind panic” as if they did not know why they were panicking or what to expect as a result of panicking. It is the severity of the description of “sheer” panic or “blind” panic that suggests that it was panic, rather than the breathlessness itself which often used to disable them prior to PR. Other patients with COPD have stated all of their focus during episodes of breathlessness is to control the panic (Fraser et al., 2006). Indeed, participants described situations in their initial interviews in this study where they were treated for panic rather than for an exacerbation of their COPD. More attention could be given to panic, its role in breathlessness, and appropriate treatments for COPD patients as part of community based PR programmes.

6.3.4.4 A positive attitude and pushing death further away

Completers of a PR programme were able to push their perceived ‘closeness of death’ further into their future following PR. Prior to PR their ‘closeness of death’ was characterised in their experiences of breathlessness and panic. Similar experiences of the fear of dying during breathlessness have been reported in other studies (Toms and Harrison, 2002, Gysels and Higginson, 2011, Halding and Heggdal, 2011, Williams et al., 2011). Pushing the ‘closeness of death’ further from current experiences appeared to enable participants to gain a positive attitude, think further into their future, and appears to be a new finding from this research. This finding may communicate a reduction in the participant’s disease burden, highlighted by the longitudinal nature of the study.

6.3.4.5 Summary

Participants gained a positive attitude between pre- and post-programme interviews. Relaxation appears to have helped participants gain a positive attitude. With a positive attitude, participants appeared to be able to push their ‘closeness of death’ further into their future. PR helps develop Corporeally conscious breathing and the participants’ perception of being able to breathe properly was associated with reduced feelings of panic.

6.4 Phenomenological summary

The discussion points above are now used to form a phenomenological summary of the participant experience of PR and COPD. PR can be described as “discovery-covering being for the COPD other, looking at others in social comparative hope”. COPD can be described as “uncertain concealed, yet temporally changeable closeness of death, and spatially changeable in grip, whereby the lungs are obstinate in their instrumentality and externalised.” This phenomenological summary highlights how PR is relevant to people’s COPD and how the lungs are perceived in COPD. The researcher believes that a full description of the phenomenological lived experience has now been provided in a concise way.

In the next part of this chapter, original findings will be highlighted in relation to how they can be implemented in practice and what further research is needed before other recommendations could be provided.

6.5 New findings from the research

6.5.1 Offering patients hope at the point of diagnosis

An increased understanding of the change in hope temporarily through the participant PR journey has been developed. GPs should offer patients hope at the point of diagnosis, and if COPD patients are acutely struggling with stress (anger, frustration or panic), GP's or practice nurses could refer to PR regardless of their MRC score. If those patients referred to PR closer to diagnosis had better outcomes, guidelines could change to reflect this as a consideration when referring to PR and potentially be included in the Quality and Outcomes Framework clinical indicators for COPD. However, further quantitative research is needed in order to determine the most beneficial time to refer patients to PR following a patient's diagnosis.

6.5.2 The importance of addressing psychosocial needs

The relationship between patients' perceptions and the patients' ability to cope with COPD need to be discussed with patients as much as the possible physical gains they may have from participation in PR. This is because of the importance of 'closeness of death', 'anger with care' and panic in the lived experience of the participants in this study. Moreover, the participant perceptions of their disability seemed to affect their perception of whether they required PR and a patient's anger with care possibly contributes to why certain patients do not complete PR. It may be important to include anger management alongside stress and anxiety management within the education component of PR programmes.

The concept of ‘closeness of death’ has been introduced and the patients’ ability to push their ‘closeness of death’ further away from their present following PR has been explored. Patients who are worried about dying because of their COPD can be encouraged that these disabling feelings could diminish following PR. Furthermore, the experience of panic may be more disabling than breathlessness prior to participant participation in PR, and panic has been described as petrifying. Therefore, an increased acknowledgement of the role of panic in COPD is needed in primary care. Participants in this study discussed that they experienced their panic attack as a heart attack. More research is potentially needed with COPD patients who have had a heart attack to determine the patient perceived differences of a panic attack and a heart attack. This may better enable clinicians to make patients aware of the differences and similarities in the two differing experiences. This would have the potential to reduce unnecessary emergency admissions if patients could become confident that they were not having a heart attack and could control their symptoms of panicking. PR should be promoted as an intervention that reduces the patient experience of panic.

6.5.3 The Importance of social comparison and a COPD education seminar

Age is viewed as an important social comparison factor that people with COPD consider when deciding how well they are coping with their condition and progression through a PR programme. Patients’ perceptions of what it means to have COPD for their age should be discussed at diagnosis. Referrers to PR should encourage both younger and older patients that similar benefits can be gained as a result of being able to compare ages with other people who have COPD. The above findings indicate that it is beneficial to view COPD as a disease which is temporary or cyclical in nature in order to reduce the concern that COPD gives them. It is unknown whether these perceptions occur in a similar way for older and younger patients. This knowledge would enable clinicians to understand coping mechanisms across age groups in COPD in order to better tailor individualised care as recommended by recent guidance (National Institute for Health and Clinical Excellence, 2011, Department of Health, 2012).

Another key finding from this study was that many of the completers were able to engage in downward contrast with positive affect. If downward contrast with positive affect was a significant predictor of PR success, clinicians could use this information to improve the efficiency and throughput of PR programmes. In order to create situations whereby patients could develop downward contrast with positive affect it may be important that a mixture of MRC stages be included in COPD programmes. Furthermore, patients could be trained how to compare with positive affect prior to PR participation at a COPD education seminar. Therefore, COPD education seminars should be provided prior to patients entering PR in order to allow them to compare their COPD with others and to break up the waiting time to enter PR, which some participants in this study described as contributing to their experience of “floating”. When participants in this study perceived that they had waited too long to enter a PR programme it seemed to reduce their expectation of benefit from PR and increased their frustration, anxiety and uncertainty. If social comparison was seen to be nurtured by patient attendance at a COPD education seminar, patients may be more encouraged to attend and complete a PR programme. This may be important to improve the efficiency of PR at a time when the NHS has to supply an effective service while reducing its budget. A possible question that referrers to a PR programme could ask a patient prior to referral is “what do you think would be the benefits of meeting others with COPD on a PR programme?” As the themes from this research show that participants in the non-completion group made social comparisons as a means of gathering information rather than making upward and downward comparisons of ability, these patients may address their needs within a social support setting and not necessarily PR. For example, a single session of a COPD education seminar, coming to chat with patients in a maintenance group or be provided with information about attending their local Breathe Easy support group and contacting the British Lung Foundation.

This research included participants who were going through their normal clinical process. The strict exclusion criteria of many previous studies may have excluded these participants with comorbidities, yet the majority of people with COPD will have comorbidities (Divo et al., 2012). Further discussion is needed to include patients in clinical practice relevant research in order to be able to use clinically applicable evidence more appropriately for the majority of COPD patients which clinicians treat.

6.5.4 How to manage those patients who do not feel PR is appropriate for them

Some participants in this study did not seem to be concerned with potential improvements that could be made from PR if they accepted they had COPD, viewed their COPD as temporary, or wished to remain “in-the-dark”. It is possible that those participants who wish to stay “in the dark” about their COPD may delay seeing their GP. This could occur prior to diagnosis or during an exacerbation in order to prevent themselves from “freaking out” about gaining too much knowledge. Delays in diagnosis and treatment are incredibly expensive for the NHS as it costs far more to treat severe disease than mild and moderate disease (Department of Health, 2012). Interviewing GP’s and practice nurses about their experience of treating patients who wish to remain naïve may illuminate current successful practice methods that help patients change patients’ perceived need to understand their disease. However, these interviews may also show a gap in knowledge that has not been addressed sufficiently.

This research suggests that non-completers of a PR programme can gain perceived benefits from differing structures of care and non-completers also have a poorer ability to cope with the interaction of their comorbidities compared to completers. Therefore, patient choice is vital in considering whether a referral to PR is appropriate, particularly if they are already finding it difficult to cope with their comorbidities. Another important consideration for clinicians treating patients with comorbidities is to provide significant education on disease management of comorbidities such as arthritis, cardiovascular disease and diabetes as part of the education component of PR. Moreover, depending on resources, COPD patients could be grouped into their level of COPD according to their COTE index which is a measure of mortality risk according to their comorbidities (Divo et al., 2012). PR programmes could therefore be individually catered for those most burdened with comorbidities. However, this may have a negative impact on the individual patient’s ability to engage in downward contrast with positive affect. More research is needed to determine the effects of grouping patients depending on their burden of comorbidities.

6.5.5 PR may encourage disavowal rather than acceptance

It seems that many non-completers used disease acceptance as a coping process. Completers used disavowal as their coping process and disavowal in COPD has been labelled as the discovery-covering of COPD in this study. This may highlight a potential difference in the aims of PR for clinicians and patients. Clinicians may believe that PR educates patients so that they can accept their condition and therefore be better able to self-manage their COPD. Conversely, patients may want to find out more information and strategies in order to cover-up their disability again. Rather than helping patients accept they have COPD, PR may be doing the opposite. PR may be helping patients fight COPD. By covering up what is known, the COPD patient may feel as though they are able to cope with the condition and positively compare themselves with positive affect because they are better able to cover up their disability than others. This may also relate to those COPD patients who did not feel that PR was appropriate for them because they experienced COPD as temporary. These participants may have felt they had the power to cover-up the disease once the temporary symptoms subsided. It may also be true that patients only wish to be referred to PR once their ability to cover-up their COPD was challenged. PR could be marketed to those patients who appear to use disavowal as their coping strategy as a way to hide their disability or to be able to appear normal and not affected by a respiratory condition on a day to day basis. If disease acceptance is a more common coping strategy amongst non-completers in larger studies, clinicians could be encouraged to refer patients to PR programmes before this stage is used as a coping strategy. More research is needed in order to determine whether disease acceptance negatively impacts PR completion rates.

6.5.6 The importance of the PR clinicians age and sex

Older men disliked being “told off” by younger women in PR. This may have come to light because the researcher in this study was a young male which is rare in the field of respiratory physiotherapy and the majority of qualitative respiratory research in the past has been performed by women. Therefore, it may have been difficult for male patients in previous studies to describe situations that they dislike, involving women, to other women. It may also be the fact that many men in their late sixties, seventies and eighties came from an upbringing that was very male dominated and were not accustomed to women being in an authoritative position. However, it was clear that participants appreciated situations whereby there was less of an authoritative style of professionalism in the PR programmes, and a fun and friendly rapport could be built between the participant and clinician. Therefore, clinicians may consider nurturing banter within the PR programme to enhance social cohesion. Further research is needed in order to determine the effect that differing sexes of the clinician and perceived age of that clinician who runs the PR programme has on patient perceptions and PR outcomes.

6.5.7 Patient transport may not be an issue in community PR

Finally patient transport was not a significant problem for the majority of participants in this study. Participants in this study were referred to community based programmes. This is important because previous research involving hospital based programmes has indicated that transport is an issue for patients. This research provides evidence that community based programmes are potentially more convenient for patients, should be marketed as such and indicates that further community based PR provision is needed.

6.6 Strengths of this study

6.6.1 Original methodology used in PR research

To the researcher's knowledge this is the first longitudinal study using applied phenomenology in community based PR research. The high level of phenomenological understanding enabled the researcher to develop a rigorous research method that was appropriate for the clinical academic nature of the study, and a rich insight into the lived experience of COPD patients who have been referred to PR. Participants were interviewed before and after PR. This longitudinal design enabled the participants to give a true reflection of their experience through their PR journey rather than retrospectively, which has occurred in previous research. Participants were able to have sufficient time to reflect on what life was like following rehabilitation because of the deliberate delay of at least four weeks post PR before interviewing them in their second interview.

The participants were unaware of the researcher's involvement in PR. Therefore there may have been less potential positive bias in the experiences that were shared. The reflexive approach used as part of the methodology enabled the analysis to be grounded with an understanding of the researcher’s biases and clinical experience. This research recruited participants from two PR programmes. This allowed for variant experiences to be explored. Furthermore, the mean length of time of participant reported diagnoses in this study was less than three years. Compared to previous research, this study has explored experiences of people who have been recently diagnosed with the condition. This is likely to be relevant to a Primary Care population and linked with the importance in “finding the missing millions” (Department of Health, 2010). These experiences may represent those missing millions who have only recently discovered they have COPD.

6.6.2 The power of including participants with comorbidities

Participants in this study discussed how they coped with their comorbidities because comorbidities did not form part of the exclusion criteria in this study. Consequently, qualitative data has been discussed in relation to previously published quantitative data in order to show what impact these comorbidities, which increase patient risk of mortality, have on the participants lived experience and ability to perform PR.

6.6.3 This research is clinically applicable

It is viewed that one of the greatest strengths of this research is how closely related it was to clinical practice that was occurring at that time. The clinical academic pathway enabled thorough researcher engagement in the context within which this study was performed. Moreover, this was real world research and incorporated all types of COPD patients who were referred to a PR programme. Consequently the lived experience of these participants may be similar to other patients who are referred to the PR programme which the researcher now runs as part of his clinical practice. Furthermore, it is rare that a young male clinician performs research in this field and therefore the interaction between the participants and the researcher enabled new findings to be discussed.

6.7 Limitations of this study

6.7.1 Referral process and diagnostic criteria

The aim of this real world research study was to recruit patients that had been referred to PR with the same diagnostic processes that were used in the clinical setting. At the time of recruitment this would have meant that participants would have had COPD written on their referral form to enter PR. Therefore a recognised limitation of this study was a possible incorrect diagnosis of some participants. This could be attributed to three possible errors. Firstly, the participant may have been diagnosed with COPD, but thought it was another condition. However, nothing could be done about this and potentially highlights what is occurring in practice. Secondly, the doctor or clinician who wrote on the referral, labelled another condition as COPD. Thirdly, the referral form did not have COPD written on it but another condition and the invitation letter was sent out incorrectly. However, the team secretaries were encouraged to send out invitation packs to patient referrals having COPD written as a diagnosis. Therefore, as spirometry was not used in the diagnosis of COPD in this study it is difficult to say what severity of COPD these participants had. From the disability described within the interviews, it is probable that all stages of GOLD severity were included in this research (Global Initiative for Chronic Obstructive Lung Disease, 2011). However, only one participant out of 25 was using Long Term Oxygen Therapy. Therefore fewer very severe COPD participants may have been included in this study compared to other stages.

6.7.2 Clinical changes

There were two PR programmes in this study. The clinical team that provided PR A was newly developed and changed from the beginning to the end of the study. The PR programme in PR A went from a x 2 weekly, 6 week PR programme to a x 1 weekly 10 week programme. This affects the contextualisation of the findings because some participants were on the programme as it changed structure.

6.7.3 Participants' partners involvement in interviews

Some of the participants' partners were involved in the interviews. This could not be helped because it was felt that participants would choose the most comfortable situation to be interviewed in, which was usually their own home. Secondly, it was the partner's right to stay in their own house during the interview within which the researcher was the visitor. No analysis has been included that is based on what participants' partners said during the interview. In the majority of interviews that partners were in the house, they did not engage in the interview or interfere greatly with what the participant was saying, but this did occur on a few occasions. On these occasions the participants' partners discussed their opinions regarding the participants COPD experiences and referral to PR on prompting or in conversation initiated by the participant. It is unclear whether all participants said what they would have said if their partner was not in the room. However, this is part of real world research which is often impossible to predict (Corbin and Morse, 2003).

6.7.4 Data analysis

The post-programme interviews commenced before all of the initial interviews had been analysed fully. Due to time limitations because of the longitudinal nature of the study and the single period of recruitment it was inevitable that this would occur. This may have led to different questions being asked in the participants' second interviews that may not have been asked if all pre-programme interviews had been fully analysed. However, an advantage of performing the second interviews before the full analysis of pre-programme interviews was that the researcher's mind was still open, using a sense of wonder, in line with the phenomenological method. Consequently the second interview was more focused to the individual rather than prematurely comparing what the participants were saying to that of other participants.

6.7.5 The researcher's perspective and participant uncertainty

The researcher does not have COPD and therefore the interpretations are created from restricted pre-conceived scientific conceptions of the condition. Moreover, the participants themselves lived in uncertainty with regard to their COPD and PR. In order to gain an in-depth phenomenological insight into how phenomena are experienced, it may be necessary for the phenomena to be meaningful for participants. Although the labels of COPD and PR were not necessarily that meaningful for participants, the experiences of COPD, PR and lack of experience of PR were perceived as meaningful.

6.8 Reflections on my role in the research

This PhD candidature has been performed as part of a Clinical Academic Pathway. Therefore, this research is closely related to my area of clinical practice. There have been consequential advantages and disadvantages in the research process as a result. The main advantage is the ability to apply any of the research findings directly to my own clinical practice because the research was performed directly in my clinical practice environment. Furthermore, all clinical staff were informed of my research ideas from their conception, to the planning of the protocol and performing the programmes of which the participants were part. They could therefore give instant feedback whether they thought the research was valuable and realistic to perform with resources available. As a result the ethical, research and development application and recruitment all were very successful. However, because I was a clinician performing interviews as a research student, there were times during the interviews where I felt I was showing that I understood what participants were telling me where a non-clinician may not have necessarily understood. It was also difficult listening to negative participant experiences of their PR journey in a programme within which I worked clinically.

There was no preparation for re-referral of participants post-discharge and then seeing them clinically later. One of my research participants was re-referred to PR after being discharged as a non-completer. This participant then went on to complete a programme. She enjoyed her clinical experience. However, I understood the level of uncertainty and disappointment that she experienced during her time as a research participant and I felt that she may have thought I had some power in changing her prior situation at that point. There was confusion for a few participants who sent their reply slip back clinically. I do not think they fully understood whether the research was part of their clinical process. These participants were excluded from the study.

I had little involvement in the PR B clinical team over the four years which may have limited contextual reflection to that programme. However, I visited the programme and had regular discussion with the service manager and other members of staff at a physiotherapy collaborative meeting held quarterly.

From a methodological perspective the semi-structured questions were aimed at stimulating conversation with questions about the participants’ breathing. This perhaps showed my focus was on their breathing as part of living with COPD and much of the initial inquiry in the interviews revolved around the participants’ breathing compared to the focus on other lived experiences of COPD. However, the focus of breathing was used because it was thought many of the individuals were unclear what the phrase COPD was.

The following chapter summarises the thesis.

7. Summary

This Clinical Academic Pathway PhD candidature aimed to fill a knowledge gap with regard to the lived experiences of COPD patients as they moved through their Pulmonary Rehabilitation journey, from referral onwards. Patient perceptions regarding PR attendance and adherence have previously been researched, but rarely longitudinally, in community-based programmes or performed by physiotherapists. The aim was to interview completers and non-completers of a PR programme. This was achieved and their lived experiences have been explored.

A phenomenological methodology was chosen in order to investigate participants' lived experiences. The phenomenological method was specific to the research setting and the clinical academic nature of the PhD candidature. The phenomenological contextualisation is seen as one of the strengths of this PhD candidature. This PhD candidature is original in its use of its longitudinal design, which included completer and non-completer experiences of community-based PR.

It appears that the main lived experience for participants prior to attending PR was that of uncertainty. This uncertainty seemed to be associated with experiencing panic. Participants' COPD remained 'cloaked', and they were brought 'closer to death'. Many participants experienced 'being-in-limbo' as they were 'floating', waiting for care or information. PR was seen as an intervention that was free, an opportunity to help other people, and was approached with a "give it a go" attitude for many. However, participants had many different illness perceptions and seemed confused about their COPD. This reinforced the lived experience of uncertainty.

For completers, the experience of uncertainty reduced following PR which was associated with being able to push their ‘closeness of death’ further into the future. Social comparison was important for participants in their understanding of their disease severity, coping, and ability to perform in the PR programmes. A COPD education seminar seemed to enhance social comparison. Completers appeared to change their coping style from avoidance to disavowal post-PR. Moreover, breathing properly was associated with relaxation, panicking less and gaining a positive attitude.

Many non-completers were angry with the care they had received, were less able to cope with their comorbidities, viewed their COPD as worsening, but were still able to gain benefits similar to completers when interviewed following PR. They were able to gain a positive attitude for example. Many of the non-completers did not want to do PR and were content in their decision. The main coping style used by non-completers was that of acceptance.

New findings from this research have been highlighted. These include the phenomenological exploration of the longitudinal experience of ‘closeness of death’. The ability to cope with comorbidities appears to be different between completers and non-completers of PR in this study. However, there was a lack of participant concern for health improvement from PR. This occurred when participants described acceptance coping, when COPD was viewed as a temporary condition, or when participants wished to remain “in-the-dark”.

Many practice recommendations that were provided in the discussion were focused on improving communication to patients closer to the point of diagnosis. A COPD education seminar before PR should be included in a PR programme and patients who are concerned about their ‘closeness of death’ should be encouraged that this perception may reduce following participation in PR. Further research is needed to better understand how to manage patients who wish to remain ‘in the dark’, or who have difficulty coping with comorbidities. Moreover, further research is required to understand the impact of time since diagnosis, as a demographic variable, on PR attendance and completion. More research is required which investigates disease acceptance in COPD, social comparison, and the value and outcomes of a GOIS.

This CAP PhD candidature has enabled real-life research to be performed in a Primary Care setting. These participants have reported being recently diagnosed, many of whom live with comorbidities. This is clinically applicable research which has direct relevance to the researcher's own clinical practice environment. This engagement has benefitted the research process and the researcher's clinical development equally. Therefore, this PhD candidature has fulfilled the aim of the CAP. Findings highlight the need to target the lived experience of uncertainty for COPD patients in Primary Care and the role PR has in changing perceived uncertainty. This research has also provided valuable data on the lived experience of non-completers of a PR programme without which clinicians would remain living with uncertainty in their understanding of the non-completer patient experience of PR following a referral to a programme.

8. Appendices

Appendix 1: Key to Interview transcripts

Text taken from interview transcripts that is included in this thesis is shown in italic text within a bold outlined text box. The use of bold text within the quote shows the focus of the quote which particularly impacted on the researcher during the analysis and is specifically linked to the part of the analysis in which the quote has been included. Italic text which is not in bold provides further information, which puts the bold text into context.

… : Indication of other parts of the transcripts that have been excluded from the quote. This may have been when the participants were stuttering at the beginning of their sentences or when the participants' speech has been interrupted by the researcher saying 'mm' or 'yeah'. These agreement phrases were then removed and the participants' speech was joined together.

A: : The researcher's speech

P: The participant's speech

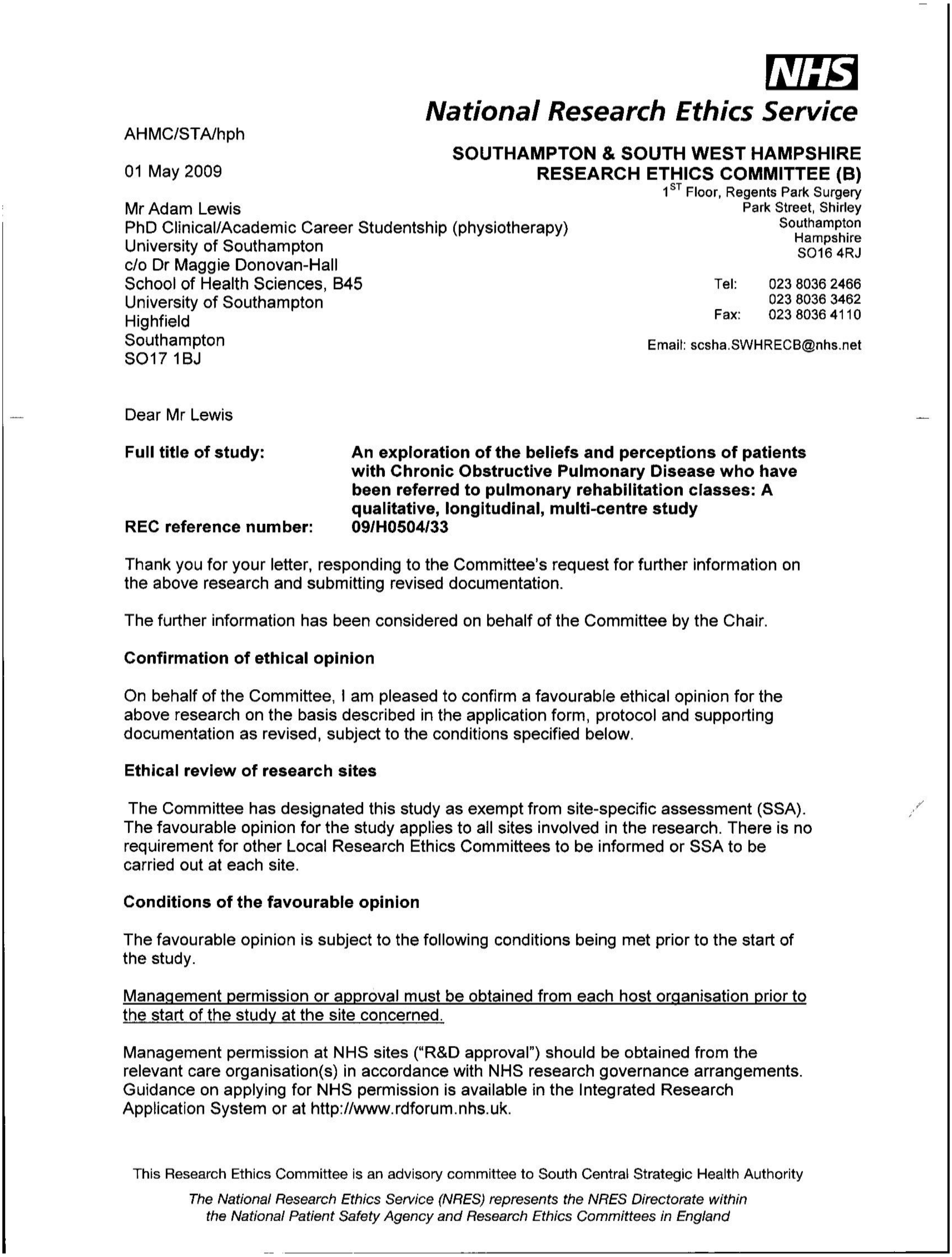
(): Used when words have been completed or amended from the original transcript in order to make sense to the reader. For example 'can' was changed to '(can't)'.

(): The participant or researcher performed an audible action such as laughing or gasping during the interview.

(name): A name that was said during the interview that has been anonymised for participant confidentiality.

Names: All participant names are pseudonyms.

Appendix 2: Ethics approval letter



NHS
National Research Ethics Service

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AHMC/STA/hph

01 May 2009

Mr Adam Lewis
PhD Clinical/Academic Career Studentship (physiotherapy)
University of Southampton
c/o Dr Maggie Donovan-Hall
School of Health Sciences, B45
University of Southampton
Highfield
Southampton
SO17 1BJ

Dear Mr Lewis

Full title of study: **An exploration of the beliefs and perceptions of patients with Chronic Obstructive Pulmonary Disease who have been referred to pulmonary rehabilitation classes: A qualitative, longitudinal, multi-centre study**

REC reference number: **09/H0504/33**

Thank you for your letter, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). The favourable opinion for the study applies to all sites involved in the research. There is no requirement for other Local Research Ethics Committees to be informed or SSA to be carried out at each site.

Conditions of the favourable opinion

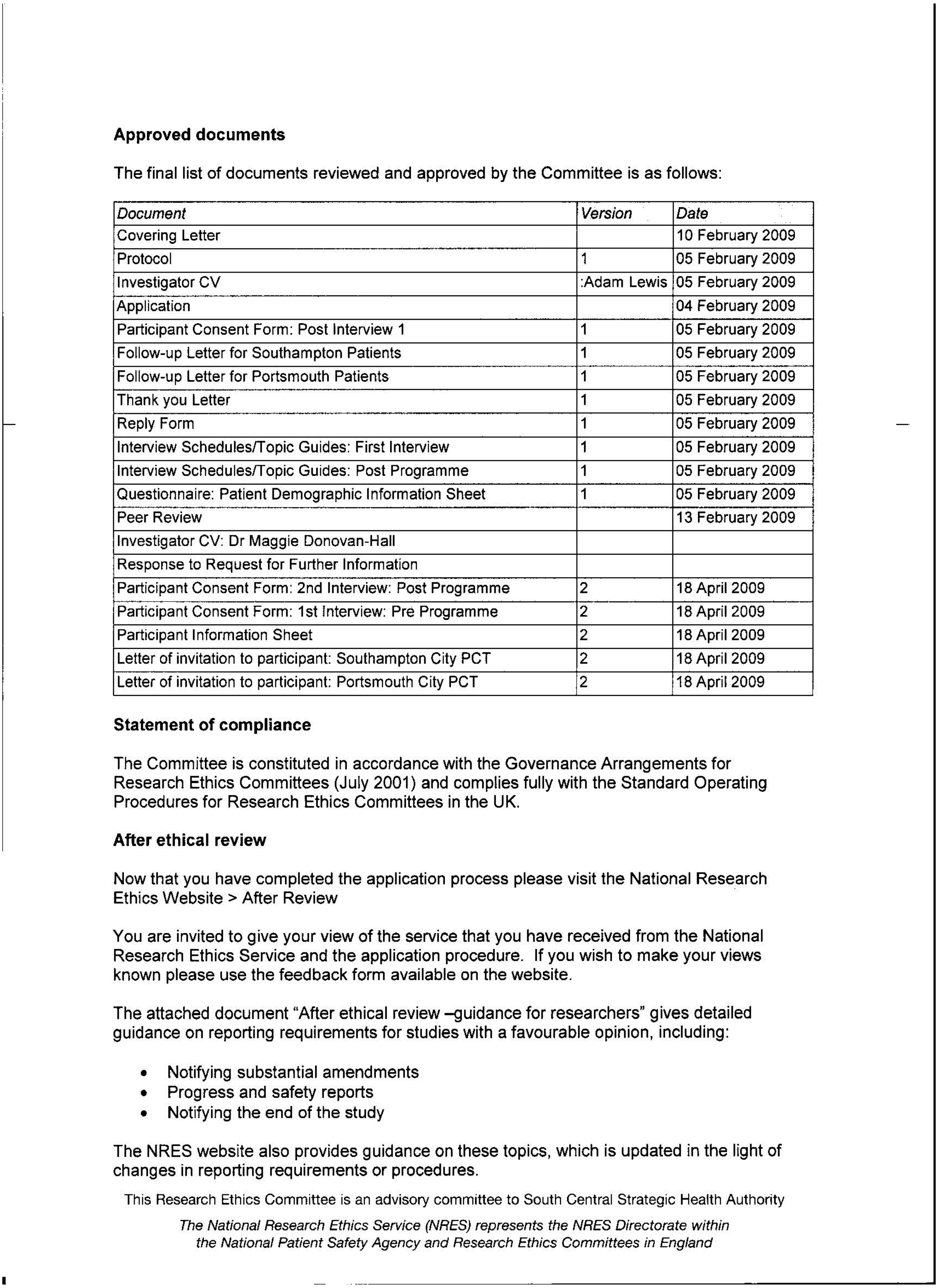
The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

This Research Ethics Committee is an advisory committee to South Central 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



Approved documents

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

Document	*Version*	*Date*
Covering Letter		10 February 2009
Protocol	1	05 February 2009
Investigator CV	:Adam Lewis	05 February 2009
Application		04 February 2009
Participant Consent Form: Post Interview 1	1	05 February 2009
Follow-up Letter for Southampton Patients	1	05 February 2009
Follow-up Letter for Portsmouth Patients	1	05 February 2009
Thank you Letter	1	05 February 2009
Reply Form	1	05 February 2009
Interview Schedules/Topic Guides: First Interview	1	05 February 2009
Interview Schedules/Topic Guides: Post Programme	1	05 February 2009
Questionnaire: Patient Demographic Information Sheet	1	05 February 2009
Peer Review		13 February 2009
Investigator CV: Dr Maggie Donovan-Hall		
Response to Request for Further Information		
Participant Consent Form: 2nd Interview: Post Programme	2	18 April 2009
Participant Consent Form: 1st Interview: Pre Programme	2	18 April 2009
Participant Information Sheet	2	18 April 2009
Letter of invitation to participant: Southampton City PCT	2	18 April 2009
Letter of invitation to participant: Portsmouth City PCT	2	18 April 2009

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

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

The attached document "After ethical review –guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

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

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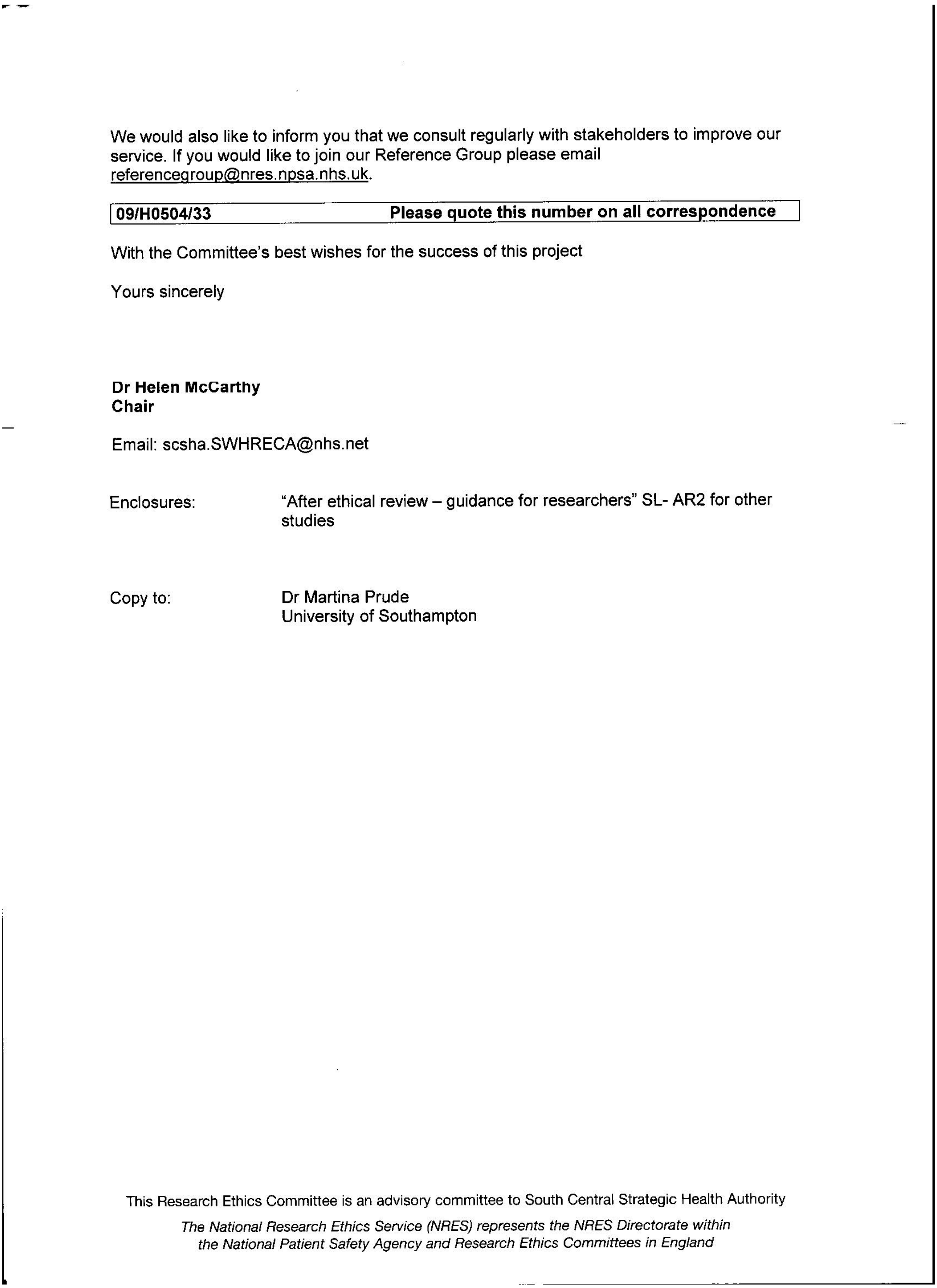

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/H0504/33 **Please quote this number on all correspondence**

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

Yours sincerely

Dr Helen McCarthy
Chair

Email: scsha.SWHRECA@nhs.net

Enclosures: "After ethical review – guidance for researchers" SL- AR2 for other studies

Copy to: Dr Martina Prude
University of Southampton

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The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

Appendix 3: Letter of Access

Portsmouth City NHS
Teaching Primary Care Trust

Human Resources Department

St James Hospital

Locksway Road

Portsmouth

Hampshire

PO4 8LD

Tel: 023 92894493

Fax: 023 92830754

Mr Adam Lewis

24 Brabourne Avenue,

Ferndown,

7 May 2009

Dear Mr Lewis

Letter of access for research – Patient adherence to pulmonary rehabilitation MWP/012/09

As an existing NHS employee you do not require an additional honorary research contract with this NHS organisation. We are satisfied that the research activities that you will undertake in this NHS organisation are commensurate with the activities you undertake for your employer. Your employer is responsible for ensuring such checks as are necessary have been carried out. This letter confirms your right of access to conduct research through **Portsmouth City PCT** for the purpose and on the terms and conditions set out below. This right of access commences on **1 May 2009** and ends on **1 November 2010** unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

You are considered to be a legal visitor to **Portsmouth City PCT** premises. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through **Portsmouth City PCT**, you will remain accountable to your employer **Southampton City PCT** but you are required to follow the reasonable instructions of your nominated manager **Christine Hayward, Physiotherapy Manager**

in this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with **Portsmouth City PCT** policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with **Portsmouth City PCT** in discharging its duties

under the Health and Safety at Work etc Act 1974 and other health and safety legislation

and to take reasonable care for the health and safety of yourself and others while on **Portsmouth City PCT** premises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice

(http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf) and the Data Protection Act

1998. Furthermore you should be aware that under the Act, unauthorised disclosure of

information is an offence and such disclosures may lead to prosecution.

Portsmouth City PCT will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform the NHS organisation that employs you through its normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely

Kate Haylett

HR Recruitment and Administration Manager

PORTSMOUTH CITY PCT

cc: R&D office, Wessex RM&G Unit

Helena Vowden, Southampton City PCT

Appendix 4: Research and Development approvals

Portsmouth City NHS
Primary Care Trust

Mr Adam Lewis

School of Health Sciences B45

University of Southampton

Highfield

Public Health

St James Hospital

Locksway Road

Portsmouth

PO4 8LD

Tel: 023 9228 4593

22th July 2009

Dear Mr Lewis,

Patient adherence to pulmonary rehabilitation

Research Ref: MWP/012/09

I am pleased to tell you that the above project has been approved by Portsmouth City Primary Care Trust.

R&D approval is separate from ethics approval and is also essential for the conduct of research within NHS trusts. It is subject to the following requirements.

1) It is a condition of the approval that the project is carried out according to Good Clinical Practice and within the guidelines of the NHS Research Governance Framework. You have responsibility for ensuring that you and any co-workers adhere to the protocol agreed by the ethics committee.

2) If there are any alterations to the protocol after the study has commenced, you must inform the Research Ethics Committee and the Trust Research Management & Governance (RM&G) Office.

3) It is my duty to remind you that as Chief Investigator you may be required to provide us with project monitoring and outcome information.

Please do not hesitate to contact me should you require any additional information or support.

I wish you well in your project.

Yours sincerely

Dr Matt Smith

Public Health Consultant

Southampton City NHS
Primary Care Trust

Research Management & Governance Office
Primary Medical Care
Aldermoor Health Centre
Aldermoor Close
Southampton SO16 5ST

Tel: 023 8024 1077
Fax: 023 8070 1125
www.wessexrmg@soton.ac.uk

Mr Adam Lewis
School of Health Sciences B45
University of Southampton
Highfield
Southampton SO17 1BJ

16 July 2009

Dear Mr Lewis

Patient adherence to pulmonary rehabilitation

Research Ref: MWP/012/09

I am pleased to tell you that the above project has been approved by the Southampton City Primary Care Trust.

R&D approval is separate from ethics approval and is also essential for the conduct of research within NHS trusts. It is subject to the following requirements.

1) It is a condition of the approval that the project is carried out according to Good Clinical Practice and within the guidelines of the NHS Research Governance Framework. You have responsibility for ensuring that you and any co-workers adhere to the protocol agreed by the ethics committee.
2) If there are any alterations to the protocol after the study has commenced, you must inform the Research Ethics Committee and the Trust Research Management & Governance (RM&G) Office.
3) It is my duty to remind you that as Chief Investigator you may be required to provide us with project monitoring and outcome information.

Please do not hesitate to contact us should you require any additional information or support

Yours sincerely

On behalf of
Dr R Patel
R&D Lead for Southampton City PCT

Trust Headquarters, Oakley Road, Southampton SO16 4GX
Telephone: 023 8029 6904 Fax: 023 8029 6960
Website: www.southamptonhealth.nhs.uk

Appendix 5: Sponsorship and insurance

UNIVERSITY OF
Southampton

Mr Adam Lewis
School of Health Sciences
University of Southampton
University Road
Highfield
Southampton
SO17 1BJ

19 February 2009

Dear Mr Lewis

RGO Ref: 6316 REC No: 09-H0504-33

Project Title **An Exploration of the Beliefs and Perceptions of Patients with Chronic Obstructive Pulmonary Disease who have been Referred to Pulmonary Rehabilitation Programmes: A qualitative, Longitudinal, Multi-Centre Study**

I am writing to confirm that the University of Southampton is prepared to act as sponsor for this study under the terms of the Department of Health Research Governance Framework for Health and Social Care (2nd edition 2005).

The University of Southampton fulfils the role of Research Sponsor in ensuring management, monitoring and reporting arrangements for research. I understand that you will be acting as the Principal Investigator responsible for the daily management for this study, and that you will be providing regular reports on the progress of the study to the Research Governance Office on this basis.

I would like to take this opportunity to remind you of your responsibilities under the terms of the Research Governance Framework, and the EU Clinical Trials Directive (Medicines for Human Use Act) if conducting a clinical trial. We encourage you to become fully conversant with the terms of the Research Governance Framework by referring to the Department of Health document which can be accessed at:

http://www.dh.gov.uk/assetRoot/04/12/24/27/041224

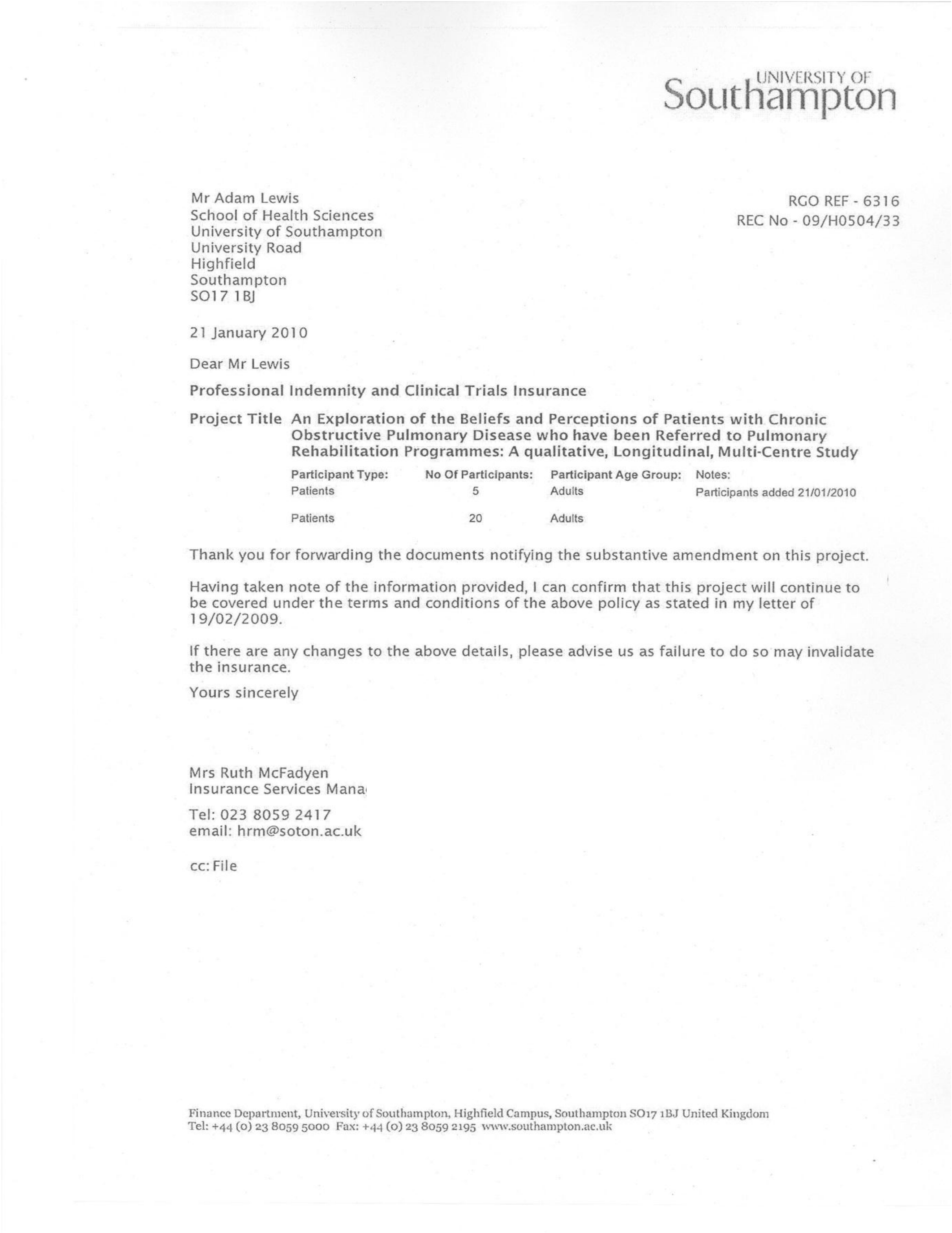
In this regard if your project involves NHS patients or resources please send us a copy of your NHS REC and Trust approval letters when available.

Please do not hesitate to contact me should you require any additional information or support. May I also take this opportunity to wish you every success with your research.

Yours sincerely

Dr Martina Prude
Head of Research Governance
Tel: 023 8059 5058
email: rgoinfo@soton.ac.uk

Corporate Services, University of Southampton, Highfield Campus, Southampton SO17 1BJ United Kingdom
Tel: +44 (0) 23 8059 4684 Fax: +44 (0) 23 8059 5781 www.southampton.ac.uk



UNIVERSITY OF
Southampton

Mr Adam Lewis
School of Health Sciences
University of Southampton
University Road
Highfield
Southampton
SO17 1BJ

RGO REF - 6316
REC No - 09/H0504/33

21 January 2010

Dear Mr Lewis

Professional Indemnity and Clinical Trials Insurance

Project Title **An Exploration of the Beliefs and Perceptions of Patients with Chronic Obstructive Pulmonary Disease who have been Referred to Pulmonary Rehabilitation Programmes: A qualitative, Longitudinal, Multi-Centre Study**

Participant Type:	No Of Participants:	Participant Age Group:	Notes:
Patients	5	Adults	Participants added 21/01/2010
Patients	20	Adults	

Thank you for forwarding the documents notifying the substantive amendment on this project.

Having taken note of the information provided, I can confirm that this project will continue to be covered under the terms and conditions of the above policy as stated in my letter of 19/02/2009.

If there are any changes to the above details, please advise us as failure to do so may invalidate the insurance.

Yours sincerely

Mrs Ruth McFadyen
Insurance Services Mana

Tel: 023 8059 2417
email: hrm@soton.ac.uk

cc: File

Finance Department, University of Southampton, Highfield Campus, Southampton SO17 1BJ United Kingdom
Tel: +44 (0) 23 8059 5000 Fax: +44 (0) 23 8059 2195 www.southampton.ac.uk

Appendix 6: Pre-programme consent form 1

UNIVERSITY OF Southampton
School of Health Sciences

Consent Form (1^{st} interview: Pre Programme)

Study Title: An exploration of the beliefs and perceptions of patients with Chronic Obstructive Pulmonary Disease who have been referred to pulmonary rehabilitation classes.

Name of researcher: Adam Lewis

Please initial the boxes to indicate that you have read and understood the text.

1. I confirm that I have read and understand the information sheet dated 18/04/09 version no 2 for the above study and have had the opportunity to ask questions, any of which have been answered satisfactorily. ☐
2. I understand that my participation is voluntary and I may withdraw from the study at any time, for any reason without my legal rights or medical care being affected. ☐
3. I understand that all the information collected from me, for the project will be retained by the University of Southampton for ten years in line with the university policy. ☐
4. I understand that the data collected may be viewed by the research supervisors. I give permission for these individuals to have access to my data. ☐
5. I agree that the interview can be recorded. ☐
6. I agree to take part in the above study. ☐
7. I understand that, although no names or identifying comments will be included, direct anonymised quotes may be used in the reporting of this study, and in the presentation of the findings to other healthcare professionals, academic staff and students ☐
8. I am happy for you to access pulmonary rehabilitation records at the end of the study to review my attendence at the pulmonary rehabilitation class. ☐

Name of Subject Date Signature

Name of Researcher Date Signature

Appendix 7: Pre-programme consent form 2

UNIVERSITY OF Southampton
School of Health Sciences

<u>Consent Form (post interview 1)</u>

Study Title: An exploration of the beliefs and perceptions of patients with Chronic Obstructive Pulmonary Disease who have been referred to pulmonary rehabilitation classes.

Name of researcher: Adam Lewis

Please initial the boxes to indicate that you have read and understood the text.

1. I am happy to be contacted again to be invited to be interviewed after the pulmonary rehabilitation programme has finished. ☐

Name of Subject Date Signature

Name of Researcher Date Signature

Appendix 8: Post-programme consent form

Consent Form (2nd Interview: Post Programme)

Study Title: An exploration of the beliefs and perceptions of patients with Chronic Obstructive Pulmonary Disease who have been referred to pulmonary rehabilitation classes.

Name of researcher: Adam Lewis

Please initial the boxes to indicate that you have read and understood the text.

1. I confirm that I have read and understand the information sheet dated 18/04/09 version no 2 for the above study and have had the opportunity to ask questions, any of which have been answered satisfactorily. ☐
2. I understand that my participation is voluntary and I may withdraw from the study at any time, for any reason without my legal rights or medical care being affected. ☐
3. I understand that all the information collected from me, for the project will be retained by the University of Southampton for ten years in line with the university policy. ☐
4. I understand that the data collected may be viewed by the research supervisors. I give permission for these individuals to have access to my data. ☐
5. I agree that the interview can be recorded. ☐
6. I agree to take part in the above study. ☐
7. I understand that, although no names or identifying comments will be included, direct anonymised quotes may be used in the reporting of this study, and in the presentation of the findings to other healthcare professionals, academic staff and students. ☐

Name of Subject Date Signature

Name of Researcher Date Signature

Appendix 9: Participant invitation letter

UNIVERSITY OF
Southampton
School of Health Sciences

Mr Adam Lewis,

Postgraduate Office, Building 45,

School of Health Sciences,

University of Southampton,

Highfield,

Southampton,

Hampshire.

SO17 1BJ

Dear Sir/Madam,

My name is Adam Lewis. I am in my first year of a PhD programme on behalf of The University of Southampton. I am very interested in research that involves people who have Chronic Obstructive Pulmonary Disease.

It has been brought to my attention that you have recently been referred to start a pulmonary rehabilitation programme within Southampton City Primary Care Trust. The University of Southampton are working with Southampton City Primary Care Trust to perform research with patients who have Chronic Obstructive Pulmonary Disease.

Enclosed in the envelope with this letter, is an information sheet which will inform you more about the research. Please take some time to read and discuss the information sheet with close friends and family. If you are interested in taking part I have included a reply slip and a stamped addressed envelope for you to send back to me. If I do not hear back from you in two weeks I will send the letter again. After another two weeks, if I have not heard back from you, I will assume that you do not want to take part in the research.

This research is not part of your NHS treatment or referral to pulmonary rehabilitation. It is entirely up to you whether or not you choose to take part.

Thank you for your consideration,

Yours Faithfully,

Adam Lewis

Appendix 10: Participant information sheet

Patient Information Sheet

Study Title: An exploration of the beliefs and perceptions of patients with Chronic Obstructive Pulmonary Disease who have been referred to pulmonary rehabilitation programmes: A qualitative, longitudinal, multi-centre study

This is an invitation to take part in a research study. This information sheet is an explanation of why the research is being perfomed and what it would involve for you if you agree to take part in a research study. This should be read alongside your invitation letter so that everything will be made as clear as possible for you.

Please take your time to read the following information carefully.

Do not hesitate to contact the researcher or research supervisor if you require any further information. This research is being carried out as part of a research programme.

Background

There are at least 1 million people in the UK with a chronic lung problem known as Chronic Obstructive Pulmonary Disease or COPD. One of the treatments for this condition is to provide patients with the opportunity to attend a pulmonary rehabilitation programme. Not everyone who is offered this treatment is willing to accept, and some people drop out before finishing the programme. If we could learn more about what people with COPD believe and understand about pulmonary rehabilitation, it might be possible to design better programmes that more people like you, would want to attend.

What is the purpose of this study?

The main aim of this research is to find out what people with COPD think about the management of their condition and gain a greater understanding of their views about being referred to take part in a pulmonary rehabilitation programme.

Why have you been chosen?

You have been chosen because we are hoping to recruit about 15 people like you who have been diagnosed with COPD and have been referred to a pulmonary rehabilitation programme for the first time. We know this because your referral to pulmonary rehabilitation was brought to our attention by a member of staff in teams in Southampton or Portsmouth who will be involved in your rehabilitation.

Do you have to take part?

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason and without your legal rights being affected. If you withdraw from the study your future treatment from the NHS will not be affected. Please note that taking part in the study will not affect your pulmonary rehabilitation in any way.

What will happen to you if you do take part?

If you decide to take part, a researcher will contact you to arrange to meet you to have a conversation (usually called an ‘interview’) with you. You will be able to choose where you want to be interviewed (either in your own home or at the University of Southampton).This conversation can be of any length that suits you, but you should allow for this to be up to about one hour. This is because you may need to take some short breaks, for example if you find talking makes you breathless. The interview will take place before you attend your pulmonary rehabilitation programme. When the researcher comes to your home (or meets you in the university), you will have a chance to ask any questions and then you will be asked to sign a consent form, stating that you are happy to take part in the study. The researcher will also ask your permission to tape record the interview. The researcher will then ask you to talk about how you feel about your breathing problems, and how you manage them. You will also be asked what you hope or expect to get from attending a pulmonary rehabilitation programme. You can ask to stop the recording at any time, and you can refuse to answer any questions that you do not wish to answer.

We would like to interview some people more than once, so after the completion of the first interview, you will be asked if you are willing to participate in a second interview, to be carried out soon after your pulmonary rehabilitation programme ends. You may or may not be contacted by the researcher with an invitation to participate in a second interview. However, if you are invited to participate in a second interview, we would very much like to talk to you again, **whether or not** you have attended any of the pulmonary rehabilitation sessions. If you are invited to take part in a second interview we will ask for your consent for us to access your pulmonary rehabilitation records, to enable us to note the number of sessions that you were able to attend.

When the study has been completed you will be offered the chance to see a summary of all the findings.

What are the costs of taking part in the research?

If you would like to be interviewed at the University of Southampton then you would have to pay for your own travel costs to and from the University. There are no other costs or payments associated with this research. Unfortunately, no compensation will be available for loss of earnings if you take time off work to be interviewed.

What are the possible benefits of taking part?

There is no known clinical benefit for you personally in taking part in the study. However, we hope that the information that will be gained from you will help improve the management of other people with COPD.

What happens when my research stops?

We will give feedback to you and the other participants, write a report for the funding organisation, publish the findings in a research journal, and present at national and international conferences so that the findings from this work can influence future practice.

What if something goes wrong?

In the unlikely event that you are harmed by taking part in this research project, or if you have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal University complaint mechanisms are available to you. If you wish to make a complaint, please contact Anne Bruton via her email address which is ab7@soton.ac.uk. The university's Research Governance Office can also be contacted through Dr Martina Prude at mad4@soton.ac.uk. If you wish to contact a support service that has no connection with this research the British Lung Foundation Helpline is 08458 50 50 20. If you do not have access to the internet, other contact details can be found at the bottom of this information sheet.

Will my taking part in this study be kept confidential?

All the information about your participation in this study will be kept confidential in accordance with the Data Protection Act 1998. Data will be collected using a recording device (a dictaphone), access to which will only be made available to the researcher, the researcher's supervisors and research and development auditors (for the monitoring of the quality of research). Any information about you will have your name and address removed so that you cannot be recognised from it, and you will therefore remain anonymous. After the study, the information that you will provide will be securely stored according to the University of Southampton guidelines. The data will be retained for future studies and research audit purposes. Although the personal data that you provide will be confidential, the interview data will be used anonymously within the researchers thesis or publications and may be discussed with the research team supervisors and members of the pulmonary rehabilitation programme clinical staff.

What will happen to the results of the research?

You will not be identified in any report or publication that is published. However, it is intended to publish the results from this study. This would mean that some direct quotations from the information that you say during the interviews could be used in future published articles. However, you will remain anonymous in any published work produced from this research. Results will be made available to you at the end of the study if you request a summary of the findings. The researcher's contact details (Adam Lewis) are provided at the bottom of this information sheet. If you let him know of your interest, he will send you the summary via mail when the study has been completed. The summary of results will contain information from participant interviews, the researchers interpretations and how this research will be used in future practice or research. However, you need to be aware that results may take months or years before being published. You also have the right to check the accuracy of data held about you and discuss with the researcher or research supervisors any errors that need correcting.

Who has reviewed the study?

The NHS research ethics committe have reviewed the study. The committee consists of a group of independent people, not associated with the reseach project, to protect your safety, rights, well being and dignity. The ethics reference number for this study is 09/H0504/33.

Who is funding this research?

NHS Education South Central are funding this research by supporting the researcher via a Clinical/Academic post.

Contact for further information:

If you want any further information then please contact the researcher Adam Lewis (apl104@soton.ac.uk), or supervisor Anne Bruton (ab7@soton.ac.uk), or Dr Martina Prude on behalf of the University of Southampton Research Governance Office (mad4@soton.ac.uk).

Contact Details

Adam Lewis

Postgraduate office

School of Health Sciences Building 45

University of Southampton

Highfield

Southampton

SO17 1BJ

Dr Anne Bruton

Reader in Respiratory Rehabilitation

School of Health Sciences 45

University of Southampton

Highfield

Southampton

SO17 1BJ

Telephone number: 02380 595283

Dr Martina Prude

Head of Research Governance

Corporate Services

University of Southampton

Highfield

Southampton

SO17 1BJ

Telephone number: 02380 598848

Thank you for taking the time to read this information sheet. Before making your decision whether to take part in this research or not, feel free to discuss the above information and your thoughts with close friends and family.

If you do decide to participate in the research and have reading glasses, and choose to be interviewed at the University of Southampton, please bring them with you to the interviews. Thank you.

Appendix 11: Lone Working Policy

UNIVERSITY OF
Southampton
School of Health Sciences

Research and Enterprise Services Office
Form RA4/February 2009/V1.1

Lone Interviewing Contact Procedure & Location Form

IMPORTANT

- Please make sure that you use the most up to date version of this information by checking with the Research and Enterprise Services Office (RESO) before you start.
- If you have any queries please contact the Head of Research & Enterprise Services (Susan Rogers, ssr@soton.ac.uk or 023 8059 7942).

Prior to your first interview/visit:
Please ensure that you have read the **Lone Interviewing Risk Assessment Guidance (RA2)** and completed the **Lone Interviewing Checklist (RA3)** with your supervisor/principal investigator (PI) and completed a **Location Form (RA4)** for the first interview. Please bring the Location Form and your completed Checklist to the Research and Enterprise Services Office (RESO) for review **before** you start your fieldwork. A copy of your Location Form should also be given to your agreed contact person (if the interviews will take place outside office hours (08.30-16.00).

Prior to each subsequent visit/interview:
Complete a new **Location Form** and hand it to the Research and Enterprise Services Office with a copy to your agreed contact person if the interview/visit will take place outside office hours.

On the day of the visit/interview:
Before the interview
The researcher should call the Research and Enterprise Services Office (if during office hours) or the agreed contact person (if outside office hours) to let them know they are about to start the interview.

After a visit/interview
The researcher should call the Research and Enterprise Services Office once the interview/visit is complete (if during office hours) or the agreed contact person (if outside office hours). It is preferable that the researcher speaks to someone in person instead of leaving a message.

If THREE hours have elapsed since the start of the researcher's interview/visit the following procedure should be followed by the Research and Enterprise Services Office /agreed contact person:

- Phone the researcher on the main contact number they have provided (preferably a mobile).

- If they are still interviewing, ask the researcher to telephone the Research and Enterprise Services Office/agreed contact person when they leave.
- If no answer, try other contact numbers.
- If contact has still not been made, phone the interviewee
- If the interviewee says that the researcher is there, ask to speak to him/her personally and check everything is well.
- If the interviewee says that the researcher has left recently (within 10 minutes), wait another 10 minutes. If there is still no contact, instigate emergency procedure (see below).
- If there is no answer from the interviewee, commence emergency procedures.

Emergency Procedures

The Research and Enterprise Services Office or agreed contact person (if outside office hours) should inform the researcher's supervisor/PI and then phone the police (Hampshire Constabulary central call number is 0845 045 4545)

If the researcher should find themselves in an uncomfortable situation:

Leave immediately:

Make an excuse to return to the car, taking car keys, and leave.

If the researcher is unable to leave the household:

- Use the telephone to contact someone, preferably the Research and Enterprise Services Office. If this is difficult, explain that the office will be alerted if you do not return.
- If you are able to make an emergency call relay a pre-decided emergency message (e.g. "Please tell my supervisor that the interview is going well")
- If the Research and Enterprise Services Office or agreed contact person hears this phrase, they should contact the police and researcher's supervisor/PI immediately.

Notes:

- *If you feel THREE hours is too long or too short a time, please indicate your time preference on the Location Form.*
- *Please take into consideration how long your interview might take to complete and bear in mind that if the interview finishes outside office hours then the agreed contact person will be responsible for checking the researcher back in and instigating emergency procedures if necessary.*
- *The researcher may also choose to add an additional 'check-in' if they are travelling a long distance before and/or after the visit/interview.*
- *If a visit is happening outside office hours or is likely to finish outside office hours, the agreed person will replace the Research and Enterprise Services Office as point of contact. The agreed person should be a reliable person who you know will be available at the time of the interview, e.g. a family member/spouse/partner.*

UNIVERSITY OF
Southampton
School of Health Sciences

Research and Enterprise Services Office

Research Location Form (RA4)

Please specify if you feel 3 hours is an appropriate time limit for your agreed person to contact you:

3 hours is appropriate

Researcher Name: Address: Mobile tel no: Home tel no:	**Adam Lewis** **18 Timberlake Court, Timberlake Road, Basingstoke, RG21 7AD** **07877 472670** **01483 474498**
Supervisor/ Principal Investigator Name: Address: Mobile tel no: Office no:	**Dr Maggie Donovan-Hall** **SOHS, University of Southampton, Southampton SO17 1BJ** **07515966980** **02380598880**
Agreed Contact Person Name: Address: Mobile tel no: Home tel no:	**Dr Maggie Donovan-Hall** **SOHS, University of Southampton, Southampton SO17 1BJ** **07515966980** **02380598880**
Researcher's Car Make Model Colour Registration	**Ford** **Ka** **Dark Blue** **ROO6 YJC**
Interviewee Name: Address: Mobile tel no: Home tel no:	**For Data Protection purposes please put these details in a sealed envelope and give them to the RESO with this form. The envelope will be opened only in cases of emergency. All documentation will be shredded when interview if over and the researcher reported safely out from the interview.**
Interview Date: Time: Location: Expected length:	**Thursday 26th November** **1.30pm onwards** **Participant Home Address** **45 mins to 3 hours**
Any other useful information?	

Appendix 12: Bias Participant

This is a descriptive account to illustrate my biases towards how I think a COPD participant will talk about their lived experience of COPD and Pulmonary rehabilitation before and after a programme. These biases have been formulated by my last 8 months' clinical experience in pulmonary rehabilitation, and my literature review to start this research. Therefore if these biases are similar to my findings, it will not necessarily just mean that I have been too closed minded about my research method, it may also mean that my level of understanding of these patients at this point of my career is commendable, and is probably such because I have known I will be performing research in this area whilst treating patients clinically, and therefore paying extra attention to things that other clinicians may not have. Conversely I hope that my stereotyped patient only scrapes the surface of understanding that I know about individuals lived experience of COPD and pulmonary rehabilitation and I will adopt the phenomenological methodological position of wonder when talking to people about their experiences.

I will now try and illustrate my bias point of view by exemplifying some sample questions with a response which would be normal for an individual with COPD. This is in line with the analytic method of bracketing what you already know and combining this method with a written account from the self. A disadvantage of using the Barritt method is that I have never had COPD or been referred to PR so to write my own account of these experiences would be pointless. Rather by pretending to be a COPD patient my subjective empirical knowledge will be bracketed in a way that the reader can acknowledge and I can come back to this account as a constant comparative analytic method.

Before PR

How is your breathing today?

Fine

Tell me about a typical day for you?

Well I gets up and takes me inhalers, have a cup of tea and make some breakfast for the wife and me, bit a toast or something then I sit down and read the papers or helps the wife with the medication if she needs it. We got the grandchildren to look after twice a week, so we takes them out you know. They like that. Not far like but get outside, fresh air does me good. Not always mind, you know when its cold or windy, you know. If I got any energy when I gets home I does a bit of dinner you know but more often than not it's a sandwich, easy. We watch a bit of t.v, she likes the soaps, I'm not bothered you know.

Tell me about your breathing?

P: well, I gets puffed out a lot. Mainly its on doing stuff, you know. Like if I am doing the hooverin, oh I can't do that for long before stopping. Then, I'm forever before startin again. It's not all the time mind, I gets on alright. I have to cos of me wife, I'm the main carer see and if I don't do it, it don't get done. I go out and do's the shopping, and that's it.

What makes your breathing worse?

I'm pretty good really. I gets on, as I said the hoovering, and hills, don't start on hills. I can't do them like I used to, bit of a problem when I'm living on one you know. I got a little workshop down the end of the garden, I enjoy that, but its things like sawin that gets me, you know.

What makes your breathing better?

I just stop and gets me breath. Sit down, wait and that's it, you know its not too bad.

How has your breathing condition affected your life?

Its slowed me down, things take a lot longer now you know, takes all day sometimes to do the simplest of things. I think a lot of it is to do with me caring for me wife. Without her I wouldn't be doin everything you know, I should thank her really, but it knackers me alright. Dunno whether I could do it otherwise mind, you know if she were doin the things she used to, too. We used to go dancing down at the community hall, we loved it, but we just can't do it anymore.

What do you know about your COPD?

I got emphysema, I've had it for a good few years now. They tell me it's from smoking you know. We both smoked. They say its something to do with the airways. I don't know much apart from that. It was diagnosed by my GP. I think he just related it to the smoking.

What advice was given?

He just told me to go and see the nurse you know, she's the one that does all the blow tests like, I see her every year down at the surgery. I got the inhalers and was just told to let the doctors know if I'm feeling chesty.

Who do you think is important in caring for your COPD?

My doctor always see's me if I phone up, he gives me the tablets and I'm fine, so its probably him really.

How do you feel about pulmonary rehabilitation?

Well I don't know really, spose it'll give me something to do, get me out of the house you know, apparently the nurse was saying it's something to do with exercises for me breathing, well I gets puffed out normally you know so if they can help it would be great. Good thing is its just round the corner from us, cos the nurse said that they do's it downstairs in our surgery.

What sort of thing would encourage you to go to pulmonary rehabilitation?

I wants be able to look after me wife for as long as possible like you know. Cos I know I have slowed down and that but we don’t want carers in if we can help it. So if it helps me keep on top of things at home that would be nice yeah.

Is there anything that would prevent you from going to Pulmonary Rehabilitation?

Nothing really, I suppose if we were going on holiday or something but we don’t do so much of that now.

What do you hope to achieve from pulmonary rehabilitation?

Well I wants to breathe better, do more you know.

How do you feel about exercise?

I have never really been one for exercise, apart from at school, bit of football, rugby, cricket like you had to you know, but once I left school and started working I never really kept that stuff up. I mean I still walk a bit you know but apart from that, I gets too breathless to do much more than a bit of a walk.

Would you like to know more about your COPD?

Yeah, definitely. I would like to know a bit more about what will happen now I got it, I need to think about what I am going to be like in a few years down the road like. The doctor hasn’t explained anything about that you know. I wanna know why I’m so out of puff too.

And what about your social activity?

Social activity, hah! What social activity? Those were the days. No we don’t get out much now, it’s just doing the essentials you know, like shopping and that. We sometimes go into town if the markets on but not for long like cos there's places to sit down by the market there and she loves seeing all the bits and bobs. We sees the family when they come to visit, our daughter lives near so it gives us a chance to see the grandkids occasionally, not as much as I'd like mind.

Do you know other people with COPD?

No.

After Pulmonary Rehabilitation

How are you feeling today?

Fine thank you, better actually I think, I have been a bit rough over the last few weeks but I am out of it now so yeah plan on doing some of those exercises again.

Tell me about your experience of the first assessment before the rehabilitation started?

Oh the lady at rehabilitation she asked me about my smoking and what I did for work, you know. She checked my chest and then I did a walk test. Well I couldn't do it, I had to sit down two or three times, she said that was normal, I don't know it was pretty simple really, just finding out if I was gonna be able to be put on the exercises you know.

Tell me about your experience of being on the programme?

Well after that assessment I started a few weeks later cos we had a few hospital appointments the week before see. I got there and I thought it was good actually, they taught me how to breathe properly and I found that I was able to walk more. There were some people there that had to sit down and do the exercises but I was fine to do them all you know, did quite well. They are a good group, some funny characters you know. The staff knew what they were talking about too which helps.

Were there any negatives from going on the programme?

I didn’t get on with the relaxing really, in a group when they’re all coughing, well that’s not relaxing is it. No I could have done without that.

How many pulmonary rehabilitation sessions did you manage to attend?

I missed a few over one week didn’t I cos we were looking after our grandson, my daughter went on holiday so. No apart from that went to them all.

What did you learn in the education talks?

All about the lungs you know and whats going on inside, very interesting. We had another nurse come in and show us how to use the puffers properly, which of course I wasn’t was I, that made us all laugh, see we didn’t mind having a bit of fun cos most of us were in the same boat see. There was one know it all though, she was a bit serious. What else, um, no can’t think now, that was about it really.

Has this information changed how you manage your COPD?

I know what’s happening now when I get breathless and when to stop now, so yeah I think I pushes things a bit more now.

To make pulmonary rehabilitation more relevant to you as an individual how would you change the programme?

No, I don’t think you could really, but I do wish I had known about this a long time ago cos I would have probably asked for it you know.

How do you view your experience of living with COPD now compared to before rehabilitation?

Well I can do more, I feel less puffed out now after helping me wife you know so and I know who to call now if I need some advice you know they said just cos you have finished on the programme, doesn’t mean we’re not here to help so that’s positive you know.

Do you feel any different as a result of attending pulmonary rehabilitation?

Well I’ve still got it I know that but I guess it doesn’t bother me as much now, I know how to deal with it better now.

What activities have you been doing in your own time?

Nothing out of the ordinary really, same old same old, goes out for the shopping you know. I have been keen to go to the market and have a good walk round but me wife hasn’t been up to it recently and I am just getting over what they like to call an exacerbation, I did remember something see. They put me on steroids this time which my doctors never did in the past, seems to be working so.

Tell me more about your experience of doing the exercises, walking at home?

Well to be honest I found that my time has been taken up by chores around the house, my wife used to do em at double speed you know but it takes me a lot longer so, and by the evenings you know after dinner it’s a bit late. I will gets round to doing them, maybe more in the summer when its lighter for longer, go out for more walks then you know.

Has your opinion of exercise changed since starting the programme?

Yeah, I thought exercise was things like football and stuff but basically its anything that's gets you out of puff, we only did a few minutes on each exercise and you were out of puff you know like the step or the sit to stand exercise, well I can do those round the house, well I will do those round the house, yeah.

What will be important for you to continue with exercise in the future?

Just being able to look after me wife really, you know I know it's a bit much to go out playing with the grandkids now but as long as I can do stuff round the house then I'm fine.

What will be important in applying what you have learnt during rehabilitation?

I have kept all the talks so there's no problem there, I find looking at the breathing one helpful if I get a bit out of puff, helps me calm it down with the controlling the breathing so yeah. I did miss out on one of the talks but I'm okay with what I've learnt its helped so.

Appendix 13: Pre programme semi-structured interview schedule

Sample interview questions (first interview)

Hello, My name is Adam, I am doing research on behalf of the University of Southampton. Thank you for taking part in my research project. I must remind you, that all the information that you provide will remain confidential and you will remain anonymous. If at any point during the interview if you feel uncomfortable with what I'm asking you or you get too stressed, let me know and we can stop. The interview should only take approximately sixty minutes.

So just to make you aware of what I know about where you are in your NHS treatment, you have just been referred to a pulmonary rehabilitation programme because you have a disease called COPD which causes you to have breathing difficulties, is that right?

How is your breathing today?

Ok, I will now be asking you some questions related to your breathing and how it has affected you. Don't worry if you can't think of an answer immediately, take your time and we can always come back to a question if we get stuck. There are no right or wrong answers here, I am just looking to get information from your thoughts and feelings.

COPD

Tell me about a typical day for you?

- What makes your breathing worse?
- What makes your breathing better?
- (How does your breathing problem affect you now?)

When did you first notice problems with your breathing?

- Why do you think you got breathing problems?
- Why do you think you still have breathing problems?

How has your breathing condition affected your life?

What do you know about your COPD?

- When was your COPD diagnosed?

- by whom
- how
- what advice was given
- Who do you think is important in caring for your COPD?

- How satisfied are you with the care you are given for your breathing?

If needed - Do you get many chest infections?

- Why do you think this is?

- What happens?

- How do you cope?

If needed - Tell me about your current living situation

- social relationships

Pulmonary Rehabilitation

How do you feel about your referral to pulmonary rehabilitation?

-What do you know about PR/What do you think PR will be like?

-What sort of thing would encourage you to go to PR?

-What sort of thing would prevent you from going to PR?

What do you hope to achieve from pulmonary rehabilitation?

How do you feel about exercise?

- With other people?

Is there anything else in your opinion that I should have asked you?

Is there anything else you would like to ask me?

Do you have any other comments related to your COPD or Pulmonary Rehabilitation?

Thank you.

Appendix 14: Post programme interview schedule

Hello. Thank you for agreeing to let me interview you again. This interview will be similar to the last. I must remind you again, that all the personal information that you provide will remain confidential and you will remain anonymous. If at any point during the interview if you feel uncomfortable with what I'm asking you or you get too stressed, let me know and we can stop. This should only take approximately sixty minutes.

Now please help yourself to either a tea, coffee or water and we can then start when you are ready (if interviewing at university)

How are you feeling today?

How did you get on with the pulmonary rehabilitation programme?

How many pulmonary rehabilitation sessions did you manage to attend?

If you missed any, what made you do so?

If you attended them all, what was it that made you choose to do so?

Did the pulmonary rehabilitation programme meet your expectations that you had before you started?

- Why?
- why not/were there any that were not met?

What activities have you been doing in your own time?

What made you decide to exercise/ walk etc or not during the times that you were not taking part in the pulmonary rehabilitation class?

Please tell me more about your experiences of performing the exercises/walking at home.

Are your breathing problems any better, same, or worse than before pulmonary rehabilitation?

Do you think you got any benefit from the pulmonary rehabilitation programme?

- In what way?

Has your opinion of exercise changed at all since starting the pulmonary rehabilitation programme?

What would make it easier for you to attend pulmonary rehabilitation?

And what was important to you about the educational talks that you heard during the classes?

What else can you remember about the talks?

In what way have you used the advice taken from the talks?

What was it like being in the programme with a group of people?

To make pulmonary rehabilitation more relevant to your COPD as an individual, how would you change the programme?

What has been important for you in continuing your own pulmonary rehabilitation now that the classes have finished?

What will be important for you to continue with pulmonary rehabilitation in the future?

What will be important in applying what you have learnt during pulmonary rehabilitation in the future?

Do you feel any different as a result of attending pulmonary rehabilitation?

- If so how?
- What has changed?

Is there anything else you would like to tell me about your experiences of your COPD?

Is there anything else you would like to tell me about your experiences of pulmonary rehabilitation?

Thank you for answering those questions I will now present you with a summary of what you said in your last interview. If you can reflect on what you said in your first interview, before pulmonary rehabilitation, what would you say about your comments?

Thank you for taking the time to answer my questions. If you wish I will send you a summary of the results from this study at a later date.

Appendix 15: Example of interview transcript

A: Okay

P: Modern technology

A: Modern technology that's right um so again thank you very much for uh letting me come into your home um and uh agreeing to take part in this research I'll remind you that's its um on behalf of the University of Southampton um and any information that you say any personal information, people's names things like that will be kept confidential and you will remain anonymous should this research get published. So you won't be identified um just to encourage normal conversation.

P: Freedom

A: Freedom of speech everything like that um. Should you get um stressed or worried about anything I'm asking, or your talking about, let me know and we can stop

P: Sure

A: or we can take a break um this should take approximately sixty minutes depending on obviously

P: Right

A: how much you want to, to let me know.

P: Well there's not a lot to let you know (laughs).

A: Okay um I'll be asking uh some questions related to your breathing predominantly um and how it's affected you um don't worry if you can't think of an answer straight away. There's no right or wrong answers. Um I'm just interested to find out information about your thoughts, about your experiences, and your feelings um. So just to let you know about what I know about your current NHS treatment. You've been referred to a clinical team that as part of their process offers pulmonary rehabilitation because you have a condition called chronic obstructive pulmonary disease, is that right?

P: yes

A: okay good okay so um yeah how you feeling today?

P: Pretty well okay

A: Yeah good, good and your breathing?

P: Variable but on the whole very good, you you said breathing, I have no pains across my chest and uh, normally I can walk up to the top and back my limbs get more tired than I do um no I can breathe, but the only thing is which I don't understand and this is relatively recent. Come down in the morning, have breakfast sit down here and have something oh just sit here. I'm short of breath, just like that, soon as I stood up doing anything it eases off again so. But that's for the doctors to sort out uh, or its just me,

A: okay

P: but on the whole, I think one thing you should know as far as the exercise is concerned I don't do as much external as I would like to do, walking because i'm a great believer in walking, for two reasons well the main one being I've got a funny inside.

A: Right

P: Bowels

A: Right

P: Up here that's, what they call it um, diverticulitis

A: Okay

P: if you know it, and uh that restricts one quite a lot but over and above that I was with one fairly recent doctor said and referred to me as a sprightly old gentleman or something or words to that affect which was quite complimentary but uh no for my age uh got two good limbs, excetra excetra. I'm not grumbling.

A: Okay so you said um, it can be variable you said your breathing can be variable?

P: Yes

A: Mm, in in what way?

P: Well sometime get a bit shortage of breath but normally doesn't inter, w, worry me much at all. Um give an example. I've a r, fairly routine one is we go to Waitrose on Friday and, and sometimes going round there say. But how much of that is shortage of breath, environments low ceilings or anything else I don't know, but I get tired, I have never had to stop yet.

A: Right okay and also you were saying that in the mornings when you come up you get little bit of out of breath but then once you get going you're okay.

P: Yes, that's fairly recent yes.

A: Okay why do you think that is?

P: I don't know.

A: Okay.

P: Haven’t a clue.

A: Okay.

P: And I’m not unduly worried about it because I’ve got a blue inhaler which is a, if it gets out of hand I can take it, and I think I have used it once, I say blue one because I can never remember the horrible names.

A: Okay, okay. Um okay so what makes your breathing worse in general do you find?

P: Breathing

A: worse

P: No nothing really, other than I suppose exertion, but I don’t do a hell of a lot of that.

A: Mmm

P: Now you can see the distance up to the, see there, I can walk up there and the thing that will slow me down more is my legs rather than my breathing, and if I do get a little bit short of (gasps) I just pause and carry on (phone rings) oh god

A: It’s okay.

P: Get rid of these things

A: No its fine.

W: Hello?

A: It’s fine, um and uh okay, is there anything else that makes your breathing worse?

P: No

W: Yes (on the phone).

A: No okay.

W: That’s right (on the phone).

A: And what do you find makes your breathing better?

W: bye bye.

P: Fresh air.

A: Fresh air okay and in what way do you find that fresh air makes

P: Well you, it’s it’s a love, open that window now and put your head outside and you’ll feel it, it’s good.

A: Brilliant okay so

P: it’s the least of, least of problems I, you see you come in at, at the stage of it, I not oh really over stressed with my COPD because I think a lot of it is toned down by my overall physical age affecting me as a human being.

A: Right.

P: But um, I wouldn’t expect to go and have a game of rugby now, I envy people who go running along the road, I can’t do that.

A: Okay so it’s your relating um the COPD um to yourself as a whole?

P: Yes.

A: Yeah okay um so tell me about your, your typical day?

P: This is pretty serious as well. Six fifteen, radio’s on automatic, get out of bed seven fifteen.

A: Right

P: Wash and shave and eating breakfast half past eight by half past eight um idling till about half past nine or ten oh just think I also do a little bit of physical exercise before I get dressed just a few stretches to reaching out type and then I next thing is I normally do and I like doing is twenty minutes Alexander technique if you know what that is?

A: Okay.

P: I been doing that now for many years.

A: Okay whats, whats that?

P: Lie flat on the ground

A: Okay.

P: He, head rested and get absolutely straight the whole body balanced and then bring your legs up but all generally moving and controlling it’s a bit like that you see.

A: Okay and how does that help you?

P: Physically gives you flexibility I think once again when I talk about being tired and things like that flexibility, I’m pretty good, I won’t that, I’m as flexible as you, but I can lie on the floor now and crawl crawl up and get up without using my hands

A: Mm

P: which a lot of people can’t do.

A:mmm yeah yeah sure.

P: If I could just interrupt cos I may give you a little bit out of the unknown run but if you’re wanting to know what has happened in the past periods

A: Yeah, sure.

P: It’s uh I’m saying this now because my wife (name) will have to go out

A: Yeah no problem, absolutely no problem.

P: and, and, and she is the one who’s been uh what’s it, what was that hurdly word and you were taught to use or could use?

W: Instrumental?

P: No patient power.

W: Oh patient power.

P: Patient power and that’s why I am now going on this rehabilitation thing.

A: okay

P: Because its patient power that focus me using the uh piece of paper there which we’ve only recently

W: I think it’s because of the, I think its all here yeah, understanding the management of their conditions.

A: Yes.

W: Now they weren’t hi, we weren’t too sure of what you meant by that.

A: Okay

W: If you mean in part getting a say on this course?

A: mm

W: Did you mean things like that?

A: Um basically what I meant by the um uh on the patient information sheet about wanting to know what you understand about your condition is uh my, my research is is focused mainly um very much so on patient knowledge of how they how they feel and their experiences of their disease and their understanding of it so that research can be very much patient focused rather than you know um research coming from the other side.

P: Involve the patient.

A: Exactly

W: Well then I I

P: I’m

A: and try and try to understand people more.

P: With that but that has not happened.

W: No no.

A: No okay.

P: No not until that piece of paper arrived which came from our doctors surgery from prescriptions it wasn’t handed to me or anything.

A: Mm okay.

W: Okay.

W: Now that was a superb session.

P: It was absolutely first class that

W: First class first class session.

A: First class.

P: And the people who ran it they only nearly one mistake and they hadn’t got their sp sp speakers working.

W: Absolutely.

P: But that didn’t worry us we were in the front row and it was brilliant.

W: Yeah

A: But but they didn’t sweep it did you say?

W: Oh no no, no no no its really what happened no

A: Sorry.

W: What happened was they didn’t make it clear that the the actual venue was well off the road road.

A: Oh

W: Up a hill.

A: Oh right

W: So for some people it was a big problem

A: Okay, okay.

A: So your GP gave you that?

P: No

W: One of them we don’t know who.

P: It came from the GP’s department.

W: It came from the surgery.

A: Oh okay.

W: Okay very quickly.

P: We shouldn’t start suspecting who sent it as it was another doctor there.

W: Very quickly, it came from the surgery we went to this session

A: Mmm.

W: Superb session if you’re interested in the management then you ought to see if you can get on one of those.

A: Okay.

W: You got a phone number here I’ll give you.

A: Yeah yeah great yeah definitely.

W: Um, my they talked about this rehabilitation right.

A: Okay.

W: This pulmonary rehabilitation

A: Okay.

W: because they said what you were getting was a kind of a feedback you get breathless you get wired because you’re breathless so you don’t exercise therefore you get more breathless when you do.

A: Okay.

W: Rehabilitation courses, my husband said right I'd like to go on one of those, got himself signed up, we didn't hear for about three, four weeks.

A: Okay.

P: This is all my wife cos I think I'd have said sod it, put it back.

W: So I rang them, said you know haven't heard, oh they said um, give it another week or two and then if you haven't heard from us get onto your surgery got on to the surgery after a week or two, receptionist are then helpful said I'll talk to the nurse. She came back to me and said oh the nurse said that you weren't suitable my husband wasn't suitable for the course

A: Right

W: because he ha, a heart condition,

P: This is this is important.

A: Right.

W: so I thought this heart condition is nothing, I got back onto the rehabilitation group

A: Mmm.

W: I explained the situation said the heart condition was next to nothing.

A: Mmm.

W: The man one of the men the man I spoke to said, leave it to me, he got on to the surgery got back to me or us and said don't worry um they are going to do the assessment and they will let me have your husband's assessment, and he said what went wrong?

A: Mmm.

W: was that the form they send that is sent to the general surgery has a blanket question like does the, does the person have a heart problem to that extent.

A: Okay.

W: Yes or no.

A: Okay

W: Right

A: Okay

W: and he said that form is so out of date because you could have a problem which is incredibly minor.

A: Mm

W: Now the the thing that upset to strong a word but irritated me was a the comm, the person concerned at the surgery whoever it was didn't tell us that the form had arrived and they had said no, didn't really send the form back as far as I can understand it in the rehabilitation centre

A: Right

W: and did not or could not have looked at my husband's notes to say yes he's got a heart condition.

A: Mm

W: But it's nothing

A: Mmm, mmm

W: and it was then that the rehabilitation said to me cos I said well you know what a shame there was in the lack of communication

A: Mmm

W: and that's when he said I'm afr that's when they said I'm afraid to say you need patient power.

P: And we're not mentioning any names now

W: Because no

A: No no that's fine even if your

P: There was there was more than one person there that was very good

W :Very helpful

P: Very helpful

A: Sure

W: The person in this centre was most helpful.

A: You can say the name that's fine, it will be kept confidential

W: No

P: No no

A: Okay

W: But the person here was really most helpful because they're really keen to get people managing you know their illness

A: Mmm, patient power.

W: and their their condition I should say, but he really said it was patient power that you know virtually saying that look if you hadn't tried to pursue it you would have never gone on the course

A: Mmm

W: and never have known he'd been turned down

A: Mmm

W: for no good reason.

A: Mm, so what do you think about all of that about this day and what happened?

P: Well I think its I understand it happening and how it happened, but um

W: I don't

P: but um, sublime and the ridiculous you got the people who were really trying hard these people to get things going and whether, I don't know what goes on in the doctors surgery, now don't get me wrong there my doctors, I, I been with now for twenty five years thirty years.

W: Oh thirty years

P: Thirty years and he's kept me alive nicely.

A: Mm

P: He even advised the best thing to do is drink whisky, I mean so he's a good doctor (laughs).

W: (laughs)

P: But I think you used the word earlier, there's too much paperwork around and I think I and I think they are up to their eyes here, bureaucracy.

A: Mmm

P: Better word probably, but uh but I want, this is why my wife said what happened was as I said to you earlier a few minutes ago, if she hadn't done that I'd have probably said well sod it I'm not going to spend all my time waste any more energy, because I'm not exactly dying.

A: No

P: But I am now very interested in going, in going on the uh exercise which apparently is an hour and hour and a half.

A: Right

P: I'd be interested to see how they use it because I think that's what I think anyhow, I'll tell you in a fortnight's time, I think I'll probably be as good if not better than most of the people on the course.

A: Okay and how did you feel that session, the day went?

P: That thing?

W: Yes

P: Fabulous

A: Mmm

P: Very well explained at all levels, very well organised from a point of view of question and answering and generally saying well I am trying to look after you and even a bit more that that, this is apparently a would say not experimental, this is an initiative they are trying to put into other areas where this is for people, COPD.

A: Right

P: As far as I can gather they are trying to introduce this sort of environment for other oh what do you call them?

W: Conditions

P: Yes other conditions, but uh

A: Right

P: To help in anybody's whose

A: Yeah

P: I would say blind and deaf that they're not one but the other one.

A: Yeah, so what benefit did, did you think you got from, from the day?

P: A good explanation of what goes on.

A: Yeah

P: A good explanation of the different treatments that are possible. Cos I am now sitting with three different sniffers.

A: Right

P: I call them sniffers because I can never remember the names. Br, brown, green and blue and um I don't know what they are for I know a bit more about them what they are supposed to do.

A: Mm

P: I know more about they're going tickle, tickle the hairs inside my lungs and things like that. No it was well done, well laid on apart from hiding as I say in the middle of the hospital but hiding.

A: Right okay, um very nice thank you, um okay, so going back to the um, that's valuable information by the way thank you um going back to the questions about the your breathing now um, when did you first notice problems with your breathing?

P: I don't know, that's, the that's the, the best answer.

A: Yeah and as I said at the beginning there's no right or wrong answers and the fact that that you may not know the answers to some of these questions is just as a valuable information as if you did for me.

P: Do you, do you know whether I ever grumble about breathing say I wasn't playing a game or sports or tennis or anything like that so that that sort of thing didn't hit me.

A: Mmm

W: About two or three years I would have thought.

P: Something like that.

A: Okay, okay and why do you think you got breathing problems, pardon me.

P: Oh smoking

A: The smoking

P: Oh yes oh and uh Dr (name) said I was with him saying see this graph here you see cos they said when did you stop smoking I said oh I don't know about forty, he said right and it was a graph which showed the longer you smoke, it's a geometric progression.

A: Mmm

P: The older you get.

A: Mmm

P: Stop when you're young and you'll keep going like that but if you carry on it's going like that all the time.

W: Yes its

A: Okay, okay um and how, how do you see your breathing condition has affected your life?

P: Now it's a bit hard to, hard to say that because the thing that's affected my life more than anything else is my insides. I mean I was standing well I've got I've got to say this

A: Yeah, anything

P: I dare not do not do anything before ten o'clock in the morning as a standing rule. Because anything can happen. For example, two day, two days ago, went to the loo came down here after breakfast I had my tea I thought oh oh, and I went and sat on the loo and I blew, literally blew up and mess all over the place you know that sort of thing.

A:Mmm

P: And you cant go and stay in people's houses like that.

A: Right

P: And uh that started marking that's, that's the background to, our def, my life is affected

A: Mmm

P: and that started many years ago, cos I was out in (name) my law, where I was with my daughter and I thought oh oh and I went into a shop I didn't know them. I said got a loo I can use urgent and they said yes and a similar sought of thing not quite so bad happened there.

A: Mmm, mmm

P: Well that's it. It's something you can't put up with, but that is what slows me down.

A: Mm

P: Not that it ever has been the breathing I don't think.

A: No, okay, okay um so what do you know about your chronic obstructive pulmonary disease?

P: Everything it tells you in, well I have got a very good report on the email which I can pull off the net, well I think I know all that's necessary to know about it. It's a oh, its I'm not a I'm not a surgeon.

A: No

P: But it's a it's, just what it says. It's, it's an obstruction of the passages to the the lung to chest and well everything else round there and I have a fleeting idea that that affects other parts of your organs as well.

W: I don't know

A: Right, so how does that make you feel when you know what's going on in your lungs?

P: Oh yes I know what I'm doing that's why I'm happily doing my sniffers, as I call then and that's a thing I always have some sniffers for my nose but that is for (sniffs) that's sniffing.

A: And what's this balloon thing you were talking about?

P: Which one's that then?

A: You said you sometimes you have to come in but you're alright cos you can use your balloon.

P: Blue.

A: Blue sniffer

P: Blue sniffer

A: Sorry I miss, mis heard I beg I beg your pardon.

P: That's my fault.

A: Okay so

P: And I never used it very much but that on this course which I didn't know about the damn thing till about and they explained what the blue one is for it's got another word it's not the same thing as COPD.

A: mmm, mmm

P: it's, it's a allergy type of thing. And it affects all sorts of other things

A: Right

P: You will know what the answer is.

A: Okay um so how do you think your breathing is related to your co, chronic obstructive pulmonary disease?

P: Directly I suppose, I can see anything ext, any other connection

A: mm

P: That is there.

A: Okay, okay and when was your COPD diagnosed? It doesn't have to be exact dates.

P: The only bit I've got for quite a long time I was going and having examination after examination after examination at (name), (name) hospital actually, they are all heart. And then I get a letter back well (Dr's name) got the letter back it doesn't tell you much whether I can find it for you (searching through paper) I don't know where I got all this from, oh

A: Right

P: (laughs) the whole story's there really.

A: and and and did you get that information?

P: I got that that yes that's me, I only got it fairly recently I think.

A: Yeah

P: No August late year, August last year.

A: Right

P: I don't know if I can find it, but it's one that just it was a final one from (name) I don't know why I keep it all in here.

A: Its okay.

P: It doesn't tell you anything because it just says what's the matter with me? I'm just trying to find that letter from (name) which says COPD.

W: Oh yeah

P: Because that's the only, only real thing I don't have in writing.

W: (name) Wasn't he's the bowel man

P: Hhm?

A: So who who who diagnosed it?

W: Um heart man.

P: There you are

A: Right okay ah ha ha, this is it okay

P: That'll do you.

A: So do you

P: Oh he's retired now.

A: July 2008

P: But I, I been having heart tests for what year, two years?

W: I can't remember darling it went on and on and on.

A: Right okay so this was um a heart doctor was it that?

W: yeah.

A: That detected it okay.

W: Because the um our GP said well breathlessness is either heart or lung let's start you off with heart.

P: and he just guessed it on one to start with, but they examined everything.

A: Mmm

P: So how they know, how they say well we know its COPD I don't know.

A: But you don't know how they know?

P: No

A: No

P: Except now they can.

W: Most say that.

P: Because I have got shortage of breath and things a lot of the symptoms of it and that's what it

W: I think it's that it's a diagnosis by elimination, elimination.

P: elimination.

A: Mmm

P: But if you leave it long enough you'll eliminate it alright (laughs).

A: (laughs) Okay so tell me about how you feel when you get breathless?

P: excuse me my language my dear, pissed off.

A: Right that's yeah

P: That uh conveys it that's exactly what it is.

A: Okay and why's that?

P: Well I'm one of those lucky people right through my life I've ever been a great sportsman but I have always been pretty active. I spent best part of my life in the army, infantry

A: Right

P: and you know you don't take kindly to kind of things you can't do what you want at five o'clock in the morning and ca, carrying on all day long and night aslinstery its uh, but see you, the other thing you've got to I've got to wrap it in and I prefer age in to this.

A: That's absolutely fine.

P: A good example is I decided two or three days ago I wish I did it a long time ago but got down to it two or three that my study downstairs, it's a got to be sorted out and it will be. Well this meant bending down and picking up a box there, pulling those flowers out from under there putting some uh more up that sort of thing, a lot of physical work.

A: Mm

P: That not only made me out of breath but also I've got p, I gotta poorly back as well.

A: Right okay

P: I'm, I'm decrepit if you listen, take two or three words here.

A: No

P: Normally the back don't affect me much. It's there all the time that's why I do the what I call the Alexander technique cos I think that's brilliant it really gets all those that and the help of an osteopath which

A: Mmm

P: I don't go to so much now but they're they are good but, my friend who's from Southampton does.

A: Right okay, so the bending over and moving things that got you a little bit out of breath did it?

P: Well yes oh yes

A: Okay

P: As you see it's it's exertion that seems to put you out of breath, that's how I find it, that's right I never thought of that before. You see not long ago I would paint this room I did, right trying to think of an example but I but couldn't flat out now and it this is e, e energy and out of breathless doing one wall listen dear very recently what was it?

W: Town maybe or something.

P: Can't remember anyhow doesn't really matter.

A: Mmm no it it will be.

P: It's the energy. Use of energy seems to take you out of breath. That's, that's, the that's the relationship.

A: Right.

P: Walking ya, your using energy, breathlessness.

A: Okay so the walk

P: I think its all in together that's all, mmm.

A: The more energy you use the more breathless you get?

P: Yeah, I have never thought of that before, but I think it's true that, in my case anyway.

A: Okay um

P: Well I never had that problem in my life it's um

A: It's a recent thing?

P: It's only recent which has stopped me climbing ladders and going on skates.

A: (laughs) okay, so was any advice given to you um at the time of diagnosis, no?

P: You're talking about back in the general practitioner's surgery.

A: Okay, okay that's yeah.

P: I don't think so.

A: No that's fine and as I said you know sometimes

P: Well you see the sort I think I'd have expected in retrospect this

A: Right

P: I'd have expected that when (name) said well it the problem's eighty the wording was eighty percent COPD, I'd have thought that knowing what I know now that the doctor would have said well we got these exercises units running we'll get you on that (clock beeps).

W: No it's that, little clock.

A: Oh okay.

P: Oh don't worry about it.

W: On the hour.

A: Oh okay I was thinking

W: On the hour

A: Oh okay okay

P: Yes dead on

A: Um okay so (bowel doctor name) said uh it was

W: It was (other doctors name)

A: Eighty percent.

P: Eighty percent.

A: So what do you think the other twenty percent was?

P: Oh where was that piece of paper.

W: Heart, heart.

P: A bit of it, a bit of it what's happened to it.

A: Why you

P: Oh you got it haven't you?

A: Have I?

W: No no, twenty percent, now remember the one, its here look.

P: I thought we had it in our hands

A: I think its there actually yeah.

P: Its on the same sheet isn't it in there.

A: Its okay if it wasn't it wasn't written down.

W: No it was.

P: Oh yes it was written down.

W: Yeah

P: Oh oh don't we have (name) paper.

W: Not (name) darling (heart doctor name) (name) is your bowel here we are I think this gentleman's breathlessness is eighty percent related to COPD with a smaller component from his ischemic heart disease.

A: Right okay

W: and dystatolic dysfunction.

A: Right

W: Okay

P: I worked those out (laughs).

A: And what does that mean to you?

P: Nothing.

W: Angina

P: Well its angina that's a

W: Myo valve or.

P: been around for yonks.

A: Okay um so who do you think's important for caring um for your COPD?

P: Who's from the caring point?

A: Who who do you believes important in caring for it?

P: Well now I know what's going on I put it straight pack onto these people, prior to that my GP.

A: Right

P: and myself as well and talk about it.

A: Mm, mm and how satisfied are you with the care you're getting at the moment?

P: Where from?

A: In g, in general

P: On cpu COPD?

A: Yes

P: Well actually basic care, zero. But what I’m expecting to get is hundred percent next Wednesday.

A: Okay

P: Well if these people are, I’ve gotta say because it’s you. You’ve caught it when I’m not being looked after except it’s all going to happen.

A: Okay okay. And how does that make you feel?

P: Great I know I’m longing to go on these exercises just as I told. As I mentioned earlier I believe in walking is a good exercise whether you do long distance or fast or whatever it is, walking.

A: Mmm

P: But I’ve re restrictions on my walking.

A: Mm

P: like my limbs a little bit and little bit rusty I had one or two nasty scrapes when I was in the army.

A: Mmm

P: and uh

A: Right

P: Not as fa fit as I could have been if I otherwise.

A: Mm okay um do you get many chest infections at all or?

P: No

A: No okay so tell

P: More than influence uh

W: Touch wood darling.

A: Touch a, um so uh tell me a little bit about your social activity.

P: Zero.

A: Okay.

P: Apart from my wife.

A: Okay.

P : No yes it is fairly we're lucky how far back do you want to go?

A: Well

P:You see I worked for IBM after the army. I left the army and then went straight into IBM,

A: Mmm

P: moved down here with them I should get, reluctantly, and my wife was only at that stage working at IBM and uh we got into this house. We liked the area and uh we never had a hell of a lot of social down here. There used to be a very good bunny club along here which we used to go to regularly, and uh there's a royal naval club around the corner which I joined which is, don't like, but uh otherwise the, the big asset here in many ways apart from location

A: Mm

P: uh the the friendliness of this group round here.

A: Friendliness?

P: Yes

A: Of the lo local houses?

P: Oh say local here just round here, its uh, we don't argue with the postman, he'd leave anybody's with you or you with them. And uh yeah and the trades people as well, such that you see trades people now.

A: Mm

P: Now it's a

W: And

P: But where we've one thing that has had to had to stop because of this (points to stomach)

A: Right

P: is going off to see friends and also where are my old friends I've done that in there before till 'ey die, I was thinking (name) and (names) off you go you see.

W: (names) yeah.

A: Mm.

P: And uh and then I have another very old friend who she's, she's in her husband died and then she's in hospital now. I can't go to see her, it's the first time I haven't but my wife's carried along going. That's over in (name).

A: Right

P: I can't finish the journeys.

A: Right okay.

P: But that is

A: Because of

P: Primarily yes.

A: Right okay, um

P: It has nothing really to do with the COPD.

W: No it isn't actually.

P: Nothing at all to do with it.

W: That won't interfere with your social life.

P: Apart from not being able too well no COPD doesn't interfere.

A: Mm

W: Its other things

A: Okay

P: Its my ins

A: Mm mm sure okay um okay so lets see how we're doing for time oh fine yeah absolutely fine.

W: I'll give you that.

A: Oh thank you very much.

W: That's the name of the session he's on and that's the phone number and (name) is the admin assistant.

A: Oh great thank you very much thank you, appreciate that.

P: Is that (name)?

W: Yeah that you know worth

P: Mm

A: Thank you um, I'll put that in this folder actually just so I don't get it um (coughs) okay so we'll uh, we'll move on to talk a little bit more about this p uh pulmonary rehabilitation then um what do you know about pulmonary rehabilitation?

P: Nothing, other than its

W: May I say

P: Hmm

W: Seven weeks

A: Mm

P: Oh sorry about that yes.

W: Seven weeks two sessions a week

P: an hour and a half each time.

A: Right.

W: For seven weeks and next week my husband's going for the think you're having an initial assessment.

A: Okay

W: And then what happens after that on the ac on the assess on the sessions is based on the rehabilitation.

A: The assessment.

P: Well depending that assuming I'm fit enough or not fit enough.

W: I'd think you would be.

A: Okay.

P: I'll be fit enough for that.

A: Okay.

W: Right okay, bye.

A: Very nice to meet you, thank you very much for letting me in I I appreciate it very much so.

W: Yes I'm off I I'll take the key darling.

P: Okay bye

W: Bye

A: Um okay um so how do you envisage it envisage it being like?

P: Well I do I don thi, I have a feeling I was sitting in (name) surgery they do it over at (name) clinic actually.

A: Mm

P: I was in there as I say and I think I saw them, a, a group coming in that looks as if they're, the they looked like old dodderers actually.

A: Right.

P: If that's what I'm going to cope with, I, I think all they'll do is sit down and, and do this sort of thing, I don't think they'll be doing the exercises that I would expect like well we'll jump and down and touch your toes and all that um you know the old the ones we used to do at school and because that I'm certain has helped me a lot because when you when you doing exercise of that sort and I'm doing that largely because I can't walk well I can but uh

A: Mmm

P: Not the sort of walking I'm talking about.

A: Mm

P: So uh well, I'm looking forward to it because I think it'll um it'll either discourage me on my expectancy see how much do you know about me?

A: Only what you've told me

P: How old am I?

A: No idea.

P: Guess.

A: Um oh I wouldn't like to um that that's one of the questions on one of the pieces of paper actually.

P: Is it?

A: Yeah, yeah um

P: Well if it's on the way we'll get it you down.

A: Yeah

P: No I'm a coming up to eighty nine now

A: Oh are you?

P: and uh I don't think I'm doing too badly for that.

A: No

P: Its

A: not at all um.

P: I've beaten my mother which is what I wanted to do.

A: (laughs)

P: But at eighty three she was climbing trees.

A: Was she?

P: On a, on ladders but you well there you are but uh

A: Okay um so you were saying it might change your expectations by going.

P: I don't think it oh well it was extent I don't understand.

A: Well that's, what I was going to ask you um

P: No I don't reveal to, if as I feeling that they're a bit more decrepit than I think they'll be that'll be an make me feel big headed.

A: Yeah

P: Which I suppose is a good thing in a way but uh I want to go and see what it is and what they do, and quite frankly its seven uh did I say twice a week for seven weeks or something, anyhow its it's an hour and a half each time it's seven weeks over at um I'm interested in seeing what they do.

A: Mmm

P: I'm a great believer in exercise and I think sc, schools and the young nowadays they don't have to play football and cricket and skating or anything like that you got to do some of it but um it's not an essential. But an active a life I think is. And I have been lucky having had an active life or at least I did until I joined IBM.

A: Um okay uh so what would what would encourage you to go to pulmonary rehabilitation?

P: Oh just get keep me fit, get me fitter

A: Okay

P: I'm not so interested so much about the COPD or my breathlessness. Cos I think that will automatically come naturally anyhow. As long as I get exercise and I'm all for somebody trying it on.

A: Mmm, and what would prevent you from going?

P: Nothing, well, short of anyth, short of anything my legs dropping off or something oh no and I'll be up there, it's a bit of a nuisance it's cross at (name) the other side of the island.

A: Right okay

P: But you see uh there again I stopped driving um and quite frankly I think I'm, I use a taxi mostly now, and it's cheaper using a taxi than it is a car.

A: Mmm, mm

P: For what we're doing cos I'm not going on distances.

A: Mmm, mmm, mm

P: But uh, and we've got good bus services here, and it's free when

A: Mm, um so how do you feel about exercising in a group of people?

P: Okay

A: Mm

P: As at work, I've done that all my life.

A: Mm

P: At the RSM, sergant majors parade your on it full stop that's the end of the crowd now. I have never, I'm not an isolationist never have been, I'm not a club man though, never have been.

A: Right.

P: I'm a member of all sorts of things but never got into this idea we got to go to a club to have a drink and,

A: No okay um so would you like to know more about your chronic obstructive pulmonary disease.

P: No I don't think so.

A: No

P: Well I think what, what is on the email, a the net, and what these boys, the, if you as I think I was saying if you haven't been on one of these ones go on one.

A: Mm

P: Brilliant

A: Mmm

P: and what you see they had four people taking part one who basically involves in all the treatments.

A: Right

P: There was um oh dear physical expert there, there was a fully qualified doctor and I've forgotten what the other one was but they were there were four fully qualified people running that, you know all in their own rights, all knew what they were talking about all could answer the questions or get one of them would answer.

A: Mmm

P: It's not often I don't even start me on the NHS because I've got decided views on that. That it's an exception.

A: Right and your views on the NHS are somewhat different?

P: yes, well I don't know about overall but a fortn, a month, winter before last I had an dare on Christmas just after Christmas and before New Year I had a an inter a bleeding haemorrhage and uh, my home doctor was very good and they got me in there quickly da da da. Now obviously my specialist, I went there, he said oh don't worry its quite normal you'll get over it quickly but in there, there was one nurse who knew what she was doing and she was good, the rest of them I don't know whether they did or they didn't.

A: Right.

P: And, but the nursing side I wouldn't criticise apart from that, a because I'm not calling by you, but the management of it, atrocious.

A: Right.

P: You know ailments I have a way now I have got a lot of very bad catarrh at the time they said oh we'll fix that well uh nothing they ever did happened, you know and that sort of thing but I, when are you gonna let me go home? oh we'll fix it uh, we'll tell you tomorrow, I said I want to go home today, it's my birthday tomorrow, it was actually I was genuine that (laughs) and in the end I more or less just left full stop you know.

A: Mm

P: One one of the nurses said oh I'll them you're gone that's it you know that's, I'm afraid I go back to the days of the old matron who ran the wards that was the end oh ran, senior sisters ran the wards.

A: Mm

P: Nobody else interfered now and I think you'd agree to something you said earlier, bureaucracy, paperwork.

A: Mmm, mmm

P: Trust.

A: Mmm, okay um, do you know anybody else with COPD?

P: No, nope, I don't know why I expected that's what you were going to ask, no.

A: No

P: I, I don't want, I think I know one or two that I'm surprised they haven't got it.

A: Right.

P: Maybe they have as well you never know, purely on the smoking grounds,

A: Right.

P: Because an awful lot don't give up you see from about forty or fifty.

A: Right.

P: I don't know what made me give up I gave up three times in my life, one genuine you know the last one and I gave up twice previously, but you see it doesn't need a lot if you give up it doesn't need a lot to trigger you off again.

A: Mmm

P: Arrived in Singapore my married quarter. Yes all fixed oh no, you wouldn't believe this but there were two major (name) each with a wife and a child on the same boat going out there they got the names mixed up and gave my house to the other person

A: Mmm

P: and I said first thing I did as soon as I got into the mess was give me a cigarette that you know that's the sort of thing.

A: Mm

P: I don't know what started me off the next time but uh

A: Mmm um

P: well smoking do you smoke?

A: No, um so is there anything else in your opinion um that I should have asked you if you were in my position and you wanted to?

P: No I think you see I think you got the key story was that's why I wanted my wife to be here because she said this is, she went with me on that, we never actually said well come on we, we better go and I said yes well we'll see what it's all about, because I had lost a lot of, a lot of faith really in being told I had got COPD and I'd been given this nice blue, my sniffer, which I don't think, which I didn't have my one o'clock one now you see, or at least I don't think I did, um and well better just check and I went on it, and that lifted my idea of the national health service was good.

A: Mmm

P: The people were good, the organisation was good

A: and that's the key thing.

P: Except we couldn't get there we couldn't find our way it was so

A: Mm, but you think that's the key experience with your COPD do?

P: what?

A: You said

P: Oh that

A: that the key thing with your wife being here was that she would be here to talk about that is that correct?

P: Yes

A: Okay

P: Well as I comm, she, she did the work on it because uh she didn't go into all the details but you know talking to people don't want to know or will not know or we'll pass the message on and never do.

A: Mmm

P: well got a bit sick of those.

A: Mmm

P: But um

A: And you said you, you, said you think you wouldn’t have bothered if it was you.

P: I lie a, like that, well I rely the do, I would have bothered, but, but if I did I’d have lost my cool with somebody.

A: Right

P: She’s very good like that she just.

A: Okay, okay, um and is there anything else you would like to ask me?

P: No, one thing that’s, that’s personal, your background

A: Mm

P: What are you studying?

A: Mmm, I’m doing a um PhD in um chronic obstructive pulmonary disease and pulmonary rehabilitation

P: And what before that?

A: Be before that I did a batchelors, yeah at the University of Southampton again

P: Southampton

A: So I’m just continuing on, yeah, is there any anything else you want to ask?

P: I don’t think so

A: No do you

P: Well, well, well except, where does it what’s, what’s the next step as far as you’re concerned and moving it forward?

A: Right okay um the next step if you agree, obviously there’s another sheet there to, to um sign obviously that’s, that’s up to you if you sign it, is NHS choice obviously it’s up to you if you participate or not in the pulmonary rehabilitation after that rehabilitation has finished so.

P: Oh yes eight weeks’ time or something.

A: Okay, okay, if that’s

P: is that what you are saying at the very end

A: Yes, yes um and uh yeah just have another talk to you then and and see, and see how you are doing.

P: and if I lose my cool in the middle

A: Yes and

P: at that time I'll let you know.

A: Well I would still like to speak to you, if, if you decide not to as well so

P: well I'll let you know if I'm not

A: Yes yeah, so um that's the next stage really

P: Because that was only the only reason I would, wouldn't carry on is if I thought it was a waste of time.

A: Mm

P: and uh

A: Mmm

P: If anybody any of the people in this room asked got anything to do with it

A: Mm

P: I think they have um, I've forgotten what these what they call these people, nurses who look after your goo goo (hits his legs),

A: okay

P: um you know psych, not psychiatric I've got the wrong end of um, anyhow it doesn't matter.

A:Mmm

P: A qualified uh,

A: Mm okay

P: yeah they're running it and it seemed.

A: Why do you think it could be a waste of time?

P: I don't think will be.

A: no oh sorry.

P: But don't forget a lot of what I have said is that I think I've only said one complimentary thing possible about the NHS.

A: Mm

P: Two if you like, like this.

A: It will be kept confidential don’t worry.

P: No it’s just good nursing well I mean that’s all.

A: Mmm, okay well I think we can stop the recording there now.

P: Okay

A: um that was that was brilliant, that’s good information.

P: As long as it’s helping you.

A: very much so it is of course yeah.

Appendix 16: Example of NVivo Node export

Name: Experience of breathlessness

<Internals\Interviews\P13> - § 5 references coded [10.00% Coverage]

Reference 1 - 1.32% Coverage

A: okay and um tell me a little bit more about the experience at that time when you noticed that was happening

P: um, I would just lose my breath, when you’ve been saving if you climb up (name) hill, lose a dog or something and your go you’re walking up (name) hill but you would feel comfortable going in normal circumstances

A: yeah

P: you get to the top and you’re going (gasping) like that well that was what I was like I was thinking I’m only in the gym

A: mmm

P: and um it just didn’t it doesn’t register yeah I just you just think oh good you’re not as fit as you thought you are

A: mmm

P: but it really was gasping for breath you know as if you’ve overexerted yourself, mind you I suppose a lot of the stuff I used to do at the gym it would be overexerting a lot of people anyway but it was my level I knew where I was and it was

Reference 2 - 2.25% Coverage

A: okay um you said that you f, you felt a lot better and, and you changed your diet

P: yeah

A: what, what triggered that change?

P: Well I this time last year well June, July last year, July last year we went to the, my friend and I went to the Great South Show

A: right

P: in the New Forest

A: okay

P: and I hadn’t long been definitely diagnosed if you get my drift

A: yeah

P: and I was in a hell of a state and um she said are you going to be alright going, um and I said, yeah we’ve gotta go because I mean I love it there, but I was so exhausted I couldn’t walk, we she I was like an old lady you know we linked arms for God’s sake you know you look at people doing look at women doing that and think I’m never going to be like. I’m never going to link arms with a friend you know but she was dragging me round and I had my puffer and oh it was terrible, um

A: how did that make you feel?

P: Oh I thought I was going to die. I thought I said to I said to her you know I reckon I’ve got five years or something I said I reckon I’ve only got five years, she said oh don’t speak like that, so I phoned my ex up because um he’s still got it, we used to have a place in mexico and of course I’ve got rather the thin end of the uh, (laughs) the deal and I said to him look I have got to go to Mexico. I said I’ve got to go because I thought feasibly it’s not going to be long before I’m not going be able to get on an aeroplane it was really that bad.

Reference 3 - 0.26% Coverage

P: I didn’t you know it’s difficult you don’t really take any notice I you just think to yourself well I won’t do that anymore you know and it’s I’m not as fit as I should be

Reference 4 - 4.29% Coverage

P: 2007 is when I had the thing in (name) high street when I that was the very first time because I didn’t have a clue what was happening and it was so and I that was the very first time that I consciously knew there was something wrong with me because I, I had that’s what I’d done as I walked out of the hairdressers, I popped a boiled sweet in my mouth

A: right

P: and walked in out of the hairdressers into a head on wind, as you do when you’ve spent God knows what on your hair you know

A: (laughs)

P: and uh I couldn’t catch my breath and I thought it’s because it’s a strong wind and I’m sucking a boiled sweet, well I suppose it was actually

A: mmm

P: but I actually had to lean against a building in (name) high street now are you not from this area are you

A: no

P: you see lots of people in (name) high street leaning against building cos there’s about four open all hours pubs in down there

A: right (laughs) okay

P: and, and I was really appalled because I’m trying to get to the building society to put this big check in the bank and I thought oh people are gonna think I’m drunk but I really couldn’t and I got th, well I got like um have you had indigestion? Yet are you of an age where you’ve ever had indigestion

A: I’ve I’ve had it uh no I have had it yeah

P: and like where it really sort of is quite hot across there

A: right yeah

P: it was like that and I thought blimey, so I threw the sweet away cos I thought it’s cos I can’t it’s cos it was really, really windy. I’ve gotta say it was you know mental wind, um and I went to the uh the the bank building, can’t remember where I put it now. It was a building soc um yeah I think it was a building society I put it in and it was um I thought brilliant, brilliant and it was such a brill day you know me godson had cut my hair and decently and I was lo, I had loads of money and I kept thinking what on earth is up with my chest? What on earth’s that? Anyway I drove back home and I was mooching around and I was going (gasps) and I couldn’t get my breath and I had to call an ambulance, I really had to call an ambulance

A: mmm

P: because I thought Christ, it’s like I’m drowning and it was like I was drowning and it that is really the very first time that I thought there’s something wrong here, you know I’m, I’m not so

A: mmm

P: so I would say that that is when I was very first aware and they turned up and they said oh you’re having a panic attack dear, and I said oh well I don’t think I am actually and it did I cos, I had a look cos I, I want to know about these things and I and it did seem to have a lot of, it could have been, you know and I know panic attacks are nothing to do with being whatever but I knew there was something else there was something else.

Reference 5 - 1.88% Coverage

P: but anyway we'd been and seen this woman in a glass case and she did look real, she did look real, um and um and then she said right well go up to the eagle's nest well we got up these steps and I'm laying on the steps saying, I can't go, I can't go any higher, co we were very high up so the air was quite thin anyway

A: mm

P: but I was really, that now that was an incident when I thought blimey there's something wrong here, but then I carried on with my holiday and completely forgot about it

A: mm

P: but it was saying to you about I shouldn't go mountaineering

A: yeah (laughs)

P: well I was on a mountain

A: (laughs)

P: (coughs) yeah it was um, yeah I said I can't go I said to my friend I can't go but that was actually after, no that was after because I go there in it was November it was November so it was the same year thinking about it.

A: right

P: so there were these two incidences and then that were pretty major

A: yeah

P: I mean it was awful in Spain cos I really kind of thought my God I can't get up the stairs

A: mmm

P: had to say to her I can't come and her fitness level is on about zero anyway, co, God knows what she thought she was doing walking up the stairs you know.

<Internals\Interviews\P1> - § 14 references coded [9.52% Coverage]

Reference 1 - 0.20% Coverage

P: since I got back I was fighting for breath again I was straight on the steroids again so[1]

Reference 2 - 0.31% Coverage

P: well it’s just that I’ve had trouble breathing fighting for breath and of course what makes it worse is when I get an attack, I panic

Reference 3 - 0.53% Coverage

P: and that makes it even worse, cos when you panic and you’re trying to breathe, well

A: hmm, why do you think that is?

P: I think it’s because I’m fightin for breath and I think its gonna you know its gonna give up on me whether it’s

Reference 4 - 0.44% Coverage

A: um and and what happens to the cold when you get a chest infection?

P: well then I start getting tightening pains across the chest and everything and that’s when the breathing gets really bad

Reference 5 - 0.25% Coverage

P: well some mornings I can get up go and put the kettle on you know, breathing heavy, well fighting for breath[2]

Reference 6 - 0.43% Coverage

It’s just that if I try walking around quick that’s when I find it, if I just walk at a slow pace I’m okay but since I start hurrying that’s when I get it worse so I don’t rush around so much[3]

Reference 7 - 0.86% Coverage

P: it’s nowhere near as bad as twas I don’t have to fight for breath I can climb up stairs now without fighting for breath whereas before I couldn’t climb a flight of stairs I used to do about four stairs and stop

A:mm

P: and then um carry on I can couldn’t run for a bus or anything like that so, cos I felt as if I was gonna pass out I came over dizzy and everything with it so[4]

Reference 8 - 1.20% Coverage

P: I just used to have trouble breathing you know, mainly when I went upstairs for anything I go up to the airing cupboard to get anything out or go upstairs to bed and think well I gone tight why? Cos it used to go really tight so I thought I’d just get it checked out with the doctor and I went across and um he turned round he said he didn’t think it was anything serious n just give me antibiotics, and uh after a while it’s getting worse. So I went back over, I left it about six months, n he said here do a test for asthma and that.

Reference 9 - 0.91% Coverage

A: in what way was it getting worse?

P: Well I seem to be getting more attacks you know. I seem to be getting tighter all the time, trouble breathing and gasping and when I went to take a drink as well you sort of, it’s, it’s as if its stuck in your throat, you couldn’t, get it down

A: right

P: you know if I was going to

A: hmm

P: mouth for a drink it’s as if I wanted to throw it back out but[5]

Reference 10 - 0.52% Coverage

P: he didn’t like it cos I couldn’t play cricket I couldn’t play football, because running around you know used to

A: mm

P: really make me fight for breath but I can’t get over how the change since I given up smoking has helped.

Reference 11 - 0.53% Coverage

P: cos you find when you're carrying anything heavy that does effect you, you know heavy bags or heavy things and I think carry that hoover up. No why should I stick it on there and send it up so. But I walk up and take it off at the top so

Reference 12 - 0.93% Coverage

P: I honestly don't know, see I noticed when I been shopping and bought meat and veg and everything like that and the bags pretty heavy

A: mmm

P: I have to keep putting down and resting for a while and on a couple of occasions I have had to use my blue inhaler, not the green one just the blue one anywhere I have been short of breath really carrying heavy stuff. So that's why I don't bother if I can help it

Reference 13 - 0.48% Coverage

P: Cos at first when I had problems breathing I thought oh no its the other, it's come back I'ts gone to me lungs or something but no it wasn't cos I went and had the x rays and everything they said no that's okay so.

Reference 14 - 1.94% Coverage

A: you were saying if you sit down too long you think a bit too much

P: yeah and that's when you start panicking and that's when you start getting all your breathing and God knows what else so as long as you're on the go and you are keeping active you don't have time to think about anything

A:hmm

P: so and yet you think being active would make it worse. The only time it does is sort of rushing around or carrying anything heavy I'm okay when I am creeping around

A: so what sort of things do you thinking about when you know

P: well nothing in particular just you know being on your own having nothing to do cos it's all been done through the day and it's just sort of boredom really. I start reading then I get fed up reading book I do a crossword then I get fed up doing that. Tele bores me. I can't stand it.

A: so it it's the feeling of boredom

<Internals\Interviews\P3> - § 9 references coded [3.32% Coverage]

Reference 1 - 0.19% Coverage

P: breathing problems, if I get out of breath, I stop, I sit down, I used to do the garden spend hours in the garden, now I spend about an hour then sit down.

Reference 2 - 0.54% Coverage

A: okay, um so what, what do you think makes your breathing worse?

P: talking a lot, talking too quickly, too fast

A: okay

P: instead of slowing down, and sometime when I'm talking and going up a hill I have to stop, people say stop you, you you're out of breath and I have got to stop, and this does affect your breathing. I have always been a quick talker, I had to be in the job. You know I giving out the orders in the kitchen, I could shout[6]

Reference 3 - 0.57% Coverage

A: okay, um is there anything else which makes your breathing worse?

P: Perfume

A: perfume

P: if I go into shop

W: Oh I, that's when he's starts sneezing and he'

P: I can't go I, a perfume shop or uh if there's washing powder or you go into like the boots chemists I can't stay long else I sneeze

A: hmm

P: and it gets on. I can smell, I can get it on my chest although I can't smell it as much I can taste it and it affects your breathing. It's like gas I spose you know[7]

Reference 4 - 0.46% Coverage

P: you know and I run around for years always very active (coughs) but I always like fresh air, another thing gets your breath too is if you're walking out, like today was windy,

A: hhmm

P: and its coming towards you, you tend to put your hand over your mouth cos the wind (pretends to be breathless) it catches your throat and that makes you cough

A: hmm

P: makes you out of breath

Reference 5 - 0.14% Coverage

P: I do get out out of breath through it. I do sit down don't I

W: yes

P: I come in here and have a break and sit down

Reference 6 - 0.46% Coverage

P: I want to start with the breathing I used to walk up this hill at the top of the road there with that bungalow on the corner

A: hmm

P: I was sit down that road (gasps) like this this was years ago when it started and then just walked back down again, I did that for about a week or two and the dog used to look at me and say where are we going, and then I went down the hill

Reference 7 - 0.08% Coverage

P: and then that really pulls it for me trying to push the mower

Reference 8 - 0.13% Coverage

P: paint affects your breathing, so while you got the windows open, I'm alright. But I did it and then two[8]

Reference 9 - 0.76% Coverage

if we go shopping, it's a bit too much for me to carry the bags too far,

A: mmm

P: like breathing goes (cough). I try to get the same weight either side (cough) and try to stand upright, sometimes we meet the buses, but if I can get the interval to the bus I can put me bags on there, and that'll help me breathin I can sit back hold me head back you see, all the time, we get a load in the trolley. We either go through town to Asdas, or we go to (name) to Sainsburys and Iceland,

W: yeah

P: but there's taxi rank round the corner

W: (laughs)

P: so it's only well eight pounds, seven eight pound

A: mm

P: it's only once a month[9]

<Internals\Interviews\P4> - § 3 references coded [2.18% Coverage]

Reference 1 - 0.29% Coverage

P: mind you I did have cos I walk all, all round the buildings here cos I was early bit puffed out then but otherwise I'm not too bad.[10]

Reference 2 - 0.27% Coverage

but when I came out, no just before I came out I found I wasn't breathing too good you know I was very chesty and all that

Reference 3 - 1.61% Coverage

P: well road running I couldn't keep up with the youngsters anymore sort of thing you know where I used to beat em easy un used to take em out on road run and that. But now I (gasps) and that was it and then I at the end of my career anyway they started this new test P.E test every six months or so, was a three miles a week, one and half miles with the group and one and a half miles on your own it was alright with the group but when it got to the s, you know the second half

A: mm

P: because we had to do it in twenty five minutes or something like, something, something ridiculous an and then ne never finished it tried it four, five times, and of course they reported me my doctor and then they sent me on to (name)

<Internals\Interviews\P5> - § 20 references coded [8.03% Coverage]

Reference 1 - 0.23% Coverage

P: and it's looking for come away from come out, I always say smoking holds a lot of it back, I, I don't know I stopped for a year and I never had so much trouble breathing in my life, and I started smoking again and I went back as I was before, so whether it, it was doing the damage once I stopped.

Reference 2 - 0.77% Coverage

well I played football, I played cricket, and I run boy's football team , I ran a boy's cricket team, and I wasn't fit but I was fit enough to do that[11]

A: yeah,

P: but since I stopped those sort of things I have gone down, you know. I retired from work, well, this will be five years this year I had to retire, I couldn't do my job. And I was only a security guard that's all I could do anyway but then I couldn't even walk round the building and do that sort of job, because I was so short of breath so, I don't know. I feel sad sometimes because mind, looking at some of the blokes you know, Cos this is retirement area anyway, and when I see someone I think well I, I'm not that bad, you know I could, I can, I can walk down the shop, down the bottom (name) but it, I stop four five times and I stop about ten times. Cos it takes me over half an hour to walk what, five hundred yards and there's nothing I can do just the smoking, the you know, the shortage of breath I take in

Reference 3 - 0.21% Coverage

I'm a my when I se, I served my time with a painter and decorating paper, I can't even put a brush, I put two, two brush fulls on, I'm sat down puffing and blowing so I can't do it so I have to get boys to come over. One of them will come over and do it for me

Reference 4 - 0.24% Coverage

and I spose I smoke ten twelve fags a day from six in the morning till midnight, which is not a great deal anyway. I can understand if I was smoking forty or fifty a day, but I'm not. You know I can go, sometimes, depends, if I go to bed early I only smoke about seven all day but I'm still puffin and blowin[12]

Reference 5 - 0.38% Coverage

I can go sometime, I can go to bed a nine o'clock at night, and I'll, I'll be up by twelve, back in bed by half past twelve up at three o'clock and it, I just cannot breathe, soon as I lay down, I'm struggling to breathe, I can breathe through me nose fine, but you, you can't do that all night long, you've got to breathe through your mouth

A:mmmm

P: you know its, it's a, t oh I just don't know. I, I don't know, I do know as I say smoking, well fair enough but I think, oh I don't know.

Reference 6 - 0.16% Coverage

P: but I thought that my time was up, I gotta admit I was ov, have over stat I was laid over there hanging out the window and it wasn't doing nothing was c, I couldn't get a deep enough breath to get into it

Reference 7 - 0.30% Coverage

P: we went to Spain, to um, (name) and my misses loves going having a look round. Alright yeah fair enough, and she booked us on one of these train things. We went up the mountain side and the air gets thinner and thinner and so I'm gasping, and then there's the dust. Oh I had a handkerchief over me mouth, you know, and I'm sure I took a hundred weight of dust in and then I was alright.

Reference 8 - 1.06% Coverage

P: uh, first thing in the morning, I am very very short of breath, I get up, I don't have a cup of tea in the morning cos it's too heavy. I have a glass of water and I can open the window and sit there, stand there and two or three minutes. I've got some air into me, fresh air into me, it's gone into me and I feel fine. But first thing in the morning I am struggling for breath (coughs). I get up two or three times a night and I'm, I'm gasping for breath, but I have a glass of cold water and I'm fine, its cooled me down inside, and I can walk from here to the toilet, and in the bedroom to send my misses the changeover time. Cos she comes here, and I'm puffing and blowing for all I'm worth, yet I've only done twenty paces, and I'm struggling to breathe. You know I can get away with it because I say I went to my, the (name) the party I went to with the

A:mm

P: and I can sit on the bed and I do what she's told me to do and I'm fine again,[13] yet as soon as I lay down, I'm gasping for breath again, you know, I can't work this out why, I sleep on three pillows now, well, usually two should be enough, but I need that extra to tilt me sort of keep me up, up the same to me up

A: yeah,

P: bit higher than me, rest of me body you know, but I know I am vastly overweight, something I have gotta live with there's nothing I can do about that

Reference 9 - 0.32% Coverage

P: but as I say I can walk down the road I can leave here and I get to the corner over there and I'm lent against the tree gasping for breath, now I've already done, what 50 yards and that's how I go all the way down the sh. But I keep walking down there, because I think eventually, it's either gonna, do something one way or the, and I'm gonna be dead, or I'm gonna. It's gonna help me with me breathing a bit

Reference 10 - 0.09% Coverage

P: but now I can't fly no more

A: right

P: because as soon as we get up thirty six thousand feet I'm gasping for air

Reference 11 - 0.85% Coverage

A: when did you first notice problems with your breathing?

P: when would that have been? ten about fourteen years ago, I left the shipyard and I went on as security guard for (name) and I worked out um (name) out at (name). They had a place (name) industrial estate and the other one, and I was out there for about four years, well there was a lot of dust when once they started pulling the place down, well we kept out of the we were we were told not to go near the dust so we just done as we were told you know we and from there it's just deteriorated year by year. It's got worse, and worse and worse, so about, I would say about fourteen years ago.

A: and what did you notice then, with your breathing?

P: I was, if I walked up the stairs I was gaspin, and I was alright when I first started out (company name), I used to do all the main building then go over where all the carpets were made, but I had to stop there, wait there half an hour, before I come back because I ju, I was sweating you know and I, I put that down that I thought I had a heart trouble, you know.

Reference 12 - 0.21% Coverage

P: but when I get in a traffic I get so short of breath, where I'm getting myself irate over nothing you know, it's everybody'd in the bloody traffic there's nothing you can do about it but,

A: mm

P: I tend to get very, very moody when I'm in traffic these days

Reference 13 - 0.30% Coverage

P: (name) road, well I can park in a car and I can walk over there and I gotta stop lean against the wall before I go in there five minutes, ten minutes then I go and book in and sit down and I'm ok, I'm okay as soon as I sit down I'm okay I'm. But she doesn't see that at nine o'clock in the morning. I go there at half past two in the afternoon, and I was well I was bright as a button.14

Reference 14 - 0.43% Coverage

P: afternoons are best yes, mornings, where I have been in bed all night, and I get up in the morning, I have to sit here in my underwear. I can't put my clothes on, I sit down I have a glass of water and cigarette.

A: yeah

P: and about ten minutes later, I can get up and get dressed then

A: mmm

P: but I can't get dressed as soon as I get out of bed. I come out here I sit in my underwear, yeah no more than about, bout twenty minutes. But it's just that first twenty minutes, to get the, the system working I suppose, I don't know.

Reference 15 - 0.27% Coverage

P:I go and have a shower. As long as I only shower I'm alright, as soon as I put me hands up to wash me hair I'm struggling to breathe. Because you're lifting everything up and then I get out the shower and dry meself and I'm sat there for ten minutes, stood there for ten minutes with no clothes on, because I, I just can't get enough air in me.

Reference 16 - 0.28% Coverage

A: right

P: to keep, you know. We've got the window open there, we have got going there. We've got a heater in when it's cold, but I just cannot where I wash me hair, I cannot get going, and I, my misses said I'll come and wash your hair. But I can't lean over, soon as I lean over the shower here, I'm struggling for breath again, so it's difficult, you know,

Reference 17 - 0.35% Coverage

P: You know, it's, it's silly things like that that, you know sometimes I, I get out of bed at night, and I go to to for a wee, and I'm stood here and I'm thinking to me self ohh and I can feel myself and we gotta a pole that we can grab hold of

A:mmm

P: and I need to grab hold of that tight because I feel quite woozy cos I'm going for a you know, that should nothing u, but I suppose it's all connected into your body

A: mm

P: you know its

Reference 18 - 0.87% Coverage

P: I'm not, I don't do much socialising, we used to do a lot, but we don't now, whether my misses is ashamed to take me you know, I'm alright I went to my sons last weekend it was my two grandson's birthday, one was on the Friday and one was on the Monday so we had to do for them on Sunday, and it got to the state that there were so many people there that I couldn't breathe. I couldn't stand too many people I went out in the garden. I went sat up in the corner and I was fine. Course then where's (name)? oh they're all up there so I'm no better up I have to come back and watch, sit in a bloody grump. I don't like being mobbed by crowds of people, I can put up with four five six, but when you're talking about twenty people it's too much. I tend, it tends to focus in I've I have a job to breathe, you know there's people round oh dear oh dear and I, I've never been one for crowds, you know[15]. Alright used to go drinking, do get me wrong. But, you know, they're all oh how are you (name)? how are? Oh dear and you keep on answering them one by one and in the end you're out of breath just talking to them.

Reference 19 - 0.20% Coverage

P: and then I went off and took my son back to Epsom, the other one, and come back and I was fine no problem at all. Yet as soon as I got back into my other son's house, with all the people there I had a job to breathe, because there's too many people in there.

Reference 20 - 0.47% Coverage

P: I do bit of exercise round here, I get the hoover out, hoover round, I dust and I wash up but I don't like standing anywhere lent over anywhere for long. You know I was standing up doing the washing up and I can feel my chest heaving so I have to stop stand up straighter (coughs) you know so I've got a seat in the shower, I can't sit there and have a shower

A:mm

P: I've got to stand up because if I sit down the waters hit and I'm st, I'm struggling. Because everything's pushed up against me lungs so, but I, I, often wonder I say to my misses if I lose some weight but would it do any good?

Annotations

[1] This quote here shows the close relationship she puts on how medication and breathing severity are so closely related

[4] Her breathing is better than it has been, stairs used to cause her problems with her breathing

[5] After initially going to the doctor her breathing started to get worse in the sense that her tightness in the chest was occurring more frequently. It even caused her problems with swallowing.

[6] talking makes his breathing worse particularly too quickly or too fast, which according to this interview happens a lot. He has had to talk fast in the past because of his job as a cook in the kitchen giving out orders, and now people have to tell him to stop when he is talking to fast when walking up a hill. It is not clear whether he has to stop walking or talking, this may be important to clarify.

[7] Perfume and washing powder exacerbate his breathlessness. This affects his ability to go into shops like boots for long periods of time before it affects his breathing, it makes him sneeze. He says that it's the taste rather than the smell that affects his breathing, it "gets on his chest" again this is a saying that is restrictive in nature, restriction is something potentially imposed on the lungs and

an obstrution is something imposed in the lung reducing the ability for the air to come out. With this individual it is more of a restrictive disability so far.

[8] Painting the kitchen adversely affects his breathing but having a constant stream of fresh air helps

[9] bit too much for him to carry the bags when he goes shopping. In terms of performing this difficult activity he plans it in terms of how to carry the load and when to stop to catch his breath and can change the activity accordingly (either stopping at the taxi rank or at the bus interchange). He tries to separate the weight out evenly, walking with weights would be a good activity to do in PR with timed stops to try and improve his functional ability to carry shopping. However this would be on the assumption that he finds this activity as disabling. Currently, although it does affect his breathing his ability to cope with the task is good.

[10] walking puffs him out

[11] he used to have a very active lifestyle

[12] Regardless of how many fags he smokes he is still breathless by the end of the day

[13] He thinks that he can cope with his breathlessness now because of what he has learnt from the lady who has helped him with his panicking

[14] he has chosen a time to see his healthcare professional when his breathlessness is not so troubling for him.

[15] big crowds cause him to have a claustrophobia effect.

Appendix 17: Example of notes taken during an interview

- Losing weight?
- They have done the opposite of where he wanted to live but now no help
- In wheelchair
- Got up once and nearly fell down, put on nebuliser
- Lost feeling in legs, fell down.
- General life upheaved, council paying for two places.
- Gentleman round to look at oven, community support worker tidy up.
- Friend suffers COPD.
- All people have ventolin.
- Taught to use nebuliser, self administrating.
- Nothing above third floor.
- More in control?
- Lungs functioning but tubes from COPD scarred.
- Phone call to friend.

Appendix 18: Participant demographics

Below is a copy of the participant demographics. Those highlighted in green completed the programme. Participants whose demographics are highlighted in red did not complete a programme.

Participant	living arrangements	Age	Time since Diagnosis	Diagnosed by	Referred by	Smoking Status
P46	lodger and pets	59	5 months	Consultant	Practice Nurse	Ex Smoker
P43	Family	42	1 year (12 months)	GP	Practice Nurse	Ex smoker
P33	alone	66	3 years (36 months)	Hospital	GP	Smoker
P30	alone	54	9 Years (108 months)	GP	Practice Nurse	Ex Smoker
P27	alone	50	6 weeks (2 months)	Don’t Know	GP	Smoker
P25	alone	90	5 years (60 months)	GP	Surgery	Non Smoker
P13	alone	56	1 Year (12 months)	GP	Don't Know	Smoker
P11	with spouse	88	1 and a half years (18 months)	Don't Know	Surgery	Ex Smoker
P12	Partner	48	5 Years (60 months)	Pharmacist	GP	Ex Smoker
P9	with spouse	71	2 Years (24 months)	Doctor	GP	Ex Smoker
P4	Family	68	9 Months	Don't Know	Practice Nurse	Ex Smoker
P3	with spouse	76	2 years (24 months)	GP	GP	Smoker
P1	alone	63	5 weeks (1 month)	GP	Practice Nurse	Ex Smoker
P5	with spouse	65	14 years (168 months)	Hospital	GP	Smoker
P41	with spouse	77	18 months	GP	Practice Nurse	Ex Smoker
P42	daughter	79	2 months	Practice Nurse	GP	Ex Smoker
P39	alone	67	7 years (84 months)	Hospital	GP	Ex Smoker
P6	with spouse	65	3 years (36 months)	GP	Practice Nurse	Ex Smoker
P14	alone	79	Don’t Know	Don't Know	GP	Ex Smoker
P23	with spouse	57	3 years (36 months)	Consultant	Practice Nurse	Smoker
P24	with spouse	68	2 years (24 months)	Hospital	Practice Nurse	Ex Smoker
P31	with spouse	80	not yet diagnosed	N/A	Cardiac Nurse	Ex Smoker
P32	with sister	74	Don't Know	Don’t Know	Don't Know	Smoker
P38	alone	86	3 months	Don’t Know	Consultant	Ex smoker
P40	with spouse	74	Don't Know	Don't Know	GP	Non Smoker

Appendix 19: Interview Timeline

The participant interview timeline is provided below. The letters A and B following participant numbers relate to which programme participants were recruited from. 09 refers to 2009. 10 refers to 2010. (U) means that the interviews were performed at The University of Southampton. (H) means that the interviews were performed in the participants home. Numbers 1 and 2 correspond with the first and second interviews.

	Aug 09	Sep 09	Oct 09	Nov 09	Dec 09	Jan 10	Feb 10	Mar 10	Apr 10	May 10	June 10	July 10	Aug 10
P1 A	1 (U)					2 (U)							
P3 A	1 (H)					2 (H)							
P4 A		1 (U)						2 (U)					
P5 A		1 (H)				2 (H)							
P6 A		1 (U)											
P9 B			1 (H)					2 (H)					
P11 B			1 (H)					2 (H)					
P12 A			1 (H)							2 (H)			
P13 B			1 (H)					2 (H)					
P14 A			1 (H)										
P23 B				1 (H)									
P24 A				1 (H)									
P25 B				1 (H)								2 (H)	
P27 B				1 (H)							2 (H)		
P30 A				1 (H)							2 (H)		
P31 A				1 (H)									
P32 A					1 (U)								

P38 B						1 (H)							
P40 B							1 (H)						
P33 A							1 (H)				2 (H)		
P41 B							1 (H)						2 (H)
P39 A							1 (H)						
P42 B							1 (H)						
P43 B								1 (H)				2 (H)	
P46 A								1 (U)			2 (U)		

Appendix 20: Participant summary letter

Health
Sciences

UNIVERSITY OF
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Adam Lewis

Postgraduate office

Faculty of Health Sciences Building 45

University of Southampton

Highfield

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SO17 1BJ

Participants Name

Address

Date

Dear……

My name is Adam Lewis. I am a research student at the University of Southampton. You kindly participated in my research between..…2009/10 to ……2009/10. I came to your house/you came to the University and we had a conversation about your Chronic Obstructive Pulmonary Disease (COPD) and Pulmonary Rehabilitation. Thank you so much for agreeing to take part in this research. Your help has been invaluable. I can now describe the main findings from the research and explain why your help was so important. Although everyone had different views and experiences, the ones described here were some of the more common things that people talked about.

- Many research participants experienced feelings of uncertainty when dealing with their COPD.
- Some participants reflected on the confusion that different diagnoses had caused in the past, the gradual onset of the condition and a general lack of knowledge as a result of little explanation coming from consultations with their doctors.
- The experience of uncertainty continued in the way in which some people felt like they were kept floating in the health care system. This often led some participants to be fearful that their condition was deteriorating whilst waiting for treatment. The experience of uncertainty led many people to describe associated experiences of panicking, particularly when they became breathless. Relaxation seemed to help some people control panicking.
- Some people viewed Pulmonary Rehabilitation as something that had been offered to them, it was free, it might have helped them or somebody else, and so were willing to try it to see what it was like.
- People had many different ideas about how COPD was caused and its effects on their lungs. Some thought COPD was caused through work, growing up in polluted areas, bronchitis, smoking or bronchial cold. Others believed having COPD meant their lungs were worn out and the hairs in their lungs were getting soft, or that only part of their lungs were working properly and stale fluid was left in the bottom of the lungs.
- Many people in this study did not view themselves as disabled as others who have COPD. For example, people viewed their ability to perform activities, or their degree of breathlessness in a more favourable way compared to that of other people who possibly had COPD. In general many understood this comparison with others in terms of how fit they felt for their age.

- Those people who completed Pulmonary Rehabilitation found that their experience of uncertainty was lowered in comparison to when they started, which led to reduced experiences of panicking.
- Many people thought that Pulmonary Rehabilitation was good fun and thought that they performed well on the programme compared to others.
- Many people learnt ways to manage their battle against their breathlessness by being shown how to breathe properly.
- Many of those who did not complete a Pulmonary Rehabilitation programme were still able to gain a positive attitude towards their COPD and a certain level of control in their condition when interviewed again. However, these participants tended to view their condition as worsening (in the same way as they had before the Pulmonary Rehabilitation programme).
- Those people who did not complete a Pulmonary Rehabilitation programme felt less able to cope with other conditions they were dealing with, such as arthritis or diabetes, compared with those who completed a programme. Many of those who had not completed a Pulmonary Rehabilitation programme were angry with the care they had received, while others just did not want to participate in a programme. These people gave reasons such as a lack of motivation, or not wanting to exercise in a group, or feeling unable to leave the home or feeling it would waste the clinician’s time because they believed they did not require any further help.

The above is only a brief summary of some of the findings from this study – so please do not be concerned if some of the points you made have not been described here. The full findings will be written up and published in a PhD thesis as well as in academic journals. These new perceptions have provided me with a deeper understanding of the experience of living with COPD for people who have been referred to a Pulmonary Rehabilitation programme and given me some insight into the on-going experience, whether people participate in that programme or not. I am hoping to publish the findings to a a wider audience with the intention of helping clinicians to be more empathetic to the confusion and uncertainty that many COPD patients deal with. This may lead to developments in better structuring the care that is provided for people with COPD. Also, future

Pulmonary Rehabilitation programmes could be developed to better cater for the needs of individuals who could benefit from participation.

Thank you very much again for your participation in this research. Should you have any further questions, please do not hesitate to contact me.

Yours Sincerely,

Adam Lewis

apl104@soton.ac.uk

9. Glossary

Authenticity: Heideggerian terminology used to describe a mode of being that we as humans recognize that we are going to die and live accordingly with that present in our concern.

Being-in-the-world: Heideggerian terminology used to describe phenomenologically, how humans live within the world.

Being-in-the-dark: Analytic terminology used by the researcher to describe the lived experience of uncertainty in the past.

Being-in-limbo: Analytic terminology used by the researcher to describe the lived experience of uncertainty in the present.

Clinical Academic Pathway: An MPhil/PhD pathway that encorporates clinical practice with academic study. It is the basis upon which this MPhil PhD was undertaken by the researcher.

Chronic Obstructive Pulmonary Disease: A progressive respiratory condition usually caused by smoking.

Cloaked: Analytic terminology used by the researcher to describe the participants' experience living with their COPD for some time in their past. On reflection they were not aware of having COPD at the time. It was concealed from their consciousness as such.

Epistemology: The study of the nature and status of knowledge.

Floating: Analytic terminology taken from participant quotes used to describe the feeling of waiting for care and information with uncertainty.

Grip: Terminology used by Merleau-Ponty to describe how well we perceive something. We have a loose grip on something if it is not well perceived and a tight grip if it is well perceived.

Ideographic: An analytic approach used which focuses on the experience of the individual

Idealism: A philosophy that an individual’s thoughts are their true reality

Inauthenticity: Heideggerian terminology used to describe the mode of being in which we as humans are preoccupied with fulfilling the perceived needs of what society (the they) deem the norm or of value.

Interpretivism: A philosophy that the researcher has an impact on research findings and the findings will be based on the researcher’s interaction with their social surroundings.

MRC dyspnoea score: Measure of the extent to which breathlessness causes an individual functional disability. This is scored out of five with five being the most severely disabled.

Normothetic: An analytic approach used which focuses on comparison between individuals and generalization.

Ontology: The study of being

Phenomenology: A branch of philosophy that studies how phenomena are experienced by individuals. Phenomenology can be a descriptive and interpretive process and is reliant on an awareness of one’s own pre-understandings in a reflexive process.

Pulmonary Rehabilitation: An evidence-based, holistic, multi-disciplinary programme of education, exercise and an opportunity for patients to socialize with others who have a respiratory disease.

Positivism: A philosophy with the assumption that what a researcher reports is a genuine report of reality. The aim is for the researcher to be objective with their findings.

Realism: A philosophy with an assumption that there is a separate reality to the researcher’s report of that reality.

Reflexivity: A concept used commonly in qualitative research to acknowledge the researcher’s impact on the research and the research’s impact on the researcher.

Spirometry: A lung function test which is used to diagnose COPD and determine the disease severity.

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