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**Understanding the barriers and
facilitators to successful
behaviour change in self-
management within the context
of Pulmonary Rehabilitation
using a Critical Realist approach.**

Frances Helen Butler

PhD

2021

Understanding the barriers and facilitators to successful behaviour change in self-management within the context of Pulmonary Rehabilitation using a Critical Realist approach.

Frances Helen Butler, BSc, MSc

A thesis submitted in partial fulfilment of the requirements of the University of Northumbria at Newcastle for the degree of Doctor of Philosophy

Research undertaken in the Faculty of Health and Life Sciences

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Abstract

Introduction

This study aimed to explore the opportunities and challenges associated with behaviour change in self-management within the context of Pulmonary Rehabilitation using the principles of Critical Realist philosophy. Self-management in chronic respiratory disease and long-term conditions management is a challenging area of healthcare. A complex interplay between issues surrounding adherence, self-management and ultimately behaviour change makes research and clinical practice in this area a challenge. The relationship between the physical and psychological health in individuals with chronic respiratory disease requires an individualised and holistic approach to management of the disease symptoms.

Methods

A qualitatively-driven mixed-methods approach was employed using focus groups and survey methods. A series of focus groups were conducted with a purposive sample of individuals who had recently completed a local Pulmonary Rehabilitation programme (2 groups, total 4 participants), Healthcare Professionals (2 groups, total 8 participants) and Members of the Breathe Easy support group (2 groups, total 8 participants). Themes were described using the Thematic Networks Tool (Attride-Stirling).

A survey was carried out with members of the Association of Chartered Physiotherapists in Respiratory Care (ACPRC) (32 participants) to investigate how behaviour change in relation to self-management was understood and implemented in clinical practice from the perspective of Respiratory Physiotherapists. Data was analysed using the Theoretical Domains Framework (Atkins *et al*, 2017).

The focus group and survey data were then combined and analysed using behaviour change theory using the Behaviour Change Wheel (Michie *et al*, 2011) and the Capability, Opportunity and Motivation of Behaviour (COM-B) Model (Michie *et al*, 2011).

Findings

Findings from the focus groups included the global theme of the 'Influence of behaviour on self-management' followed by four organising themes. These included: 'Motivation to exercise', 'Influence of education on self-management', 'Psychological impact of symptoms' and 'Perceived benefit and engagement in Pulmonary Rehabilitation'. Basic themes included a range of known barriers including: anxiety and depression, fear, motivation, blame, education, support networks, goal setting and exacerbations.

Survey findings shared some similarities to the focus group findings. Time, expertise and knowledge were noted as barriers from a service perspective. Whilst motivation, knowledge, education and support mechanisms were seen as both enablers and barriers to successful self-management from patient and Physiotherapist perspectives. Behaviour change techniques commonly employed included goal setting, health coaching, self-efficacy and motivational interviewing. The most frequently cited domains within the Theoretical Domains Framework included: knowledge, skills, social and professional role and identity, beliefs and capabilities and beliefs about consequences.

Using behaviour change theory and models the data from the focus groups and survey were combined to look more closely at behaviour change in self-management. The COM-B model was used to determine elements in relation to patients' Capability. Physical aspects included: skills, tools, exacerbations and breathlessness, whilst psychological elements included knowledge, education and anxiety and depression. Aspects related to the Opportunity from a physical point of view included: time, transport and work-related barriers and from a social point of view included: socio-economic status and the expert patient role. From a Motivation perspective, reflective aspects included: goal setting, self-efficacy and empowerment and from an automatic point of view included: fear and anxiety and depression. The main intervention functions cited included: education, and training using skills and tools. There was some consensus on the definition of self-management as being patient-centred and individualised using empowerment. In contrast, there was some variation on the role of being educated verses educating and the purpose of self-management in achieving long-term commitment to managing their own condition.

Conclusion

The unique contribution from this thesis highlighted a conflict between the biomedical and psychosocial model of healthcare. A missing link was identified between the intentions and actions by Healthcare Professionals in supporting behaviour change in self-management compared to the needs of patients to be able to achieve behaviour change. The unique viewpoint of analysing the data from a Critical Realist perspective allowed for investigation of the underlying causal mechanisms associated with the ontological domains of the Real, the Actual and the Empirical. The COVID-19 pandemic has provided an opportunity to develop a workforce transformation to embed new philosophical thinking from a Critical Realist view on behaviour change in self-management.

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Declaration

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contributions from the work of others.

Any ethical clearance for the research presented in this thesis has been approved. Approval has been sought and granted by the Integrated Research Application System (IRAS) on 10th September 2015 with REC reference number 15/SW/0240 and IRAS project ID 167849. NHS trust ethical approval was granted on 15th October 2015 and Northumbria University ethics approval was granted on 3rd April 2018.

I declare that the Word Count of this Thesis is 91,371 words excluding appendices and references.

Name: Frances Butler

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List of Contents

Chapter 1: Introduction	21
1.1 Overview of chapter.....	21
1.2 Background and rationale.....	21
1.2.1 Personal context.....	21
1.2.2 Clinical context: Complex intervention.....	22
1.2.3 Chronic Obstructive Pulmonary Disease (COPD) A biomedical perspective.....	25
1.2.4 Incidence and Prevalence.....	26
1.2.5 Symptoms - Breathlessness.....	26
1.2.6 Management of COPD.....	29
1.2.7 Pharmacological Management.....	30
1.2.8 Non-pharmacological Management.....	31
1.3 Pulmonary Rehabilitation.....	33
1.3.1 Structure and Content of Pulmonary Rehabilitation.....	38
1.3.2 Clinical Outcomes in Pulmonary Rehabilitation.....	39
1.3.3 Adherence, Compliance and Concordance.....	40
1.4 Self-Management.....	42
1.5 Context of Health Behaviours and Behaviour Change.....	51
1.6 Health Behaviour Frameworks and Models.....	56
1.7 The Impact of a Global Pandemic.....	64
1.8 Chapter Summary.....	67
Chapter 2: Literature Review	68
2.1 Overview of chapter.....	68
2.2 Literature Review Methodology.....	68
2.3 The Exploration Phase.....	70
2.3.1 Search Strategy.....	72
2.3.2 Evidence-base for Pulmonary Rehabilitation.....	73
2.4 The Interpretation Phase.....	78

2.4.1	Theme 1: Adherence.....	79
2.4.1.1	Subtheme: The Psychological Influence of Chronic Respiratory Disease..	80
2.4.1.2	Subtheme: Health Status including Disease Severity.....	85
2.4.1.3	Subtheme: Social Factors and Support Networks.....	91
2.5.	Quality Assessment.....	95
2.6.	Theme 2: Self-Management.....	101
2.7.	Theme 3: Behaviour Change.....	106
2.8.	Communication Phase.....	110
2.9.	Chapter Summary.....	113
Chapter 3: Methodology.....		115
3.1	Overview of chapter.....	115
3.2	Research Aim.....	115
3.3	Research Objectives.....	115
3.4	Clarification on Terminology.....	116
3.5	Methodological Strategy for the current study.....	116
3.6	Philosophical Paradigm.....	117
3.6.1	Critical Realism.....	120
3.7	Research Framework.....	125
3.8	Methodology.....	129
3.9	Methodological Triangulation.....	134
3.9.1	Confirmation.....	135
3.9.2	Completeness.....	135
3.9.3	Abductive Inspiration.....	136
3.10	Thesis Approach: Practitioner-Researcher Role.....	136
3.11	Chapter Summary.....	143

Chapter 4: Methods	145
4.1 Overview of chapter.....	145
4.2 Rationale for the structure and sequence of methods.....	145
4.3 Focus Groups.....	146
4.4 Sampling and Recruitment.....	147
4.4.1 Pulmonary Rehabilitation Patients.....	149
4.4.2 Healthcare Professionals.....	150
4.4.3 Breathe Easy Support Group members.....	151
4.4.4 Invitation to Participate.....	151
4.4.5 Group Sizes.....	151
4.5 Data Collection.....	152
4.5.1 Consent.....	154
4.5.2 Location.....	154
4.5.3 Moderator.....	155
4.5.4 Data Recording.....	158
4.6 Data Analysis.....	158
4.6.1 Phase 1: Familiarising yourself with the data and transcribing the data.....	161
4.6.2 Phase 2: Generating initial codes.....	161
4.6.3 Phase 3: Searching for themes.....	161
4.6.4 Phase 4: Reviewing themes.....	162
4.6.5 Phase 5: Defining and naming themes.....	162
4.6.6 Phase 6: Producing the report.....	162
4.7 Survey.....	164

4.8	Recruitment.....	165
4.9	Sample Size.....	165
4.10	Pilot Survey.....	166
4.10.1	Survey Design.....	167
4.10.2	Development of the survey questions.....	168
4.11	Data Analysis.....	168
4.11.1	Stage 1: Transcription.....	171
4.11.2	Stage 2: Familiarisation with the data.....	171
4.11.3	Stage 3: Coding.....	171
4.11.4	Stage 4: Developing a working analytical framework.....	172
4.11.5	Stage 5: Applying the analytical framework.....	172
4.11.6	Stage 6: Charting data into the framework matrix.....	173
4.11.7	Stage 7: Interpreting the data.....	173
4.12	Wider Ethical Considerations.....	174
4.12.1	Independent Review.....	174
4.12.2	Consent.....	174
4.12.3	Anonymity and Confidentiality.....	175
4.13	Conceptualising Behaviour Change in self-management.....	176
4.14	Chapter Summary.....	180
	Chapter 5: Focus Group Findings.....	181
5.1	Overview of chapter.....	181
5.2	Background to analysis and presentation of focus group findings.....	181
5.3	Response Rate.....	181
5.4	Thematic Networks Analysis.....	184

5.5	Global Theme: Influence of Behaviour on Self-Management.....	191
5.6	Organising Theme 1: Perceived Benefit of and Engagement in Pulmonary Rehabilitation.....	202
5.6.1	Basic themes.....	202
5.6.1.1	Physical ability.....	202
5.6.1.2	Adherence / compliance.....	205
5.6.1.3	Improved breathlessness.....	206
5.7	Organising Theme 2: Motivation to Exercise.....	207
5.7.1	Basic themes.....	207
5.7.1.1	Support networks.....	207
5.7.1.2	Fear / Anxiety.....	208
5.7.1.3	Location / structure.....	210
5.8	Organising Theme 3: Influence of Education on Self-Management.....	212
5.8.1	Basic themes.....	212
5.8.1.1	Knowledge.....	212
5.8.1.2	Exacerbation management.....	216
5.8.1.3	Goal setting.....	217
5.9	Organising Theme 4: Psychological Impact of Symptoms.....	218
5.9.1	Basic themes.....	218
5.9.1.1	Fear/anxiety.....	218
5.9.1.2	Motivation.....	221
5.9.1.3	Enjoyment.....	225
5.10	Chapter Summary.....	226
	Chapter 6: Survey Findings.....	228
6.1	Overview of Chapter.....	228
6.2	Background to analysis and presentation of the survey.....	228
6.3	Sample characteristics.....	229

6.4	Presentation of Survey Findings.....	234
6.5	Quantitative data analysis: The Barriers and Enablers to Self-Management.	234
6.5.1	Service Delivery View.....	235
6.5.2	Enablers from a Physiotherapist and Patient Viewpoint.....	236
6.5.3	Barriers from a Physiotherapist and Patient View.....	237
6.5.4	Behaviour Change Strategies.....	239
6.6	Qualitative data analysis.....	241
6.6.1	Knowledge.....	249
6.6.2	Skills.....	250
6.6.3	Social / professional role and identity.....	251
6.6.4	Beliefs about capabilities.....	252
6.6.5	Optimism.....	254
6.6.7	Beliefs about consequences.....	255
6.6.8	Reinforcement.....	255
6.6.9	Intentions.....	257
6.6.10	Goals.....	258
6.6.11	Memory, attention and decision processes.....	259
6.6.12	Environmental context and resources.....	260
6.6.13	Social Influences.....	261
6.6.14	Emotion.....	262
6.6.15	Behavioural Regulation.....	263
6.7	Chapter Summary.....	264
Chapter 7: Conceptualising Behaviour Change in Self-Management.....		266
7.1	Overview of Chapter.....	266
7.2	Critical Realism.....	266

7.3	Methodological Triangulation.....	268
7.3.1	Retroductive Reasoning.....	269
7.4	Causal Mechanisms.....	269
7.5	Background to the Behaviour Change Wheel as a framework.....	270
7.6	The COM-B model analysis.....	271
7.7	Intervention Functions.....	275
7.8	Policy Categories.....	277
7.9	Defining Self-Management.....	278
7.10	Chapter Summary.....	285
Chapter 8: Discussion and Conclusion.....		286
8.1	Overview of chapter.....	286
8.2	Review of the Research Objectives.....	287
8.3	Critical Realist Ontological Domains.....	288
8.4	Defining Causal Mechanisms	294
8.4.1	The Real.....	296
8.4.2	The Actual.....	304
8.4.3	The Empirical.....	309
8.5	Policy Context.....	319
8.6	The Impact of COVID-19 on Pulmonary Rehabilitation.....	323
8.7	PhD journey - Researcher reflections.....	328
8.8	Strengths and Limitations of the Study.....	331
8.8.1	Strengths of the study.....	331
8.8.2	Limitations of the study.....	333

8.9	Summary and future recommendations for Physiotherapy research and practice.....	336
8.10	Conclusion.....	339
Appendix I:	Focus Group Invitation Letter.....	342
Appendix II:	Focus Group Participant Information Sheet.....	343
Appendix III:	Focus Group Consent form.....	351
Appendix IV:	Focus Group Topic guide.....	353
Appendix V:	Confirmation of permission to contact Association of Chartered Physiotherapists in Respiratory Care (ACPRC) members.....	354
Appendix VI:	Integrated Research Application System (IRAS) Ethical Approval Permission letter.....	355
Appendix VII:	NHS Ethics Permission.....	356
Appendix VIII:	Northumbria University Ethical Approval Letter.....	358
Appendix IX:	Survey Participant Information Sheet.....	359
Appendix X:	Survey Consent form.....	365
Appendix XI:	Survey Questions.....	367
References.....		369

List of Tables

Table 2.1 Key papers summarised with quality assessment.....	97
Table 2.2 Recommendations from the literature related to key themes.....	112
Table 3.1 Methodological Strategy.....	117
Table 5.1 Summary of the Pulmonary Rehabilitation and Breathe Easy group participants' demographic details.....	182
Table 5.2 Summary of the Healthcare Professional group participants' demographic details.....	183
Table 5.3 Steps 1 and 2 of Attride Stirling Method analysis of focus group data.....	185
Table 5.4 Attride Stirling data analysis presenting themes.....	187
Table 6.1 Demographic details of survey participants.....	231
Table 6.2 The coded responses and association with individual theoretical domains.....	243
Table 7.1 COM-B model analysis for self-management.....	273
Table 7.2 Intervention Types highlighted from focus groups and survey responses.....	276

List of Figures

Figure 1.1 The Breathing, Thinking, Functioning Clinical Model (Spathis <i>et al</i> , 2017).....	27
Figure 1.2 The COPD Value Pyramid (London Respiratory Network, published in Thorax 2014).....	32
Figure 1.3 The Behaviour Change Wheel (Michie <i>et al</i> , 2011).....	58
Figure 1.4 The COM-B system (Michie <i>et al</i> , 2011).....	59
Figure 2.1 Step 1: Exploring beliefs and topics (Adapted from Onwuegbuzie and Frels, 2016).....	71
Figure 4.1 Thematic Networks (adapted from Attride-Stirling, 2001).....	160
Figure 4.2 The Behaviour Change Wheel (Michie <i>et al</i> , 2011).....	177
Figure 4.3 The COM-B model (Michie <i>et al</i> , 2011).....	179
Figure 5.1 Thematic Networks of Global, Organising and Basic themes from focus groups.....	189
Figure 5.2 Interaction of the global, organising and basic themes as represented from the focus group analysis.....	190
Figure 6.1 Physiotherapists saying what the enablers are from a service perspective.....	235
Figure 6.2 Physiotherapists saying that the barriers are from a service perspective.....	236
Figure 6.3 Physiotherapist saying what patients' enablers are.....	236
Figure 6.4 Physiotherapist saying what the enablers are from their own perspective.....	237
Figure 6.5 Physiotherapist saying what patients' barriers are.....	238
Figure 6.6 Physiotherapist saying what the barriers are from their own perspective.....	238
Figure 6.7 Response to behaviour change strategies used by participants.....	240
Figure 7.1 The Behaviour Change Wheel (Michie <i>et al</i> , 2011).....	271
Figure 8.1 An iceberg metaphor depicting the ontological domains taken from Fletcher (2017).....	289

List of Publications and Abstracts

Below are a list of abstracts and conference posters associated with the content of this thesis.

Published abstracts

Butler, F., Baker, K., Dawson, P., & Robinson, L. (2021) Understanding self-management behaviours within the context of pulmonary rehabilitation for patients with chronic obstructive lung disease (COPD) using the Behaviour Change Wheel. In: *Association of Chartered Physiotherapists in Respiratory Care Journal*, vol. 53, (1) supplement.

Butler, F., Baker, K., Dawson, P., & Robinson, L. (2019) Do Physiotherapists use behaviour change strategies to influence patients' behaviour and ability to successfully self-manage within the context of Pulmonary Rehabilitation for patients with Chronic Obstructive Pulmonary Disease? In: *Association of Chartered Physiotherapists in Respiratory Care Journal*, vol. 51, supplement.

Butler, F., Dawson, P., & Robinson, L. (2017) Self-management in Pulmonary Rehabilitation: A focus group study with ex-pulmonary rehabilitation patients, Breathe Easy support group members and healthcare professionals. In: *Association of Chartered Physiotherapists in Respiratory Care Journal*, vol. 49, supplement.

Butler F., Dawson, P., & Robinson, L. (2016) Adherence to exercise after pulmonary rehabilitation. In: The 35th Scientific Meeting of the Physiotherapy Research Society, *International Journal of Therapy and Rehabilitation*, vol. 23 (6).

Conference Posters

Butler, F., Baker, K., Dawson, P., & Robinson, L. Understanding self-management behaviours within the context of pulmonary rehabilitation for patients with chronic obstructive lung disease (COPD) using the Behaviour Change Wheel. At: Association of Chartered Physiotherapists in Respiratory Care Conference, Virtual Conference, 2021.

Butler, F., Baker, K., Dawson, P., & Robinson, L. Do Physiotherapists use behaviour change strategies to influence patients' behaviour and ability to successfully self-manage within the context of Pulmonary Rehabilitation for patients with Chronic Obstructive Pulmonary Disease? At: Association of Chartered Physiotherapists in Respiratory Care Conference, Birmingham, 2019.

Butler, F., Dawson, P., & Robinson, L. Self-management in Pulmonary Rehabilitation: A focus group study with ex-pulmonary rehabilitation patients, Breathe Easy support group members and healthcare professionals. At: Association of Chartered Physiotherapists in Respiratory Care Conference, York, 2017.

Butler, F., Dawson, P., & Robinson, L. Adherence to exercise after pulmonary rehabilitation. At: The 35th Scientific Meeting of the Physiotherapy Research Society, Leicester, 201

Chapter 1: Introduction

1.1. Overview of Chapter

The purpose of this chapter is to set the scene for the thesis and introduce the current study within the context of relevant literature. The National agenda for management in Chronic Obstructive Pulmonary Disease (COPD), particularly within the context of long-term conditions management and role of Pulmonary Rehabilitation will be introduced. The chapter will begin by explaining the background and rationale for the study from both the National context as well as the researcher's clinical role. The concepts of self-management and behaviour change will be introduced. The management of Chronic Obstructive Pulmonary Disease (COPD) will be presented including the medical and non-medical management of the disease. Pulmonary Rehabilitation will be introduced including reference to relevant policies and guidelines. The impact of the COVID-19 pandemic will be discussed in relation to the impact on self-management and behaviour change, particularly in relation to the impact upon Pulmonary Rehabilitation services.

1.2. Background and rationale

1.2.1. Personal context

My professional clinical role and academic background has inevitably influenced the content of this thesis. To contextualise the research within this thesis, I will firstly provide a summary of my position as a researcher. My role as a respiratory Physiotherapist and clinical lead for Pulmonary Rehabilitation and chronic respiratory disease services, as well as a researcher provides a clinical research approach to a nationally recognised problem within Pulmonary Rehabilitation. The initial interest within this field of research arose from recognising difficulties in achieving successful self-management in Pulmonary Rehabilitation in clinical practice and understanding that the issues were similar nationally in other services. I have worked as clinical lead for the Pulmonary Rehabilitation service since 2014 and have seen the service

develop over the years. Whilst it is an advantage to be able to have clinical expertise within the field of research being studied, I was also mindful of the importance of maintaining a reflexive approach to maintain a critical distance from the research to reduce the risk of researcher bias.

I embarked upon this PhD thesis in 2013 fuelled with ambition to discover new insights into tackling the issue of adherence to exercise in Pulmonary Rehabilitation. It is inevitable that over the course of a part time PhD journey the thoughts, ideas and research direction can change due to the changing nature of the research aims and objectives as critical thinking develops. A key development in my critical thinking originating from a largely biomedical approach to my clinical work and which towards recognising and understanding the value and role of a psychosocial approach has been pivotal in my learning journey. On reflection my initial bias towards a biomedical approach stemmed from the inevitable constraints and structures associated with leading an NHS clinical service. For example, financial budgets, referral processes and pathways, staffing related issues, resources such as space and availability of equipment as well as constraints such as health and safety and governance. Often, due to these constraints, clinicians within the NHS, can have a natural bias towards a biomedical approach to healthcare delivery. To be able to shift towards a more psychosocial model of healthcare delivery, there needs to be greater focus on how Healthcare Professionals can effectively support patients within the constraints of service delivery models. This poses a challenge to many Healthcare Professionals but also provides an opportunity to research the complex interplay between behaviour change and self-management within the context of Pulmonary Rehabilitation.

1.2.2. Clinical context: Complex intervention

Complex interventions are described as ‘interventions with several interacting components’ which commonly include behaviours, parameters of behaviour (such as frequency, timing), and methods of organizing and delivering those behaviours (such as type of practitioner, setting and location) (Medical Research Council, 2008).

Pulmonary Rehabilitation can be considered a complex intervention consisting of multiple components which may act independently or interdependently (Medical Research Council, 2000). For example, the core components of supervised exercise and education include influences from the patient, such as the socioeconomic background, health status, health literacy, psychological states, engagement in health behaviours and readiness to change. From the Healthcare Professional perspective, aspects to consider include knowledge and experience in Pulmonary Rehabilitation, personal background, beliefs, assumptions and behaviours. From the service structure perspective aspects include service models of delivery such as face to face, remote / digital models, funding and staffing, location of classes and access to transport.

When investigating complex interventions it is necessary to consider the context of the intervention, especially relating to the challenges to patients, Healthcare Professionals as well as the wider healthcare system. The challenges with complex interventions are associated with the multiple elements associated with it including: the properties of the intervention, the number of components involved, the range of behaviours targeted, the skills and expertise of those delivering the intervention, the number of individuals or groups and the settings in which the intervention occurs (Skivington *et al*, 2021).

Healthcare systems pose an additional layer of complexity due to their dynamic nature. A complex system comprises elements which often interact in different and often unpredicted ways (Stockley and Graham, 2022). The Medical Research Council (MRC) guidelines on complex interventions (2000) were updated (Skivington *et al*, 2021) to include a new framework which has greater emphasis on the impact of causal mechanisms on the intervention. The update recognises that complexity can arise from interactions between the intervention and its context and emphasises the importance of identifying the mechanisms of change. Therefore, research within the field of Pulmonary Rehabilitation should acknowledge the complex nature of the mechanisms involved and the associated intended or unintended outcomes. Moving

away from a traditional biomedical approach within Pulmonary Rehabilitation requires consideration of the wider aspects and influences impacting on outcomes.

At the beginning of this PhD journey, behaviour change was considered as a mechanism as well as an outcome. This will be revisited in Chapter 7 when the findings from the focus groups and survey will be considered in relation to conceptualising behaviour change in self-management.

Critical Realist investigations set out to understand why an intervention works, for whom it works and under what circumstances it works (Wilson & McCormack, 2006). In keeping with Critical Realist philosophy, research within the field of complex interventions should include consideration of the interconnecting elements of the intervention. Critical realists seek to understand social events (within the actual domain) by exploring the underlying structures and mechanisms (within the real domain) (Harrits, 2011).

Critical Realism originates as a scientific alternative to positivism and interpretivism which acknowledges that knowledge should be positively applied but with reference to unobservable structures whilst also recognising the importance of ideas, experiences, narratives, and discourses in understanding social phenomenon (McEvoy and Richards, 2006). Critical Realism also recognises that the world is an open system with a complex interplay between structures, mechanisms, and contexts (Kazi, 2003).

Patients referred to Pulmonary Rehabilitation commonly have Chronic Obstructive Pulmonary Disease (COPD) which is a complex chronic respiratory condition. To understand the complex nature of Pulmonary Rehabilitation, the context of COPD will now be presented and described. Context has been described as 'dynamic and multidimensional' (Skivington *et al*, 2021, p.4). There are interacting components of the context including the physical, spatial, organisational, social, cultural, political or

economic factors of the healthcare system, Some of these will now be presented in relation to the condition of Chronic Obstructive Pulmonary Disease (COPD), the impact of breathlessness and the intervention Pulmonary Rehabilitation to begin to understand the complex elements of the context of this thesis.

1.2.3. Chronic Obstructive Pulmonary Disease (COPD) – A biomedical perspective

Within the (Global Strategy for the Diagnosis, Management and Prevention of Chronic Obstructive Pulmonary Disease, 2018) guidelines it is suggested to complete outcome measures including health-related quality of life measures, assessing risk of exacerbations and levels of breathlessness. The NICE COPD (2010) guidelines recommend referral to Pulmonary Rehabilitation. There is a strong focus on diagnosis using clinical objective measures such as spirometry and pharmacological treatment as a first line in disease management. This is reflected in the clinical guidelines GOLD (2018) and NICE (2010) where a largely biomedical approach dominates. For example, spirometry is recommended to diagnose the presence and degree of airway obstruction which leads to a medical management pathway such as prescription of medications including bronchodilators and corticosteroids.

COPD is an umbrella term which encompasses diagnoses of chronic bronchitis and emphysema with airways obstruction (narrowing of the airways), which is usually progressive (GOLD, 2018; NICE, 2010). COPD is a chronic degenerative respiratory condition, caused by airflow obstruction which is not fully reversible caused by abnormalities in the airways (Global Strategy for the Diagnosis, Management and Prevention of Chronic Obstructive Pulmonary Disease [GOLD], 2018).

GOLD (2017, p.558) define COPD as:

“Chronic obstructive pulmonary disease (COPD) is a common, preventable, and treatable disease characterized by persistent respiratory symptoms and airflow limitation that is due to airway and/or alveolar abnormalities, usually caused by significant exposure to noxious particles or gases.”

1.2.4. Incidence and Prevalence

It is estimated that 3 million people have Chronic Obstructive Pulmonary Disease (COPD) in the UK. About 900,000 have diagnosed COPD and a further estimated 2 million people have COPD which remains undiagnosed (National Institute for Health Care and Excellence [NICE], 2010). In a more recent publication, it is estimated that COPD is the fourth leading cause of death in the world with approximately 3 million deaths in 2012 (Global Strategy for the Diagnosis, Management and Prevention of Chronic Obstructive Pulmonary Disease [GOLD], 2018). This shows the scale of the problem and the demand upon services such as Pulmonary Rehabilitation.

The impact of COPD on healthcare systems and populations globally is immense, accounting for frequent hospital admissions, healthcare utilisation, mortality and morbidity. COPD is a preventable and treatable disease that is a public health challenge, and it is projected to become more of a burden on healthcare in the future due to continued exposure to risk factors as well as an aging population (Global Strategy for the Diagnosis, Management and Prevention of Chronic Obstructive Pulmonary Disease [GOLD], 2018).

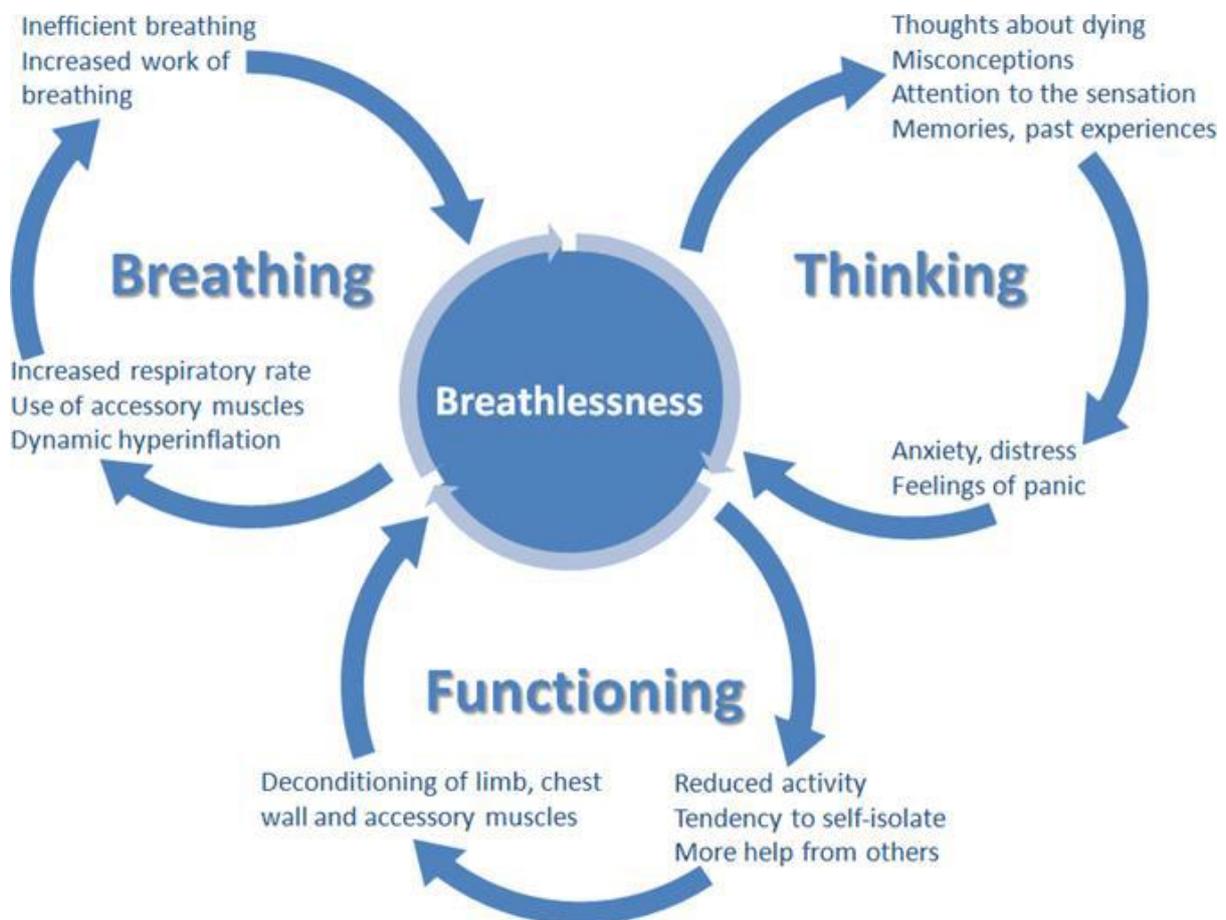
1.2.5. Symptoms - Breathlessness

There are several symptoms associated with COPD. Some patients may experience some or all of them and to varying degrees. The main symptoms include dyspnoea (breathlessness), cough and sputum production GOLD (2021). The impact of these symptoms can be experienced in both subjective and objective ways which are individual to each person with COPD.

Breathlessness is the most commonly experienced symptom of COPD which often sits at the core of an individual's daily functioning which in turn can lead to difficulties in health-related behaviours. Breathlessness is often the most debilitating symptom of COPD. There is a strong link between breathlessness associated with COPD and feelings of anxiety and panic. This relationship is particularly relevant to this thesis as the psychological impact on an individual can greatly affect outcomes, particularly in relation to self-management and health behaviours such as physical inactivity, anxiety

and depression, smoking habits, diet and nutrition and social interaction (Furlanetto *et al*, 2017) and (Chin and Booth, 2016). Healthcare Professionals response to the patient’s breathlessness can influence their perception of the breathlessness and in turn their experience of their breathlessness (Gysels and Higginson, 2011). Spathis *et al* (2017) present their Breathing, Thinking, Functioning clinical breathlessness model (Figure 1.1) which demonstrates how these three elements interact and influence one another.

Figure 1.1: The Breathing, Thinking, Functioning Clinical Model (Spathis *et al*, 2017)



Breathlessness is the prime symptom in chronic respiratory disease, especially among those with COPD. The Breathing, Thinking, Functioning clinical model depicts the vicious cycle associated with breathlessness and how the psychological and physical

elements can interact and influence each other. The cyclical process demonstrates that for some patients, the psychological symptoms can influence their physical ability, whilst for others their physical symptoms can influence their psychological health. Relief of breathlessness has been identified as an important research priority in a recent study (Michalovic *et al*, 2021) due to the impact upon an individual's functioning. This thesis builds upon already well recognised issues related to the debilitating symptoms of COPD but aims to delve deeper into the mechanisms and processes associated with these symptoms from the unique perspective of understanding behaviour change from both patients and Healthcare Professionals' perspectives. It is, therefore, imperative that the biomedical model approach is challenged. There is clear evidence to suggest that pharmacological interventions are effective in managing symptoms in COPD (GOLD, 2018; NICE, 2010), but it is also important to focus on the holistic, non-pharmacological management with the patient including Pulmonary Rehabilitation, education and supported self-management. These aspects are outlined in more detail in the updated version of Global Strategy for the Diagnosis, Management and Prevention of Chronic Obstructive Pulmonary Disease [GOLD], 2021. This will ensure that individuals with COPD are supported with behaviour change to be able to self-manage their condition rather than just adhering to treatment recommendations and taking prescribed medications. To achieve long-term behaviour change in relation to self-management, it is necessary to invest time in supporting patients with holistic patient-centred management.

Many patients with COPD experience breathlessness daily. Usually this is worse during an acute exacerbation, during which breathlessness is often associated with perceived impending death. Therefore, there is a strong link between breathlessness and fear and anxiety (Harrison *et al*, 2015). In turn, fear and anxiety can influence an individual's ability in health-related behaviours such as physical activity and exercise. Breathlessness management is complex and challenging to manage. Pharmacological management is often a first line of treatment. However, there is evidence that other non-pharmacological treatments such as exercise, cognitive behavioural therapy (CBT), mindfulness and fan therapy are effective, but these treatment interventions require the patient to be actively engaged in self-management (Spathis *et al*, 2021). Healthcare Professionals also lack the expertise to effectively

support self-management. Pulmonary Rehabilitation provides structured support in non-pharmacological management of breathlessness, but there can be barriers to attending and completing the course. The Breathing, Thinking, Functioning model provides a structured approach to breathlessness management. The model acknowledges that there are a variety of causes of breathlessness and individuals may experience these differently. The model also recognises that breathlessness can be viewed more holistically within a biopsychosocial model of healthcare rather than focussing on a biomedical model to breathlessness management. Spathis *et al*, (2021) conducted a pre and post course questionnaire at a breathlessness management study day to evaluate the delegates' confidence and experience in managing patients with breathlessness using the model. Consensus from this paper was that the model enabled Healthcare Professionals to understand the complex interactions and cycle of breathlessness which in turn enabled the Healthcare Professionals to personalise their approach to supporting self-management of their breathlessness.

Managing breathlessness is challenging due to the complex nature of the causes and consequences. Up to 80% of patients with COPD in the community experience some level of breathlessness and it can have a negative impact upon physical and psychological well-being as well as the quality of life of the patient and their family (Spathis *et al*, 2017). The Breathing, Thinking, Functioning model outlines the impact of a dysfunctional breathing pattern upon continued breathlessness and how this impacts upon increased anxiety and fear which leads to avoidance of physical activity and in turn an increase in breathlessness due to reduced exercise tolerance.

1.2.6. Management of COPD

COPD symptoms can significantly improve when appropriately managed. Hence, all COPD patients should be invited to a comprehensive annual review during which lung function, history of exacerbations, levels of breathlessness, physical activity levels and prescribed medication are evaluated (NICE, 2018). There are numerous elements of aspects of disease management that patients are required to be able to manage. There are several aspects to disease management and patients are required to

manage numerous elements pertaining to the disease at the same time. This is one of the reasons why self-management is so complex and challenging for patients. On a daily basis patients are required to take their prescribed medications including using the correct inhaler technique, manage their breathlessness using appropriate techniques, maintain physical activity levels and recognise and treat exacerbations often including appropriate use of rescue medication packs of antibiotics and oral steroids. A patient may also need to complete airway clearance techniques for sputum retention, ensure they have their annual flu vaccination and annual review with the respiratory or practice nurse. Stopping smoking and ensuring a healthy balanced diet are also advised (Jordan *et al* 2015).

The biomedical model approach to COPD management is a reactive, disease-focussed approach to care, often orientated around presence or absence of symptoms and the emphasis is upon diagnosis and medical management of objective markers such as lung function, disease severity and exacerbation rate (Fromer, 2011). Often the focus of treatment for COPD in a biomedical model is related to pharmacological management in the event of an acute exacerbation or hospitalisation. There is a lack of structured care for patients in a stable state (Fromer, 2011). In primary care there is a limited amount of time for clinical appointments and often these are heavily focussed around assessing and treating patients with acute exacerbations of their condition rather than supporting self-management in a stable state. To be able to support long-term behaviour change in relation to self-management, the patient needs on-going support when in both a stable and acute state (Newman *et al*, 2017).

1.2.7. Pharmacological management

It should be emphasised that pharmacological treatments should be assessed on an individual basis considering the individual's symptoms, severity of the condition, exacerbation history. Patient preference of treatments should also be taken into consideration (Global Strategy for the Diagnosis, Management and Prevention of Chronic Obstructive Pulmonary Disease [GOLD], 2018). Common pharmaceutical medications include bronchodilators to open the airways, and corticosteroids and steroids to reduce inflammation within the airways. Medication is often administered

via inhalers, nebulisers, and oral tablets. It is common for patients to take a combination of both oral and inhaled therapies. During an exacerbation, antibiotics are commonly prescribed, and some patients hold a rescue pack of antibiotics and oral steroids at home (NICE, 2010). Whilst pharmacological treatments are vital for symptom control, halting the speed of disease progression and treatment during an acute exacerbation, it is key to recognise the value of a holistic approach to disease management and not solely a biomedical model of care.

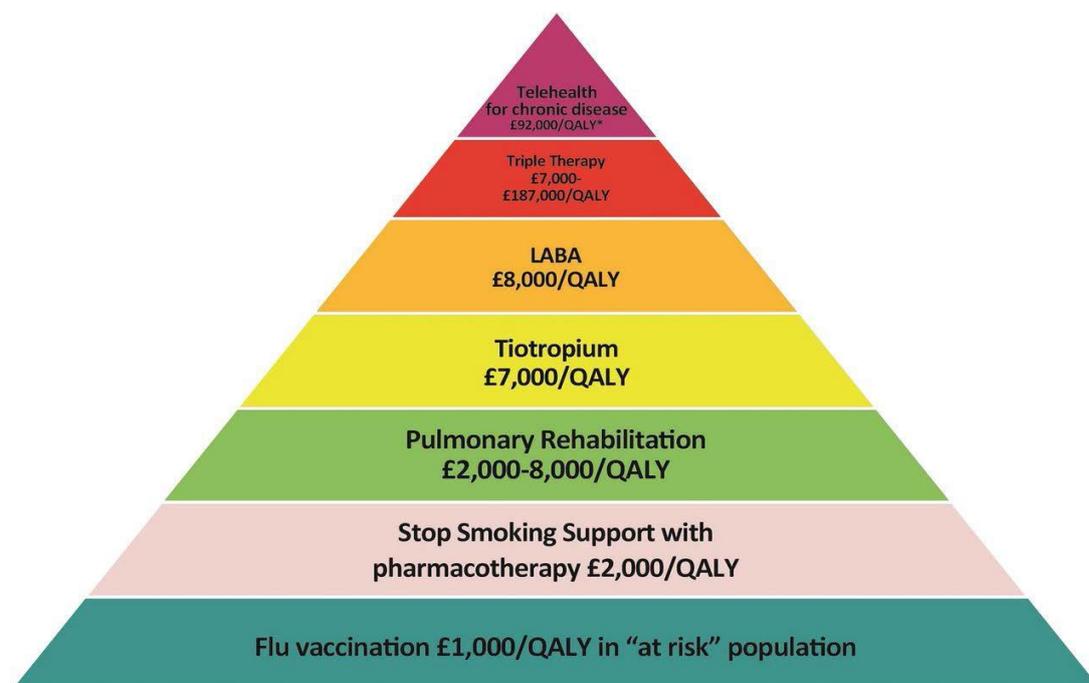
1.2.8. Non-pharmacological management

An alternative model to the biomedical model is one focussed on preventative measures encompassing a holistic and patient-centred care model and taking a proactive rather than reactive approach. This approach is reflected in the House of Care Model (The King's Fund, 2013) which advocates a patient-centred approach to long-term conditions management. Non-pharmaceutical interventions should be used alongside pharmaceutical treatments to assist with the management of COPD. A holistic multidisciplinary approach is paramount to be able to offer a combination of smoking cessation, with nicotine replacement therapy as well as behavioural support, Pulmonary Rehabilitation, breathlessness management and airway clearance techniques if appropriate and education on a range of topics to support self-management of their condition (The King's Fund, 2013). Whilst in clinical practice there is still a tendency towards the biomedical model approach to self-management in COPD.

Pulmonary Rehabilitation is recognised as one of the most cost-effective management strategies for COPD, with an approximate Quality Adjusted Life Year (QALY) of £2,000-£8,000 (Vogiatzis *et al*, 2016). Only two strategies have a lesser QALY than Pulmonary Rehabilitation. These are smoking cessation with pharmacotherapy at £2000 per QALY and flu vaccinations at £1000 per QALY (Vogiatzis *et al*, 2016) (See Figure 1.2). Not only is Pulmonary Rehabilitation effective in terms of patient outcomes, without doubt, but it is also a cost-effective management intervention. Therefore, investment in Pulmonary Rehabilitation services is key to ensure a proactive, holistic approach to COPD management. This thesis provides a deeper

understanding of the potential for a more holistic approach in Pulmonary Rehabilitation by investigating the mechanisms involved in behaviour change in relation to self-management. The emphasis throughout this thesis is on the value of long-term strategies which will, consequently, clearly show and enhance the effectiveness of an individualised approach to Pulmonary Rehabilitation programmes.

Figure 1.2: The COPD Value Pyramid (London Respiratory Network, published in Thorax 2014)



It is recommended that Pulmonary Rehabilitation should be offered to all COPD patients who meet the criteria defined in both the BTS (2013) PR guidelines and NICE COPD guidelines (2010). Pulmonary Rehabilitation programmes aim to improve the well-being of individuals with COPD, incorporating exercise and promoting physical activity, education, breathing techniques, psychological support, and medication advice with Healthcare Professionals from a multidisciplinary team (BTS, 2013). A systematic review by McCarthy *et al* (2015) synthesised the evidence from 65 randomised controlled trials (RCT's) and concluded that Pulmonary Rehabilitation is an essential component of the management of COPD. Alongside smoking cessation

and the flu vaccination, Pulmonary Rehabilitation offers more long-term benefits in COPD management than any other pharmacological intervention alone.

1.3. Pulmonary Rehabilitation

Pulmonary Rehabilitation is an evidence-based intervention, primarily aimed at patients with COPD. However, more recently it has been appropriate to include patients with other respiratory diseases. It is now a well-established and thoroughly evidenced intervention (Bolton *et al*, 2013, McCarthy *et al*, 2015, Holland *et al*, 2021). Pulmonary Rehabilitation encourages patients to take an active role in their health and well-being and it often leads to a reduction in healthcare utilisation (Carlin, 2009).

Pulmonary Rehabilitation is defined as:

‘an interdisciplinary programme of care for patients with chronic respiratory impairment that is individually tailored and designed to optimise each patient’s physical and social performance and autonomy. Programmes comprise individualised exercise programmes and education’ (NICE, 2013)

This builds upon an earlier definition from the American Thoracic Society / European Respiratory Society (ATS/ERS) statement on Pulmonary Rehabilitation:

‘An evidence based multidisciplinary and comprehensive intervention for people with COPD who are symptomatic and often have decreased daily life activities. Integrated into the individualised treatment for the patient, PR is designed to reduce symptoms, optimise functional status, increase participation and reduce healthcare costs through stabilising or reversing systemic manifestations of the disease’ (ATS/ERS, 2006)

These two definitions of Pulmonary Rehabilitation lack specific reference to self-management or behaviour change. There is a focus on the biomedically-orientated aspects such education, managing symptoms and reducing healthcare costs. The American Thoracic Society (ATS) workshop in 2019 concluded that the definition Pulmonary Rehabilitation didn’t require updating as it remains relevant and allows for

flexibility for evolving alternative models of delivery. However, there was acknowledgement that new approaches to future Pulmonary Rehabilitation delivery models are required (Holland *et al*, 2021). Primarily the focus should be on developing emerging models, defining the components and ensuring quality measurement of outcomes.

Less than 1.2% of the COPD population engage in Pulmonary Rehabilitation and only 15% of patients are referred (Morgan 2017). However, despite this low percentage of the population, it is becoming acknowledged that Pulmonary Rehabilitation is a crucial element in the management of patients with COPD. Not only does it improve exercise tolerance, but it has also been shown to improve breathlessness as well as improving health related quality of life which in turn impacts upon anxiety and depression (Lacasse *et al*, 2002 and 2006).

There has been an abundance of research and studies into the effectiveness of Pulmonary Rehabilitation over the last 20 years and Pulmonary Rehabilitation has transformed the treatment options available for patients with COPD (McCarthy *et al*, 2015). McCarthy *et al* (2015) recommend that further research into the effectiveness of Pulmonary Rehabilitation is not required as following their systematic review of 65 randomised controlled trials (RCT's), there was no question of its' effectiveness over usual care for COPD. There is good quality evidence for the effectiveness of Pulmonary Rehabilitation in terms of exercise capacity, reduced breathlessness, improved quality of life and a reduction in acute hospital admissions (Holland *et al*, 2021).

However, improvements gained during Pulmonary Rehabilitation are often not sustained once the course has finished and often patients return to pre-Pulmonary Rehabilitation levels within six to twelve months following completing the course (Busby *et al*, 2014). The benefits gained are often short-term outcomes, whilst what remains is the need for further investigation into how to ensure long-term commitment to adopting change in lifestyle incorporating aspects learned during the course encompassing self-management strategies. Pulmonary Rehabilitation has been one

of the recommended treatment options for COPD for many years. The benefits need to be maintained over time (Bolton *et al*, 2013). This is where the role of adherence and value of behaviour change in relation to self-management are recognised.

A biomedical model approach to COPD management is often a first line of treatment using pharmacological treatments such as inhaled bronchodilators, corticosteroids as well as oral antibiotics and steroids (Global Strategy for the Diagnosis, Management and Prevention of Chronic Obstructive Pulmonary Disease [GOLD], 2018). Patients with COPD often rely on a traditional biomedical approach for management of their chronic lung disease. For example, in exacerbation management, pharmacological treatments are often prioritised (Fromer, 2011). Whilst this is an important element, it is imperative to consider both the physical and psychological aspects of behaviour change as they influence one another. There remains a complex matrix between the physical and psychological impact of COPD on the individual (Spathis *et al*, 2017). In many cases Pulmonary Rehabilitation can often provide greater improvements in breathlessness as well as physical function compared to using pharmacological treatments such as bronchodilators alone (ZuWallack, 2007).

Cox *et al* (2017) conducted a systematic review of 48 studies encompassing both qualitative and quantitative research on the barriers and enablers of referral, uptake, attendance, and completion of Pulmonary Rehabilitation for people with COPD. There have been previous studies into the factors affecting adherence and successful completion of Pulmonary Rehabilitation. Nevertheless, this is the first systematic review designed to look purely at the barriers from a system, policy, and patient/provider point of view. Studies included were internationally represented from Europe, Asia, America, Africa, and Middle East. Quality was determined using a quality assessment criteria and studies included were reported to be fair methodological quality. The findings from the included studies were mapped to the Theoretical Domains Framework (Cane *et al*, 2012). This framework synthesises several behaviour change theories including common aspects such as knowledge, skills, beliefs, goals, and behavioural regulation as well as aspects related to social and environment influences. It was found that the 'environment' including aspects such as waiting time, burden of illness, travel, transport, and health system resources were the most cited issues related to barriers and enablers to successful Pulmonary

Rehabilitation. Other commonly cited influences included 'knowledge' which includes clinician knowledge of the referral process and patient understanding of Pulmonary Rehabilitation. Also 'beliefs about consequences' were also cited including aspects related to beliefs regarding the role and safety of exercise and expectations of rehabilitation outcomes. This systematic review is significant to outline the key issues related to barriers and enablers to successful Pulmonary Rehabilitation from a wide range of international studies. It confirms aspects from the previous literature relating to barriers such as location, transport, the impact of exacerbations and healthcare system resources but it highlights the need for further investigation into developing interventions which could target behaviour change. This provides an opportunity for this thesis to explore the underlying mechanisms associated with and influencing these commonly cited barriers.

Despite a plethora of evidence for its effectiveness, there remains some key issues which influence the outcomes for Pulmonary Rehabilitation. The British Thoracic Society (BTS) and The Royal College of Physicians (RCP) conducted two National audits on Pulmonary Rehabilitation services in 2015 and 2017 which has now become a continuous audit. The first audit paper entitled 'Pulmonary Rehabilitation: Time to Breathe Better' (BTS, 2015) which audited services across England and Wales highlighted that a large proportion of patients eligible for Pulmonary Rehabilitation were not referred. This suggests that Healthcare Professionals were not referring all eligible patients and that only approximately one third of all patients who were referred attended Pulmonary Rehabilitation. Perhaps this indicates that potentially referrers were not 'selling' the benefits of it adequately. There are also limitations associated with centre-based Pulmonary Rehabilitation such as transport, accessibility, and timings of sessions. However, Holland *et al* (2021) began to consider different models of Pulmonary Rehabilitation to address these issues as well as encompass more contemporary elements such as patient-centred care and personalised medicine. Prior to the COVID-19 pandemic alternative models of delivery were being considered (Holland *et al*, 2017) such as home-based programmes. The need to consider how to expand Pulmonary Rehabilitation services to provide it to a wider population using alternative methods of delivery to improve access has been discussed previously (Morgan, 2017). It has become more well recognised that one size does not fit all with

regards to Pulmonary Rehabilitation services and that alternative methods of delivery such as home-based or remote programmes with particular attention to support for self-management and behaviour change at an individual level are required (Morgan, 2017). The COVID-19 pandemic has accelerated the speed of developing alternative methods of delivery to offer it to those who may not have been able to attend a face-to-face group centre-based Pulmonary Rehabilitation programme.

Harrison *et al* (2019) cited an evidence gap related to the issues surrounding adherence and uptake in Pulmonary Rehabilitation and in particular the implication of using the term 'Pulmonary Rehabilitation' on the rates of uptake and completion. The 'Life of Breath' project was a series of activities in which individuals living with breathlessness were part of. A special interest group in this project 'The Breath Lab' discussed the meaning of the term 'Pulmonary Rehabilitation'. There were some contradictory descriptions associated with the term including defining and approaching breathlessness from a patient and Healthcare Professional perspectives. As well as the term 'Pulmonary Rehabilitation' often being a difficult term to understand, it was also described as a being 'highly medicalised' (Harrison *et al*, 2019, p.3). With a desired shift away from a biomedical model of care in Pulmonary Rehabilitation, the influence of the meaning and understanding of the term should be considered.

There is a wealth of evidence to support the theory that Pulmonary Rehabilitation improves outcomes and is an effective intervention for patients with chronic lung disease (Holland *et al*, 2021). However, there are barriers to effective participation and success (Keating *et al*, 2011 and Holland *et al*, 2013). To achieve best outcomes, it is important to ensure each component of Pulmonary Rehabilitation is delivered as effectively as possible. It remains unclear which behaviour change, and physical activity interventions promote engagement in physical activity (Hanrahan *et al*, 2022).

Complexity is an integral part of healthcare which should be embraced to be able to better understand the challenges in rehabilitation and research practice (Stockley and Graham, 2022). Interventions to change behaviour are complex in nature, as they involve several different components (Michie *et al*, 2013). Pulmonary Rehabilitation is a complex intervention in which behaviour change is essential for success. It is

important to be able to identify and recognise the components within Pulmonary Rehabilitation as a complex intervention to be able to understand the determinants of target behaviours (Hug *et al*, 2020).

1.3.1. Structure and Content of Pulmonary Rehabilitation

The benefits of Pulmonary Rehabilitation have become more widely recognised both nationally and globally with the publication of the British Thoracic Society (BTS) published the 'Quality Standards for Pulmonary Rehabilitation in adults' (2014), the British Thoracic Society (BTS) Pulmonary Rehabilitation Guidelines (2013) and the national clinical and organisational Pulmonary Rehabilitation audits (2015, 2017 and now a continuous audit). The British Thoracic Society (BTS) published the 'Quality Standards for Pulmonary Rehabilitation in adults' (2014) which outlined ten standards to standardise the structure of programmes across the UK. These standards link to the British Thoracic Society (BTS) Pulmonary Rehabilitation Guidelines (2013) for the specific detail on content of the programme. It is suggested that programmes should run twice weekly for a minimum duration of 6 weeks. Patients with mild to severe disease should be given the opportunity to participate in a programme if limited by breathlessness. Once enrolled, patients should commence within 3 months. In addition, patients should be referred following hospitalisation for an acute exacerbation and should commence within 1 month after leaving hospital. Programmes should consist of individually tailored prescribed exercise using both aerobic and resistance training as well as a structured educational programme. Regarding the educational content, clinicians can refer to the BTS Pulmonary Rehabilitation Guidelines (2013) which recommend that educational content should include, amongst others, 'confidence, self-efficacy and self-management' and 'identifying and changing beliefs about exercise and health related behaviours' (BTS, 2013, p.ii30). There is no further detail on the specific content of these educational topics. The BTS guidelines (2013) were focussed on reviewing the literature on resistance training, continuing exercise following Pulmonary Rehabilitation as well as empowering patients to change their behaviours in relation to self-management strategies. But there is little description of how specifically to change beliefs and no further description of what constitutes health related behaviours. Therefore, from the point of view of a Healthcare Professional it

is not clear how to approach behaviour change and self-management. This thesis provides an opportunity to explore the mechanisms specifically associated with health-related behaviours in Pulmonary Rehabilitation.

Whilst Pulmonary Rehabilitation offers an environment for structured and supervised exercise, there is still a lack of consistent support for the psychological aspects of chronic lung disease.

1.3.2. Clinical outcomes in Pulmonary Rehabilitation

The National Asthma and Chronic Obstructive Pulmonary Disease (NACAP) Audit includes the Pulmonary Rehabilitation Audit. The Pulmonary Rehabilitation Audit is the largest national dataset of patients undergoing Pulmonary Rehabilitation. The 2015 dataset comprised data from 210 Pulmonary Rehabilitation services whilst the 2019 dataset had some services missing due to the impact of COVID-19 on services. There were two snapshot audits; one in 2015 and another in 2017 followed by the audit changing to a continuous audit. The 2019 report showed that completion rates have steadily been improving since the audit first began in 2015. In 2015 the completion rate for Pulmonary Rehabilitation was 59%, increasing to 62% in the 2017 audit and then 65% in the 2019 report. Whilst this is an improvement, it does highlight that completion rates remain low which suggests that further investigation into the barriers to completing Pulmonary Rehabilitation are required. It is important to recognise that only a small proportion of patients are referred and then there is approximately a 40% drop out from either not attending initial assessments or not completing the course (Steiner *et al*, 2015). Another important factor to note is that a higher percentage of patients audited were from poorer socio-economical / most deprived areas. The influence of socio-economic background is crucial to recognise and understand the impact upon adherence and completion rates. These figures are important when we consider the scale of the problem in relation to adherence in Pulmonary Rehabilitation. This provides an opportunity to further investigate the underlying mechanisms associated with adherence and completion rates. This entails a deeper understanding of the mechanisms associated with behaviour change particularly related to self-management.

1.3.3. Adherence, Compliance and Concordance

Adherence is a well-documented factor associated with self-management in chronic respiratory disease. Adherence often refers to medication adherence but in chronic respiratory disease it also includes adherence to self-management interventions such as Pulmonary Rehabilitation (Scullion, 2020). Medicines adherence is a key aspect of self-management in COPD, for example, many patients use inhalers and respiratory medications as well as intermittent use of antibiotics during an acute exacerbation. Prevalence of non-adherence to antibiotics has been found to be 57.7% and to inhaled therapies has been found to be less than 50% (Scullion, 2020). Often the concept of adherence is associated with quantitative measurement of health-related behaviours such as attendance at Pulmonary Rehabilitation, taking prescribed medications and stopping smoking. Qualitative measures have shown the common barriers and facilitators associated with attending Pulmonary Rehabilitation sessions, but further focus is required to understand the specific and unique perspectives on health behaviours which ultimately impact on adherence. This thesis will look deeper at the underlying mechanisms associated with the barriers to behaviour change.

The World Health Organisation (WHO, 2003) define adherence as:

“the extent to which a person’s behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider”

This definition is still commonly referred to in adherence literature, but its focus is around the person making changes they have been instructed to, in line with a biomedical model, rather than a biopsychosocial conversation regarding behaviour change. Patients should have an active role with Healthcare Professionals in shared decision-making on their care. There should be good communication between the patient and Healthcare Professional (Bourbeau and Bartlett 2008). Bourbeau and Bartlett (2008) describe that 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).

Adherence can be determined in several ways, which can cause confusion when interpreting the literature. There is currently no consensus on estimates of adherence within the Pulmonary Rehabilitation literature (Bourbeau and Bartlett, 2008). For example, according to Bourbeau and Bartlett (2008), adherence to Pulmonary Rehabilitation classes can be anything from 50% to 80% attendance, while some programmes have defined non-adherence as being significant if patients miss one session only. On the other hand, Fan *et al* (2008) define adherence in Pulmonary Rehabilitation as 100% completion of a programme, compared to Seymour *et al* (2010) who define adherence as 50% completion. The difficulty arises when literature uses quantitative ways to measure health-related behaviours, this is consistent with a biomedical model of healthcare.

There is a need to differentiate between adherence and compliance. The main difference is that adherence requires the patient's agreement to the recommendations. Historically, the term compliance was used to describe how a patient conducted themselves in relation to advice from a Healthcare Professional in relation to taking a prescribed medication or lifestyle changes. Compliance indicates a more passive role for the patient in deciding treatment plans. This is aligned with a biomedical model approach to patient management and often the focus is on taking prescribed medications (Horne *et al*, 2005).

Concordance is a term used more recently which reflects a more collaborative approach to decision-making. Concordance allows for joint responsibility in treatment planning and allows the patient to feel empowered to play an active role in decision making (Bourbeau and Bartlett, 2008). It is recognised that there are limitations to adherence and compliance in relation to the relationships and interactions between patients and Healthcare Professionals (Bissell *et al*, 2004). These interactions should move from a hierarchical structure of reinforcing instructions to patients to a constructive conversation on healthcare provision and allowing the patient to make informed decisions about their own healthcare needs. Concordance is aligned more with shared decision-making approaches. This will be discussed further in Chapter 8: Discussion and Conclusion.

The relationship between adherence and self-management has been documented in the literature, particularly in relation to self-management in Physiotherapy treatments (Peek *et al*, 2016). Adherence to exercise in Pulmonary Rehabilitation is a crucial element in the success of self-management. But this is often situated within a biomedical model of delivery. It has become apparent in the literature that both patient and Healthcare Professionals' behaviours have an influence on behaviour change which are critical in supporting successful self-management (Blackstock *et al*, 2016). Behaviour change is essential to the success of self-management. Healthcare Professionals within the field of Pulmonary Rehabilitation are ideally placed to have behaviour change conversations to support patients with their behaviour change. Therefore, this thesis focusses on behaviour change in relation to self-management.

1.4. Self-Management

Self-management has arisen as a common component of managing long-term conditions, particularly in managing COPD (Murphy *et al*, 2017). Incorporating changes in self-management behaviours into daily activities can be challenging, especially when managing a long-term condition such as COPD (Wilkinson *et al*, 2020). Self-management can be complex, involving adherence to treatments, significant change to health behaviours and individuals are generally supported by Healthcare Professionals (Araújo-Soares *et al*, 2018). Self-management often also involves support from family members and the social community network as well as Healthcare Professionals (Wilkinson and Whitehead, 2009).

The term self-management is used in both research and clinical practice to describe the ways in which Healthcare Professionals support patients rather than focusing on how patients manage their own condition (Newman *et al*, 2017). Self-management can be seen as a place that people get to rather than an intervention to give to a patient. However, self-management is often described as an intervention. For example, self-management interventions are described as ranging from providing information on healthy behaviours through to in depth support to change behaviours and improve self-efficacy (de Silva, 2011). Self-management programmes are often designed to teach and support patients to self-manage their condition more effectively (Smalley *et al*, 2021). Pulmonary Rehabilitation is a self-management programme

widely utilised primarily with patients with COPD. Self-management in Pulmonary Rehabilitation and those with COPD is complex and challenging as it encompasses several aspects and behaviours including understanding and taking prescribed medication, monitoring symptoms, recognising and treating exacerbations, managing their breathlessness, exercising regularly, maintaining a healthy diet and smoking cessation (Jordan *et al*, 2015). These aspects of self-management are primarily focussed on Healthcare Professional directed advice and education. This model of self-management sits within the biomedical paradigm of health and illness. Despite this focus on a biomedical approach to self-management, the reality is that patients only interact with Healthcare Professionals for a short amount of time (Gilworth *et al*, 2019).

In the United Kingdom, approximately 15 million people have a long-term condition. This large number of people often put a high demand on healthcare resources and account for 50% of all GP appointments, 64% of all outpatient appointments and 70% of inpatient bed days (Kings Fund, 2013). The prevalence of long-term conditions rises with age, with many older people having more than one chronic condition. The Chronic Care model influenced Health Policy to transform healthcare for people with long-term conditions by moving from a reactive biomedical model of care to a more patient-centred care model (Coulter *et al*, 2013). The ultimate goal of a patient-centred care model is focussed on self-management in which the patient is guided to manage their own condition. To tackle the issues surrounding long-term conditions management, the House of Care model was developed (Coulter *et al*, 2013). This model, which is directed towards Primary Care, aims to support and help the patient to express their own needs and decide their own priorities. Although this model was designed for Primary Care, many of the aspects can be related to this thesis in relation to patient-centred care in long-term conditions management. For example, co-ordinated care, personalised care models, support for self-management including emotional, psychological, and practical support (Coulter *et al*, 2013). Support for self-management is central to the collaborative relationship at the centre of the service delivery (Coulter *et al*, 2013).

With this rise in demand on healthcare resources, there is a need to identify alternative models and ways of clinical services delivery. There is a requirement to investigate how to best support patients to have a sense of control whilst also reducing their dependency upon Healthcare Professionals (de Silva, 2011 and Mudge *et al*, 2015). Physiotherapists are ideally placed to be able to support holistic care and health promotion alongside support for self-management with appropriate knowledge on behaviour change theories (Hartley, 2019). Despite Physiotherapists being well-equipped to support patients with long-term conditions, there are challenges with the complexities of chronic conditions as well as constraints within the healthcare systems.

COPD is a chronic condition which deteriorates over time. It is a relapsing and remitting condition, often with worsening symptoms during an exacerbation and yet with more stable conditions when an individual is well (NICE, 2018). There is a requirement for the individual to manage their condition independently, but this requires knowledge, skills, access to Healthcare Professionals and Pulmonary Rehabilitation programmes (Brighton *et al*, 2020, Bourbeau *et al*, 2020). The role of social support mechanisms is also key in embedding support for behaviour change in COPD. For example, family members and social support networks (Fromer, 2011). COPD is a long-term condition which as the fourth leading cause of death (NICE, 2018) is currently increasing demand upon healthcare resources and so it is essential to be able to support more sustainable behaviour change. Improvements in self-management in COPD are required to be able to manage the burden of symptoms and exacerbations.

Historical definitions of self-management have often focussed on interventions prescribed by Healthcare Professionals. For example, self-management can be defined as patients taking responsibility for and having an active role in the management of symptoms (Lenferink *et al*, 2017). Self-management has been defined quite broadly by Murphy (2017):

'the provision of interventions to increase patients' skills and confidence, empowering the individual to take an active part in their disease management'
(Murphy, 2017, p.276).

Self-management definitions often have a focus on a biomedical approach with a paternalistic style of support. Often clinicians are traditionally in a position of authority and seen as the expert, often trying to control the behaviour of the patient primarily through education and motivation (Mudge *et al*, 2015). Jordan *et al* (2015) argue that within the self-management literature there is debate over the interpretation of the goals of self-management, and this may be different from a Healthcare Professional and patient perspective. Kendall *et al* (2011) focus more on a biomedical model of self-management, describing it primarily as a cost cutting mechanism, as well as self-management described as the domain of Healthcare Professional experts and self-management as emancipation, where patients feel supported and listened to.

There has been a shift towards a broader definition of Self-Management which encompasses more focus on behaviour change. This definition from Apps *et al* (2013) has a focus on education but also recognises the role of behaviour change:

'Self-management programs should aim to promote physical activity, smoking cessation, management of social interactions, medicines management, and the ability to recognize and respond to symptoms. Delivery of effective self-management skills requires the patient to have an acceptance of behaviour change. This means that the programs need to be structured to develop knowledge and skills and to address attitudes to change, so the patient can achieve the necessary behaviour change'.

(Apps *et al*, 2013, p.318)

Similarly, a consensus definition was published by Effing *et al* (2016) which specifically relates to self-management support for patients with COPD. The Delphi consensus was reached among an international panel of COPD self-management experts and is described as:

'A COPD self-management intervention is structured but personalised and often multi-component, with goals of motivating, engaging and supporting the patients to positively adapt their health behaviour(s) and develop skills to better manage their disease.

The ultimate goals of self-management are: a) optimising and preserving physical health; b) reducing symptoms and functional impairments in daily life and increasing emotional well-being, social well-being and quality of life; and c) establishing effective alliances with healthcare professionals, family, friends and community.

The process requires iterative interactions between patients and healthcare professionals who are competent in delivering self-management interventions. These patient-centred interactions focus on: 1) identifying needs, health beliefs and enhancing intrinsic motivations; 2) eliciting personalised goals; 3) formulating appropriate strategies (e.g. exacerbation management) to achieve these goals; and if required 4) evaluating and re-adjusting strategies.

Behaviour change techniques are used to elicit patient motivation, confidence and competence. Literacy sensitive approaches are used to enhance comprehensibility.' (Effing *et al*, 2016, p.51)

Key strengths of this definition include acknowledgement to the role of health behaviours and behaviour change techniques as well as the interactions between Healthcare Professionals and patients being described as iterative interactions with a patient-centred focus.

In a biomedical model of self-management the patient is often a passive recipient of information, knowledge and support. This approach can impact upon behaviours as patients can become passive recipients of healthcare (Killingback *et al*, 2021). This leads them to be disempowered and reliant upon support from Healthcare Professionals rather than being empowered to manage their condition themselves. When behaviours, emotions and attitudes are medicalised and people are made accountable for their own health, they are at risk of being blamed for their own health

choices (Battersby *et al*, 2010). This fosters a culture of victim blaming derived from a paternalistic model in which there is a focus on deficits rather than their assets.

Self-management is a core component of Pulmonary Rehabilitation but often literature is focussed on self-management purely during the Pulmonary Rehabilitation programme (Spruit *et al*, 2015) rather than looking at self-management maintenance beyond the Pulmonary Rehabilitation programme. Within the last 5-10 years there has been a growth in self-management research particularly focussing on investigating self-management behaviours in COPD (Newham *et al*, 2015). This thesis explores self-management behaviours primarily in relation to within Pulmonary Rehabilitation but with consideration to the long-term changes beyond Pulmonary Rehabilitation. Despite support for self-management being associated with improved health outcomes, there remains a challenge in defining self-management as well as understanding roles and responsibilities in achieving self-management (Effing *et al*, 2016). In relation to the management of COPD, there is scope to facilitate a movement away from a biomedical model approach to self-management by focussing on a patient-centred model, listening to patients' needs and priorities and supporting self-management (Alqahtani *et al*, 2022). This thesis will consider the key issues related to COPD as a condition, Pulmonary Rehabilitation as a structured environment and self-management as an intervention. There is a demand to consider the impact of behaviour change in relation to the management of long-term conditions.

It is recommended that patients with COPD are actively engaged in self-management, particularly in relation to exacerbation management (GOLD, 2018; NICE, 2010). Lorig and Holman (2003) describe that patients with a chronic condition may choose to not engage in self-management strategies and change their health behaviours, but this is merely their choice of how to manage their condition. The inherent nature of a chronic lung disease means that the patient must be responsible for the day-to-day management of their condition and self-management is part of daily life. How they choose to self-manage is the key variant. This poses a challenge in support for self-management when there is conflict between what the Healthcare Professional thinks a patient needs to change and what the patient believes. The Physiotherapist as an

expert and having perceived professional authority has been recognised by Killingback *et al* (2021) which can lead to an uneven power structure. There is a question of who does self-management belong to. Healthcare Professionals should respect the individual's choice and have a patient-centred discussion so that the patient's decision is an informed choice. Pulmonary Rehabilitation as an intervention is quite binary and inflexible (Holland *et al*, 2021), which doesn't always accommodate the complexity of chronic lung disease.

It is evident in both clinical practice and research that the term self-management is used to describe a multitude of methods that both patients and Healthcare Professionals can use to manage and support long-term conditions management. A range of strategies include providing information and education on healthy behaviours such as diet, physical activity, and medication through to more directive support surrounding empowerment and self-efficacy (de Silva, 2011). Self-management support strategies have been shown to improve outcomes in long-term conditions, particularly in COPD and remain a key aspect of healthcare delivery within this population. However, there remain challenges with the concept of long-term commitment and behaviour change in relation to self-management from both a patient and Healthcare Professionals' perspective (Taylor *et al*, 2014). These are particularly important to note to be able to embed support for self-management within routine clinical practice. Social community and relationships are crucial elements in embedding self-management. It is important to consider the wider community and resources available to support an individual with a long-term condition as well as their personal self-management actions (Reeves *et al*, 2014).

The NICE COPD guidelines (2010) focus on self-management in relation to symptoms and exacerbation management - a more medicalised approach, using methods to provide information and education. However, for successful behaviour change in relation to self-management, interventions need to be personalised to the patient including 'goals of motivating, engaging and supporting the patients to positively adapt their behaviour(s) and develop skills to better manage their disease' (Lenferink *et al*, 2017, p.7). Other elements of behaviour change are key to disease management including non-medical aspects of smoking cessation and support for behavioural

modification as well as promoting physical activity and increasing exercise ability. Pulmonary Rehabilitation is recommended for all patients with COPD who meet the inclusion criteria and it should be offered at all patient contacts with a Healthcare Professional. Pulmonary Rehabilitation can support behaviour change in relation to self-management through education and personalised guidance from Healthcare Professionals across the multidisciplinary team.

Jordan *et al* (2015) conducted a systematic review on supported self-management in patients with COPD. They found it difficult to determine key components of self-management interventions but noted that an exercise component was effective. They concluded that further work was required to specifically investigate barriers and facilitators to self-management as well as behaviour change interventions.

Personalised care models are central to long-term conditions management and Allied Health Professionals (AHP's). Physiotherapists are key professionals to be able to implement strategies to support behaviour change in relation to self-management. For example, education, support, and individual guidance. Personalised Care (2019) requires a whole system approach to person-centred care, allowing access to services for all, with a drive to reduce health inequalities. It is aligned to the NHS Long Term Plan (2019) and focusses on community-based care and shared decision-making. AHP's into Action (2017) outlines how Allied Health Professionals (AHP's) are ideally placed to be able to incorporate and reinforce methods within the future workforce development and to lead the transformation of health, care, and well-being. AHP's can work efficiently and effectively to meet the challenges of changing care needs. There is an ideal opportunity for AHP's particularly within Respiratory Care and Pulmonary Rehabilitation to network among Commissioners and Primary and Secondary Care to align services for the benefit of the patients.

The People Plan (2020/21) outlines how service transformation across the NHS will enable services to adapt to the new landscape of many clinical services following COVID-19. One of the key aspects of this plan is to adapt service models to include a more accessible service model for patients to reduce health inequalities. In relation

to Pulmonary Rehabilitation, this includes aspects related to remote service models and tailoring a more individualised model of Pulmonary Rehabilitation.

Long-term conditions, particularly chronic respiratory disease such as COPD have a high treatment burden. There is a growing number of people living for longer with multiple and complex chronic conditions which poses risks associated with adequate support for self-management. The NHS Long-Term Plan (2019) had primary aims which were aimed at having more integrated care with a particular focus on 'out of hospital' care and personalised care. These aspects are especially important elements of long-term conditions management. A drive towards the right care in the right place, at the right time was also a key priority within the plan. The drive to tackle health inequalities, particularly in Chronic Obstructive Pulmonary Disease (COPD) is an essential component as COPD can be more prevalent in deprived areas.

The NHS Long-Term Plan follows the Five Year Forward View (2014). However, it is wide-reaching and includes respiratory conditions amongst other additions such as cardiovascular conditions, children's health and learning disabilities. The Long-Term Plan provides an ideal opportunity to focus on enhancing services for people with lung disease. Within the context of the plan, it is essential to look at how care and management of respiratory disease can be transformed to become more aligned with patient-centred and personalised care as well as shared decision-making. There is a particular focus on Pulmonary Rehabilitation linking with key national projects such as the Pulmonary Rehabilitation Accreditation Scheme, the Royal College of Physicians Pulmonary Rehabilitation Audit alongside the British Thoracic Society Guidelines and Standards for Pulmonary Rehabilitation and more recently in 2020, the Quality and Outcomes Framework NM47. These are likely to lead to an increase in referrals into Pulmonary Rehabilitation. There is ample evidence of the benefits of Pulmonary Rehabilitation and guidelines and standards for successful expansion and improved quality of Pulmonary Rehabilitation services, but ultimately it requires support for behaviour change amongst both Healthcare Professionals and patients. There is currently a lack of evidence which would suggest and support specific ways in which

to support behaviour change among this patient group. This thesis will explore behaviour change from both Healthcare Professionals and patients' perspectives.

This thesis will explore the mechanisms associated with self-management and behaviour change from varied perspectives to be able to better understand the mechanisms at play in the relationship between the patient and Healthcare Professionals. Killingback *et al* (2021) explored the role of person-centred practice in Physiotherapy using narrative enquiry and found that there is an evolutionary journey of encounters between a patient and the Physiotherapist. These encounters all contribute to the overall experience and development of a relationship between the patient and Physiotherapist and provide an opportunity to support behaviour change on an individual level. One thread from the narrative enquiry related to the influence of Physiotherapists' attitudes and how their background experiences and personal philosophy could have an impact on their approach to their interactions with patients (Killingback *et al*, 2021).

There is a complex interplay between the concepts of adherence, self-management and behaviour change. It is often assumed by Healthcare Professionals that good adherence leads to better self-management (Bourbeau and Bartlett 2008) and therefore behaviour change but another way to look at it is to consider if behaviour change is needed before self-management can be achieved and is this through adherence. Within the complex interplay between these concepts, there are underlying causal mechanisms which influence an individual's ability to engage in behaviour change and self-management. Causal mechanisms associated with behaviour change in self-management in Pulmonary Rehabilitation will be explored within this thesis.

1.5. Context of Health Behaviours and Behaviour Change

Behaviour change is the cornerstone of successful self-management. Behaviour change among patients is important, but it is also essential for Healthcare Professionals to recognise their own behaviours and to be able to support successful

behaviour change with patients (Bourbeau *et al*, 2016). In a biopsychosocial model of healthcare, a collaborative approach to supporting behaviour change is required (Wilkinson *et al*, 2020). This involves having an individual conversation with a patient-centred approach.

Firstly, to be able to understand the concept of behaviour change in long-term conditions, it is important to define the term health behaviours in relation to the patient, and consider how these may have an impact on an individual's daily life. Health behaviours are defined as

‘Overt behavioural patterns, actions and habits that relate to health maintenance, to health restoration and to health improvement’
(Gochman, 1997, p. 3).

This definition focusses on health behaviours as positive actions whereas often in healthcare the focus is on negative health behaviours that may be harmful to health (NICE 2007 and Connor and Norman 2017). For example, common health behaviours include smoking, physical activity levels, healthy eating / diets, alcohol consumption and medicines adherence. For the purpose of this thesis study, a broader approach to self-management behaviours within the context to Pulmonary Rehabilitation will be explored. This will be based on long-term conditions management and understanding the contexts which make achieving behaviour change challenging to achieve. For example, the barriers associated with successful Pulmonary Rehabilitation such as resources, time, investment, governance structures including both staff and patient behaviours (Keating *et al*, 2011 and Holland *et al*, 2021). Health behaviours aligned with a biomedical model of healthcare are often referred to within support for self-management. For example, taking prescribed medication, learning how to monitor symptoms and manage exacerbations as well as healthy eating, engaging in physical activity and reducing sedentary behaviours, and smoking cessation (NICE, 2018). However, the context of an individual's personal situation can influence positively or negatively to their ability to achieve behaviour change which goes beyond the previously reported socioeconomical and clinical factors (Sohanpal *et al*, 2015). This thesis considers the impact of both patient and Healthcare Professional behaviours

and the importance of supporting behaviour change. The main focus is upon patient-related behaviours but there is recognition of the influence of Healthcare Professionals' behaviours upon the behaviours of patients.

In addition, it is also key to consider quality of life alongside health and well-being. Many individuals with a long-term condition have their own personal goals and set of beliefs which influence their engagement in health behaviours. To be able to support health behaviours, the psychological determinants of health behaviours need to be examined. Health behaviours such as physical inactivity and sedentary behaviours are complex and thus are difficult to change. Therefore research surrounding these behaviours should be conducted using theoretical models which is often not the focus in Pulmonary Rehabilitation research (Spruit *et al*, 2015). Such models include The Health Belief Model (Rosenstock *et al*, 1988), The Self-Determination Theory (Deci and Ryan, 2000) and The Social Cognitive Theory (Bandura, 1991). These models encompass a range of determinants of health behaviours including, self-efficacy, beliefs about consequences, motivation, and the influence of the environmental and cognitive factors. These models will be discussed further in section 1.6 of this chapter.

As Healthcare Professionals it is essential to recognise how patient-centred care models can facilitate shared decision-making by understanding the complex interplay between the psychological, social and physical impact of long-term conditions to be able to have meaningful conversations regarding health behaviours. Lifestyles and habits can influence life expectancy. Sixty-six percent of the adult population are not meeting the required levels of physical activity and 70% don't consume the recommended daily amounts of fruit and vegetables, resulting in an increasing rate of obesity, particularly in more disadvantaged groups which increases the risk of developing long term conditions (The Kings Fund, 2012).

An essential step in investigating health behaviours is firstly to be able to define the health behaviour in question. This thesis does focus on self-management behaviours. However, from a patient-centred perspective, Healthcare Professionals need to support individuals to be able to do what they want to be able to do within their own personal life. Being independent and empowered to have the control of their own

condition to be able to have optimal health and well-being for their personal goals are all essential components of supporting self-management.

The National Institute of Health Excellence (NICE) guidelines on Behaviour Change (2007) outline that within the UK there are health inequalities which ultimately create an environment in which social and economic conditions have an influence on an individual's ability to change their behaviours particularly in relation to their health. Significant events are considered key opportunities to focus on behaviour change. For example, when patients are first diagnosed with a chronic condition such as COPD, or when patients with COPD attend primary or secondary care appointments or if they are admitted to hospital. Healthcare Professionals should aim to intervene with behaviour change interventions to be able to have more potential to succeed. The NICE guidelines on behaviour change (2007) report that in the past it has been difficult to promote one model of behaviour change as there have been many different versions and adaptations of models and poor study designs. Therefore, it was recommended that individuals should focus on using 'generic skills and competencies' rather than focussing on a particular model. This makes it difficult to improve approaches to behaviour change in self-management in Pulmonary Rehabilitation as there are a wide range of skills used by Healthcare Professionals currently.

The way in which we live our lives has a direct impact upon our health. Despite knowing this, many people struggle to adopt healthy behaviours such as eating a healthy diet and exercising regularly. Behaviour change is an essential component to improving our health. However, it is often thought that this requires the person to adhere to and comply with recommendations. Healthcare Professionals frequently advise patients to adhere to certain regimens, such as taking medications, taking regular exercise and stopping smoking. Adherence in Pulmonary Rehabilitation is poor (Steiner *et al*, 2015) and in long-term conditions, adherence to prescribed medications is between 30-50% (Hemingway, 2009). When trying to encourage patients to comply with professional advice it is essential to consider their health psychology and adopt an appropriate approach to improve patient adherence. Adherence can be described as a process as well as an outcome of behaviour change

(Simpson *et al*, 2006). It is often presumed that good adherence leads to better health outcomes, but it is not always a linear pathway from adherence to behaviour change (WHO, 2003). Behaviour change can lead to improved adherence and successful self-management.

An important aspect to consider is the patient's perception of their illness. Patients with chronic disease who are required to adhere to self-management regimes often have a varied level of compliance. This can be attributed to their perception of their disease or illness. This may also be influenced by the stage of their chronic illness and what setting they are in. For example, a patient with a current exacerbation as an inpatient may have different psychological needs to someone who is at home and managing their condition well, particularly in relation to illness perceptions. Illness perceptions following an exacerbation and hospitalisation have been explored and uptake of Pulmonary Rehabilitation has been found to be poorer in a post exacerbation patient group (Harrison *et al*, 2013). The timing of interventions for Healthcare Professionals is key to the success of behaviour change. Nationally, and on average, Pulmonary Rehabilitation programmes usually take the form of a 6-week course of twice weekly exercise and education. It is important to consider whether this is long enough or indeed the right time to expect a change in an individual's health behaviour. Some Pulmonary Rehabilitation programmes have access to Psychologists. But only 19% of services had access to a psychologist on the National Pulmonary Rehabilitation audit (NACAP, 2020). This percentage is low and it is often other Healthcare Professionals such as Physiotherapists, Nurses and Doctors who support patients with the psychological impact of chronic disease and who often try to tackle an individual's behavioural needs. Health behaviours and the psychological impact of chronic lung disease are complex and therefore it is difficult for Healthcare Professionals to allow sufficient time to deal with the complexities of patients with chronic disease. Behaviour change theory and literature has become more paramount which shaped the data analysis of both the focus group and survey data. Driver *et al* (2017) conducted a systematic review of the literature focusing on the knowledge, behaviours, attitudes, and beliefs of Physiotherapists towards psychological interventions in Physiotherapy practice. Fifteen studies were included in the review and the primary findings were that Physiotherapists were aware of psychological

interventions and have positive beliefs and attitudes towards using them, but a lack of knowledge and time constraints were barriers to successful implementation into practice. Driver *et al* (2017) suggest that although Physiotherapists are aware of and willing to engage with psychological interventions, they feel they lack sufficient training in advanced psychological techniques such as cognitive behavioural therapy (CBT) and also some felt it was out of their scope of practice. This thesis will further explore the barriers associated with behaviour change in Pulmonary Rehabilitation, specifically related to self-management.

1.6. Health Behaviour Frameworks and Models

With the growth of health psychology as a discipline, there has been an expansion of current theories of health behaviour focusing on the adoption and maintenance of health behaviours which underpin wellbeing. There are many different models of health behaviour. Motivation and self-efficacy have been shown to influence behaviour change in Pulmonary Rehabilitation (Sahin and Naz, 2018, McCarthy *et al*, 2015 and Spruit *et al*, 2015). For this thesis, behaviour change models centred on self-efficacy and motivation will be explored by focussing on The Health Belief Model (Rosenstock *et al*, 1988), The Self-Determination Theory (Deci and Ryan, 2000) and The Social Cognitive Theory (Bandura, 1991). These models vary in focus and approach. It is evident that different disciplines conceptualise and approach health behaviours in different ways. These models provided a theoretical background which could be used to provide an enhanced understanding of the barriers and facilitators to successful self-management in context of Pulmonary Rehabilitation and provide platform for future intervention development and redesign of Pulmonary Rehabilitation services in a post COVID-19 era. Incorporating the key concepts from these models informed the development and identification of the research aim and objectives.

For successful behaviour change in self-management, it is important to be able to situate the approach in relation to the desired outcome. Self-efficacy, motivation and personal perspectives and beliefs in relation to behaviour change are key aspects associated with behaviour change. The key concepts from the behaviour change theories centralise around motivation and self-efficacy with particular focus on the

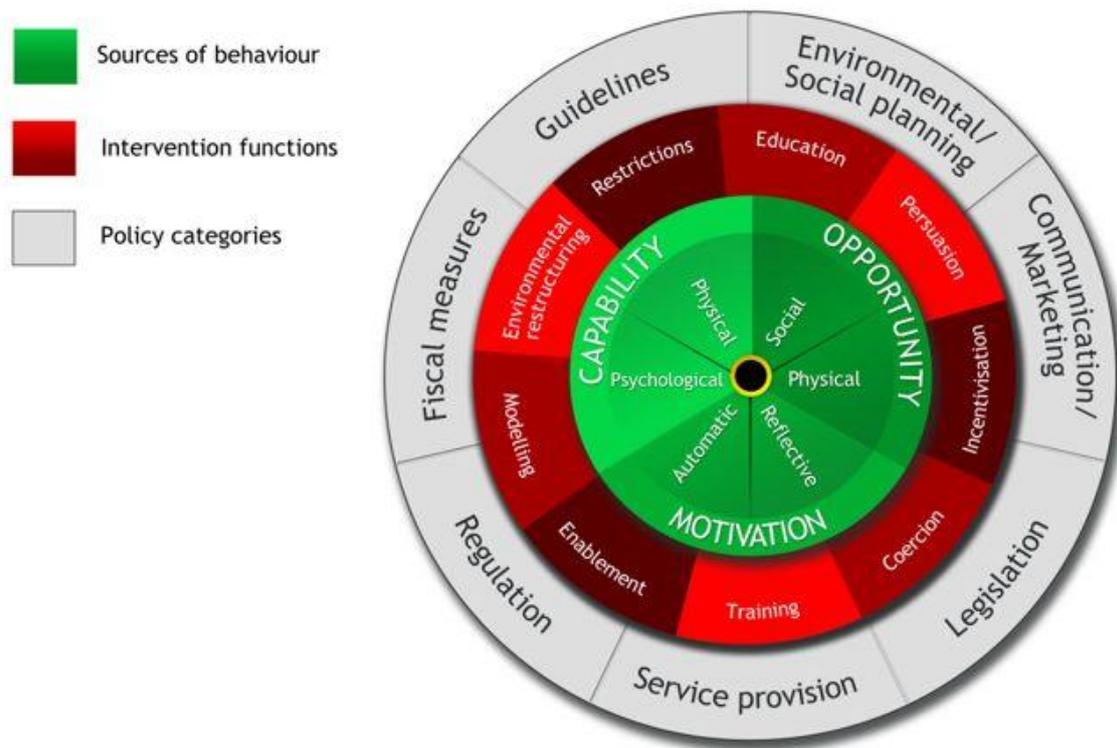
impact of the personal perceptions of the condition and the impact of the environment. To contextualise behaviour change and frame the approach to this thesis, The Behaviour Change Wheel (BCW), The Capability, Opportunity, Motivation which create a Behaviour (COM-B) model and The Theoretical Domains Framework (TDF) were chosen due to their focus on developing understanding of behaviours. These models will be used throughout the thesis to structure the approach to the methods used as well as supporting in framing the data analysis. There is a risk when only using one model that research studies can become entirely deductive if the framework is strictly adhered to and other elements could be missed (McGowan *et al*, 2020). Therefore, the different approaches to investigating behaviour change through The Behaviour Change Wheel (BCW), The Capability, Opportunity, Motivation (COM-B) model and The Theoretical Domains Framework (TDF) allowed for a thorough understanding of behaviour change through the data. An inductive approach in qualitative research is more aligned to investigating individual experiences and determinants of behaviour. By using multiple models of behaviour change theory it allows for less risk of missing key concepts that may determine a behaviour (McGowan *et al*, 2020). The Behaviour Change Wheel provides a framework to incorporate behaviour change in the context of policy and interventions. As part of the Behaviour Change Wheel, the COM-B model provides an opportunity to focus on specific aspects of the behaviour to be able to identify causal mechanisms. In addition, The Theoretical Domains Framework provides a framework to be able to identify determinants of behaviour.

The evidence for the effectiveness of Pulmonary Rehabilitation is extensive. There is a growing body of evidence to suggest that behaviours and the psychological impact of chronic respiratory disease influence uptake and adherence (Blackstock *et al*, (2016), McCarthy *et al*, (2015), Cox *et al*, (2017). However, to make effective change in health behaviours, it is essential to identify the elements of Pulmonary Rehabilitation that specifically influence behaviour change. Pulmonary Rehabilitation is a complex intervention with influences from many different sources, ranging from the referring clinician through to the Healthcare Professionals delivering the Pulmonary Rehabilitation sessions. The COM-B model and The Theoretical Domains Framework

provide a structured framework to be able to identify causal mechanisms associated with behaviour change.

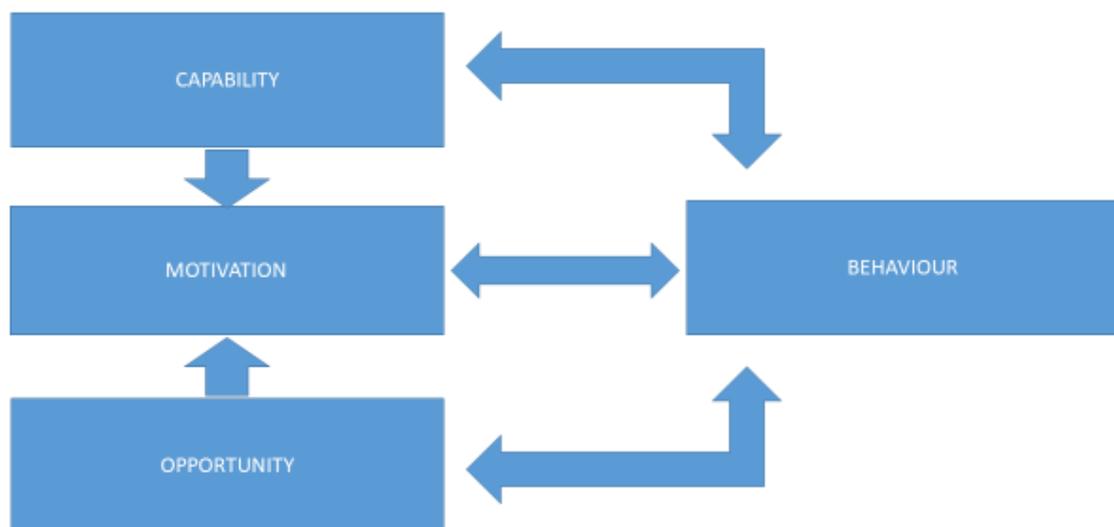
Michie *et al* (2011) recognise that improving the design and implementation of evidence-based practice depends on successful behaviour change interventions. This, however, requires an appropriate method for characterising interventions. Behaviour change interventions are described as ‘coordinated sets of activities designed to change specified behaviour patterns’ (Michie *et al*, 2011, p.1). There is a plethora of frameworks for designing and classifying behaviour change interventions, but they often lack detail regarding understanding of the behaviour to be changed and also lack an appropriate method for defining the intervention and its’ components. However, Michie *et al* (2011) developed a framework for understanding behaviours; The Behaviour Change Wheel (Figure 1.3)

Figure 1.3: The Behaviour Change Wheel (Michie *et al*, 2011)



The Behaviour Change Wheel provides a framework for the development and interpretation of the data within this thesis. The Behaviour Change Wheel places behaviour change within the context and influence of interventions and policy as a means of recognising the complex nature of behaviour change within modern society. The Behaviour Change Techniques Taxonomy was developed following on from this framework as a way of identifying the key components of an intervention. The core components of The Behaviour Change Wheel comprise of the COM-B system of understanding the behaviour. Michie *et al* (2011) recommend that three factors are necessary for the performance of a specified behaviour; 'the skills necessary to perform the behaviour, a strong intention to perform the behaviour and no environmental constraints that make it impossible to perform the behaviour' (Michie *et al*, 2011, p.4). The COM-B system is shown in figure 1.4.

Figure 1.4: The COM-B system (Michie *et al*, 2011)



In this behaviour system, capability, motivation, and opportunity interact to generate or create a behaviour, but the behaviour can then also influence these elements individually. Therefore, it can be a constantly remodelling system. This model will

inform the interpretation of the data analysis to determine the mechanisms associated with behaviour change in self-management.

Capability is defined as 'the individual's psychological and physical capacity to engage in the activity, as well as having the necessary knowledge and skills. Motivation is defined as the brain processes that form and direct behaviour, not just goals and decision-making. It includes habits, emotional responses, as well as decision-making. Opportunity is defined as the factors that lie outside the individual which make the behaviour possible or prompt it' (Michie *et al*, 2011, p. 4). This is presented as a model of behaviour, but it can also be used for designing interventions for behaviour change. Pulmonary Rehabilitation is a complex intervention. Although there are guidelines and standards for practice, the National Pulmonary Rehabilitation Audit's from 2015 and 2017 demonstrated that practice varies across the country due to variances in service provision, funding, staffing and available resources as well as the varied patient populations. With this level of variance, it is difficult to determine the active ingredients by using the behaviour change taxonomy, but the COM-B system allows for individual patient presentations to be mapped, but also to look at specific interventions within Pulmonary Rehabilitation designed for behaviour change to be examined and reflected upon. For example, Pulmonary Rehabilitation sessions provide the opportunity for behaviour change within an environment in which they are motivated and through the programme of exercise and education patients are taught and shown their capability to change their behaviours.

The Behaviour Change Wheel and the COM-B system are tools used to be able to identify the elements of behaviour change but this thesis aims to look beyond behaviour change per se. The Theoretical Domains Framework was developed to provide a theory-based, comprehensive approach to identifying determinants of behaviour (Atkins *et al*, 2017). The Theoretical Domains Framework used in conjunction with The COM-B model provide a lens through which to investigate the key issues surrounding behaviour change in relation to self-management in relation to the causal mechanisms associated with previously recognised barriers and facilitators to successful behaviour change. To be able to change a behaviour, firstly, the

influences on the behaviour need to be fully understood (Atkins *et al*, 2017). The Theoretical Domains Framework allows for behaviours to be examined to understand and identify the mechanisms associated with determining the behaviour. Within Pulmonary Rehabilitation there has been a wealth of evidence regarding motivation and barriers and benefits to attending the course and yet there is a lack of evidence to outline strategies to tackle these issues. For successful support for self-management, it is important that the Healthcare Professional understands the individual's personal perceptions of their condition and how it impacts their lives from a patient-centred approach. Research in this area is developing and the value of investigating behaviours and behaviour change using behaviour change theory in relation to patients with COPD in Pulmonary Rehabilitation is becoming more widely recognised. Hanrahan *et al* (2022) published a protocol for a systematic review to investigate the behaviour change and physical activity interventions in patients with COPD. This thesis provides a contemporary approach to the complexities of behaviour change in patients with COPD within Pulmonary Rehabilitation.

The Health Belief Model and the Social Cognitive Theory both highlight the importance of the individual experiences of behaviours and perceptions of health behaviours. The Health Belief Model is mostly used in health promotion as well as health education (Hayden, 2013). The Health Belief Model first presented by Rosenstock *et al* (1988) outlines that health behaviour is determined by personal perceptions of their illness as well as an individual's beliefs of their illness. Illness perceptions can influence uptake and adherence in Pulmonary Rehabilitation (Harrison *et al*, 2013). The Health Belief model is relevant to this thesis as it draws on the importance of recognising individual's beliefs in disease management and how these beliefs influence what we do and how we behave. There are different concepts within The Health Belief Model which are thought to have an influence upon the individual's ability to maintain healthy behaviour. These include sufficient motivation or perceived seriousness, perceived susceptibility, perceived benefits and perceived barriers (Rosenstock *et al*, 1988). Additional concepts have been added to The Health Belief Model. These are: cues to action, motivating factors and self-efficacy (Hayden, 2013). In addition, The Social Cognitive Theory describes the influence of individual experiences, the actions of others and the environmental factors on individual health behaviours. It is the dynamic interaction

between people, their environment, and their behaviours (Bandura, 1991). The key concept is the emphasis on the importance of observing, modelling, and imitating the behaviours, attitudes, and emotional reactions of others. It is important to consider how both the environmental and cognitive factors interact to influence human learning and behaviour. Beliefs about consequences and self-efficacy are key concepts surrounding purposeful human behaviour within the social cognitive theory.

The concept and theory of motivation plays a key role in understanding health behaviours. Deci and Ryan formulated The Self-Determination Theory in 1985 which is a method of understanding and defining health behaviour in terms of motivation orientation alongside the influence of personality (Deci and Ryan, 2000). Motivation is at the centre of an individual's decision-making. Healthcare Professionals strive to motivate patients to improve their health outcomes. For example, a patient is openly encouraged to take their medications, to stop smoking and to become more physically active. However, an individual's motivation can vary considerably both in terms of the amount of motivation as well as the orientation of motivation (Deci and Ryan, 2000). Motivation and self-efficacy are also linked to illness perceptions (Harrison *et al*, 2013). The Self-Determination Theory outlines two key categories: internal motivation and external motivation, also referred to as autonomous and controlled regulation (Deci and Ryan, 2000). Individuals who are internally motivated genuinely want to complete the task or gain an achievement through personal interest and passion. Comparatively, individuals who are extrinsically motivated are often coerced or encouraged with rewards such as achieving good grades or having an incentive to complete the task. (Ryan and Deci, 2000) discuss that human beings are born naturally intrinsically motivated and seek interest in new experiences and challenges. However, this motivation can be easily disrupted by the conditions which surround us. For example, in long-term conditions management motivation can often be affected by the symptoms of the disease and disease progression as well as social influences, such as support mechanisms, socioeconomic background and relationships. Key elements to draw upon from this are the impact of the personal factors or mechanisms associated with motivation. This is important when approaching support for self-management and contributes to the value of adopting a patient-centred approach and personalised dialogue with the patients rather than a didactic hierarchical approach.

Williams *et al* (2002) discuss how 'internalisation' is the process by which people transition between controlled/extrinsic and autonomous/intrinsic motivation. This internalisation highlights a transition from a person having an external influence to change to adopting an internal desire to change. Behaviour change is a complex process which often has multiple influences and triggers. Behaviour change can be related to a variety of health behaviours such as smoking, adhering to a healthy diet or completing regular exercise. People are encouraged to take ownership of their behaviour change and to be able to personally identify with it to be successful at changing the behaviour (Williams, 2002). As Healthcare Professionals, it is important to consider and appreciate the different stages of behavioural change. This is essential when considering when the most suitable time to support self-management behaviour change is. When people are more inclined towards controlled motivation, they are more likely to need more support to internalise their behaviour change and to be able to become an autonomously motivated individual. Essentially, Healthcare Professionals need to encourage and facilitate autonomous motivation for individuals to internalise their behaviour change and in turn be more successful at sustaining their behaviour change. It is essential that a patient is supported along their whole journey. However, it is more common that patients do not have regular contact with Healthcare Professionals and often there is no continuity of messages from Primary to Secondary Care. Williams *et al* (2002) emphasise the value of facilitating an 'autonomy-supportive' environment as it has been shown to facilitate successful long-term behavioural change. It has been found that when GP's provide autonomous support and counselling, patients are more successful with smoking cessation (Williams *et al*, 2000). The influence of the referring clinician has been shown to have an impact upon adherence and uptake in Pulmonary Rehabilitation (Early *et al*, 2020). As Healthcare Professionals, it is essential to provide an autonomy supportive environment to facilitate positive direction towards behaviour change. Pulmonary Rehabilitation sessions provide an ideal opportunity to work alongside patients with an individualised approach to be able to support their autonomous support for successful behaviour change. Behaviour change conversations can be commenced from the start of the Pulmonary Rehabilitation journey.

Perceived competence is another aspect of the Self-Determination Theory which influences an individual with regards to goal achievement. Perceived competence has similarities with self-efficacy and there is a link between improved perceived competence and autonomous motivation (Fortier M *et al*, 2007). The role of goal setting has been shown to enhance perceived competence and self-efficacy (Driver *et al*, 2017). In chronic illness it has been found that by setting patients short-term rather than long-term goals, they are more likely to be able to make positive behavioural change (Rosenstock *et al*, 1988). Healthcare Professionals within Pulmonary Rehabilitation work closely with patients with goal setting. The focus should be on setting short-term goals and reviewing these regularly to emphasise success and influence behaviour change. A key aspect to consider when goal setting is to ensure that a collaborative conversation takes place to move away from a biomedical hierarchical model towards a more biopsychosocial model of engagement and support.

1.7. The impact of a global pandemic

After the focus groups and survey had taken place and the data had been collected, during the data analysis and writing up of this thesis, the Coronavirus 2019 (COVID-19) pandemic caused by Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2) spread globally and consequently it changed the landscape of healthcare both globally and nationally, especially within the NHS. The COVID-19 pandemic had a catastrophic influence on national and global healthcare. Guidance from the British Thoracic Society (BTS) advised that any activity that could be delivered remotely should be delivered remotely (BTS, 2020). With this, it also paved the way for innovation and permission to change the methods of delivery of many aspects of healthcare. Notably Pulmonary Rehabilitation had a strong focus. With the advice to aim to deliver remote models of Pulmonary Rehabilitation, previous research on assessing outcomes of home-based Pulmonary Rehabilitation were revisited with interest (Houchen-Wolloff and Steiner, 2020, and Hansen *et al*, 2020). The concept of behaviour change in relation to societal behaviours and healthcare became at the forefront of advances in behaviour change literature (Arora and Grey, 2020). This influenced the data analysis of the focus group discussion and survey responses in

relation to conceptualising behaviour change. It also provided a platform to be able to situate the findings from this thesis within contemporary healthcare provision. It is even more important now to understand the relationship between self-management and behaviour change and the impact upon successful Pulmonary Rehabilitation. For example, self-management behaviours include taking prescribed medication, learning how to monitor symptoms and manage exacerbations as well as learning about healthy eating, engaging in physical activity and reducing sedentary behaviours, and smoking cessation. In a post COVID-19 model of healthcare delivery when hybrid models of Pulmonary Rehabilitation are commonplace it is necessary to explore how behaviour change in relation to self-management can be achieved.

Service models were required to be re-designed and developed to fit within the changing environment and risks to both patients and Healthcare Professionals. In particular, those within respiratory care and rehabilitation services, were figureheads in the planning and development of these service models. From a personal perspective in clinical practice, I was at the forefront of re-designing the local Pulmonary Rehabilitation service as well as contributing to national guidance and documents for remote Pulmonary Rehabilitation. Pulmonary Rehabilitation programmes were required to suspend face-to-face group sessions and embark upon remote Pulmonary Rehabilitation models, notably, research interest in remote delivery models increased (Polgar *et al*, 2020, Cox, 2021, Houchen-Wolloff *et al*, 2021). COVID-19 provided an opportunity for Pulmonary Rehabilitation programmes to develop services on a dramatic scale, which had been long overdue. The pandemic had a huge impact upon COPD management on many levels including patients on existing caseloads and waiting lists, those awaiting a new diagnosis, those with an unstable condition or exacerbating, those with an existing condition who also contracted COVID-19 and additionally those with post-COVID syndrome or long-COVID who had new respiratory and rehabilitation needs. Post-COVID or long-COVID is described as when individual symptoms persist for more than 12 weeks after initial onset of COVID-19 (NICE, SIGN and RCGP, 2020).

During the first and second waves of the pandemic, there was not a vaccine for COVID-19. Essentially, there was a profound requirement for social behavioural change among the population. Social distancing, shielding, lockdown and quarantine were collectively termed as a 'behavioural vaccine' (Speight *et al*, 2020). Many individuals with chronic lung disease, in particular severe COPD, were advised to 'shield' to reduce the risk of being exposed to COVID-19 (PHE, 2020). Although this shielding advice was intended to protect vulnerable individuals, it had an impact on their psychological health (Philip *et al*, 2020) as well as behaviour change in relation to exacerbation management, medicines adherence and levels of physical activity as well as sedentary behaviours (Coronini-Cronberg *et al*, 2020). There was a reduction in hospital admissions and acute community care for patients with exacerbations during the period February to April 2020 (Sahanic *et al*, 2020). It is unclear if this was a true reflection on a reduction of exacerbations or whether individuals were just not seeking Healthcare Professionals' advice due to anxieties associated with contracting COVID-19 (McAuley *et al*, 2020). The changes made because of the pandemic will have a long-lasting impact on the landscape of the NHS (Alderwick *et al*, 2021). In particular, the structure of Pulmonary Rehabilitation services is likely to offer the intervention to larger numbers of patients due to programmes being more accessible. Thus, breaking down some of the previously noted barriers to adherence and uptake such as location, transport and rigidity of class times. The pandemic has shown that alternative models of delivery for Pulmonary Rehabilitation are possible and that a menu of options have the potential to address health inequalities and previously observed barriers to attending and completing Pulmonary Rehabilitation.

The traditional biomedical model of Pulmonary Rehabilitation programmes include educational content as well as supervised exercise. These education sessions should include but not be limited to covering topics associated with the self-management behaviours outlined above. Exercise capacity and health-related quality of life are measured as objective outcomes following Pulmonary Rehabilitation, but it remains unclear if behaviour change in relation to self-management behaviours is an outcome to achieve by the end of the Pulmonary Rehabilitation course and if so, how it can be measured. Or, if behaviour change is a mechanism to be able to achieve successful self-management. This thesis will explore the relationship between self-management,

behaviour change and causal mechanisms. The broader definitions of self-management previously outlined focussing on a paternalistic model of healthcare delivery are not congruent with modern healthcare in a post COVID-19 world and there is a call for a more patient-centred approach with a focus on behaviour change in self-management.

There was a call for reform within the NHS prior to the pandemic with clear structure outlined in the NHS Long-Term Plan (2019). Challenges associated with the pandemic such as a backlog of unmet healthcare needs, chronic staff shortages and substantial health inequalities within hospitals which are under significant strain have only compounded the pre-COVID-19 NHS landscape (Alderwick *et al*, 2021). The NHS Long-Term Plan remains the 'blueprint' for evolution in the NHS, but COVID-19 has impacted the delivery and pace of its implementation (Thorlby *et al*, 2021).

1.8. Chapter Summary

This chapter sets the context for this thesis by introducing the key concepts of the impact of COPD upon patients in relation to their physical and psychological health. It considers the role of self-management in relation to disease management and behaviour change. Pulmonary Rehabilitation as a treatment intervention has been introduced and discussed and the impact of the COVID-19 pandemic has been presented in relation to the landscape for future healthcare direction, with reference to models of Pulmonary Rehabilitation and behaviour change. Models of behaviour change have been described with reference to the relevance of self-efficacy and the Behaviour Change Wheel which will be expanded upon further throughout this thesis. Adherence, behaviour change and self-management in Pulmonary Rehabilitation will be more closely reviewed as themes within the Literature Review in Chapter 2.

Chapter 2: Literature Review

2.1. Overview of chapter

This literature review will be presented in a narrative style providing a critique of relevant and contemporary literature surrounding the themes of adherence, self-management and behaviour change within the context of Pulmonary Rehabilitation. As outlined in the Introduction Chapter, the issues associated with adherence problems have deeper inherent causes and the understanding of the influence of behaviour change and self-management is key to being able to tackle adherence problems.

This literature review was conducted using a Comprehensive Literature Review (CLR) structure (Onwuegbuzie and Frels, 2016). The seven steps model to achieving a comprehensive literature review will be presented and described in relation to this thesis.

2.2. Literature Review Methodology

A dynamic process was used throughout the review of the literature during this thesis. Literature was revisited at several time points due to the emerging nature of the topic. A literature review is often described as a linear process which is conducted before a primary research study. Although it often precedes the primary research study, it can be influenced by the research process, it is iterative, and the researcher can move between the literature and the primary research study (Onwuegbuzie and Frels, 2016). A literature review should be approached as a dynamic process which involves searching and reflecting on the new knowledge. Onwuegbuzie and Frels (2016) describe a Comprehensive Literature Review (CLR) as the process of conducting a literature review using a series of steps which are dynamic, comprehensive, and reflective. For this thesis, a comprehensive literature review allowed for a detailed review of existing literature which informed the direction of the primary research. It was also necessary to revisit the literature during this thesis with particular attention to how Pulmonary Rehabilitation services evolved during the COVID-19 pandemic.

The reflexive approach to this thesis lent itself to this approach of re-visiting the literature during the research process. This reflexive approach allowed for the emerging literature surrounding adherence, self-management and behaviour change to be reviewed and applied to the development of this thesis during the process of planning and conducting the data collection as well as completing the data analysis.

Onwuegbuzie and Frels (2016) developed the 'Comprehensive Literature Review Meta-Framework' which incorporates seven steps to undertake the literature review. Each of the steps comprise multiple components which may or may not influence other elements, in this way, the steps are multidimensional. The seven steps in three phases are outlined below:

Exploration Phase

1. Exploring beliefs and topics
2. Initiating the search
3. Storing and organising the information
4. Selecting / deselecting information
5. Expanding the search

Interpretation Phase

6. Analysing / synthesising information

Communication Phase

7. Presenting the comprehensive literature review report

The seven steps are situated within three phases: the exploration phase, the interpretation phase, and the communication phase. These phases will now be outlined with reference to its application in this thesis. The seven-step model approach to the comprehensive literature review can be used to inform multiple aspects of the research. For example, it can inform the background to identifying the research problem as well as considering the theoretical framework before even defining the

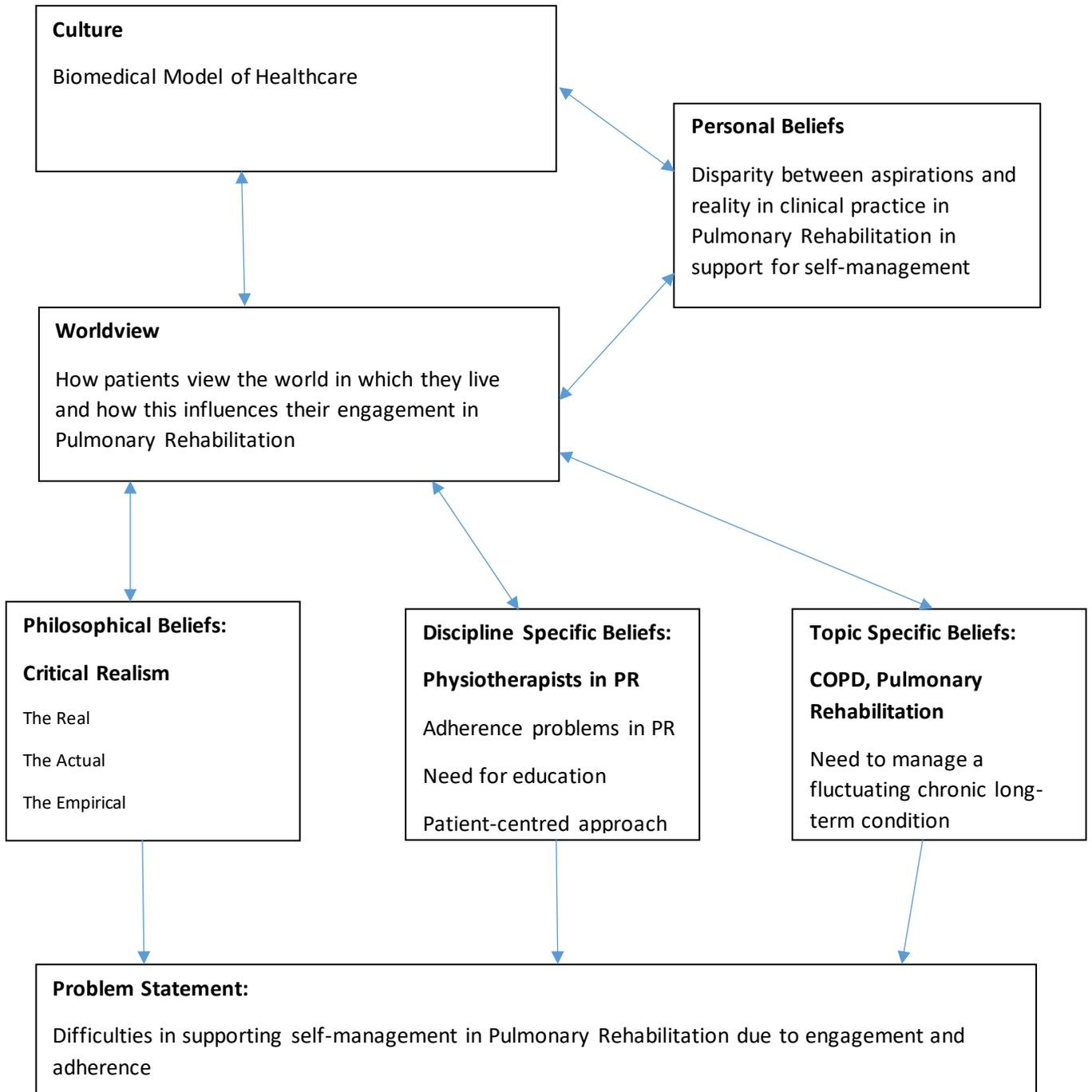
research question and conducting a literature review to be able to make evidence-based decisions on the primary research. As such, in this thesis the literature surrounding adherence to Pulmonary Rehabilitation formed the basis of the exploration phase in identifying the problem. A comprehensive literature review is a cyclical process in which the literature review is conducted several times and updated as theoretical thinking evolves (Onwuegbuzie and Frels 2016).

2.3. The Exploration Phase

Before embarking upon a literature review, the philosophical thinking, cultural beliefs as well as personal beliefs and worldview thinking should be considered. This thesis began with recognising a problem with adherence, completion, and attendance in Pulmonary Rehabilitation in clinical practice. This first sparked interest from a clinician perspective into investigating the issues surrounding adherence and researching the concept to be able to better understand the reasons why patient adherence is poor. This initial thinking around the concept of adherence was shaped primarily through the researcher's personal beliefs and experiences in clinical practice observing adherence problems and patterns within Pulmonary Rehabilitation. From personal experience the researcher recognised a disparity between approaches and attitudes towards achieving self-management. Issues surrounding adherence are well documented (Hogg *et al*, 2012, Keating *et al*, 2011). But it is necessary to understand the worldviews and beliefs of patients and their family members as well as Healthcare Professionals to understand the deeper issues surrounding adherence problems. Often cultural and psychosocial factors underpin issues surrounding adherence problems and qualitative approaches to understanding patients experiences and are required (Levack *et al*, 2018).

Within the seven-step model, the problem statement is 'based on an issue or dilemma or lack of knowing something within a general topic area linked to primary research' (Onwuegbuzie and Frels, 2016, p. 76). This forms the start of the Seven Step Model. However, at this point the problem statement is quite broad in nature but through the initial literature review the focus of the primary research can be refined. This literature review begins with a search focussed on adherence in Pulmonary Rehabilitation.

Figure 2.1: Step 1: Exploring beliefs and topics (Adapted from: Onwuegbuzie and Frels, 2016)



2.3.1. Search Strategy

A structured approach was applied to the literature search to ensure that all relevant studies were included. Boolean key search terms including 'pulmonary rehabilitation', 'adherence', 'COPD', and 'completion' were used within the initial search. Electronic databases searched were CINAL, Medline, PubMed, AMED, PedRo and Cochrane reviews. To be included, articles needed to have one of the key words within the title and abstract of the article. Articles also needed to be written in English, and studies were specific to patients with COPD and Pulmonary Rehabilitation. Both qualitative and quantitative study designs were included. Randomised controlled trials (RCT'S), systematic reviews, evaluation reports, case reviews, as well as qualitative based studies including interview, focus group and survey methodologies were also included. The aim of the literature review was to cast a wide net including both qualitative and quantitative research as well as policy and guidelines and grey literature, ensuring that literature underpinned theoretical models. This search was initially carried out between July and September 2014 and subsequent update searches were completed after this date at various time-points in 2019, 2021 and 2022 . Abstracts were reviewed after the initial searches and then full text articles were sourced for relevant articles. Articles which met the inclusion criteria were sourced, ones which were not relevant were discarded. These articles formed the basis of the initial critical thinking which informed the development of the aims and objectives of this thesis.

Once the literature searches were completed, all relevant papers were saved into a specific folder on a password protected USB stick. All relevant articles were printed out and categorised into a physical folder with subheadings for adherence, behaviour change and self-management. After reading each paper, notes were made onto post-it notes and attached to the front of each paper for easier reading when reviewing the literature to write up the findings together.

One of the key elements within the Comprehensive Literature Review model is that search terms can be revised and expanded upon to ensure the literature is thoroughly

researched. This cyclical process allows for a dynamic view of the existing literature and allows for deeper understanding of the topic area. The initial search results using 'adherence' as a key search term showed a shift in focus within the literature from purely barriers and facilitators to adherence towards considering the impact of adherence on long-term commitment to self-management and consequently a deeper questioning regarding the role of behaviour change. Following this, the key search terms were expanded to include: 'self-management', 'behaviour change' and 'behaviour'. This allowed for a more focussed search to determine the gap in the literature. The results of these searches combined will be presented in key themes in the 'interpretation' phase section of this review.

In addition to using a structured literature search using databases it is useful to use other methods of sourcing contemporary literature to be able to expand upon the search. Social media has become a way of obtaining relevant contemporary information on topics of interest. Therefore, the researcher sourced some relevant articles through freely accessible methods of people sharing papers on twitter. The researcher also reviewed the reference lists on key papers found to expand upon the bank of literature obtained through structured searches.

2.3.2. Evidence-base for Pulmonary Rehabilitation

Literature surrounding Pulmonary Rehabilitation has been developing since the first international report was produced by the European Respiratory Journal Working Group in 1992. This report promoted the value of Pulmonary Rehabilitation to Healthcare Professionals and described it as an effective intervention for patients with COPD, (Donner *et al*, 1992). The report outlined three primary aims of Pulmonary Rehabilitation:

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

This report encompasses the spectrum of elements which require attention in Pulmonary Rehabilitation: the physical, the psychological and the social aspects. The aim of this report was to drive forwards with recommendations for a multidisciplinary approach to Pulmonary Rehabilitation to ensure an individualised approach. Research and guidelines pre-dating this report were focussed on defining the components of the Pulmonary Rehabilitation programme, but the European Respiratory Journal Working Group recognised the need to develop recommendations to treat patients individually.

Spruit *et al* (2013), on behalf of The European Respiratory Society and American Thoracic Society (ERS/ATS), developed a consensus statement which mirrors the aims of the first report in 1992. Due to the strong evidence-base the consensus statement recommended that patients with COPD should be referred to Pulmonary Rehabilitation. They formed a collective and universal definition for Pulmonary Rehabilitation:

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

When the ERS/ATS definition was developed and published, the focus on studies was centralised around the effectiveness of Pulmonary Rehabilitation as an intervention for patients with COPD showing improvements in reducing ventilatory function decline and improving skeletal muscle function (McCarthy *et al*, 2015). These studies were primarily focussed on quantitative measures. For example, studies determining the optimal duration of a Pulmonary Rehabilitation course (Beauchamp *et al*, 2011) maintaining the benefits of exercise (Cockram *et al*, 2006) and understanding the effects on quality of life and physical improvements (Toms and Harrison, 2002, Persson *et al*, 2000 and Senjyu *et al*, 1999). The validity and reliability of the conduct

of field walking tests such as the incremental shuttle walk test and the 6-minute walk test (Eaton *et al*, 2006) were also key areas of investigation. However, despite the proven evidence for its effectiveness, adherence to attending a programme remained poor (Arnold *et al*, 2006, Bjoernshave *et al*, 2011, Fischer *et al*, 2007 and 2009). Understanding the issues surrounding adherence then became the focus of literature related to Pulmonary Rehabilitation. This required a shift towards a more qualitative approach to research surrounding adherence and attendance.

Earlier studies determining the barriers to attending Pulmonary Rehabilitation focus around the predominantly objective barriers such as transport, mobility impairments, programme location, lack of social support as well as exacerbations (Hayton *et al*, 2013). There seemed to be a shift in focus in subsequent studies into understanding the issues surrounding adherence problems from an individual perspective. For example, considering whether the patient ascribed value to Pulmonary Rehabilitation and whether they perceived benefits from attending (Keating *et al*, 2011a). As well as understanding the patient's psychological factors such as confidence in their abilities, how they perceive their own disabilities and their beliefs regarding the benefits of attending (Fischer *et al*, 2007).

There has been a plethora of studies into the barriers to adherence in Pulmonary Rehabilitation (Keating *et al*, 2011a, Fischer *et al*, 2007 and 2009, Garrod *et al*, 2006 and Bulley *et al*, 2009). Much of the literature is qualitative in nature, including case reviews, retrospective analysis and interviews or questionnaire-based research methods. Several studies including systematic reviews (Milner *et al*, 2018, Keating *et al*, 2011b) have been completed to determine these barriers. Whilst quantitative methods are often considered of higher quality evidence, the subject of adherence and behaviour change in self-management required a detailed analysis and synthesis of qualitative literature to understand the complexities from a patient and Healthcare Professional perspective. Commonly, aspects such as transport, lack of perceived benefit, psychological status, disease severity, social support and the influence of the referring clinician have all been cited as key factors associated with poor adherence in Pulmonary Rehabilitation. There is a complex interplay between physical and

psychological barriers from a patient perspective as well as the impact of the referring clinician on adherence to Pulmonary Rehabilitation. Arnold *et al* (2006) conducted interviews with patients who had been invited to attend Pulmonary Rehabilitation. One of the key findings with this study was the influence of the referring doctor on the outcome of adherence, this was shown to have both a positive and negative impact on the outcome. In this paper, the referrer is described as 'the referring medical practitioner' initially but then mostly referred to as 'their doctor'. This reflects a medicalised model of care where patients have a trusting relationship with their doctor in relation to the medical management of their COPD. There are many different Healthcare Professionals whom the patient may encounter and may or may not be referred by them. However, Arnold *et al*, (2006) suggest that the patient often seeks reassurance and guidance from a doctor who they trust. The biomedical model of care is a key element to understand and to be able to recognise its influence on the success of behaviour change in self-management.

An American randomised controlled trial was carried out to evaluate the effectiveness of an exercise adherence intervention (Steele *et al*, 2008). The exercise intervention included establishing a home and community-based programme on walking and advice on exercise equipment and monitoring. Whilst this study showed that the exercise adherence intervention improved adherence to exercise, it is important to note that the exercise intervention was after patients had completed Pulmonary Rehabilitation. It is difficult to draw comparisons with adherence to Pulmonary Rehabilitation as patients who complete Pulmonary Rehabilitation are likely to be more motivated to continue exercises after completion (McGrain *et al*, 2015). Despite the improvements in exercise capacity, these effects diminished over time. This highlights the need to explore how to maintain benefits gained in relation to behaviour change in the long-term.

Over the last 15 years there has been huge expansion and progression within the literature surrounding adherence in Pulmonary Rehabilitation. The national agenda surrounding long-term conditions management (2010) and the implementation of the NHS Long-Term Plan (2019) have provided political platforms for the development of

long-term behaviour change in respiratory disease and notably within self-management in Pulmonary Rehabilitation. Within the Long-Term Plan there is a growing focus on long-term behaviour change and non-pharmacological management of chronic respiratory disease. Initial studies focussed on identifying the reasons for poor adherence and common issues were related to knowledge of the benefits of Pulmonary Rehabilitation from both the referrer and the patient (Milner *et al*, 2018). Keating *et al* (2011a) also found that patient's adherence was due to a lack of perceived benefits as well as having difficulties getting to a programme due to physical limitations, transport mode and cost and the impact of exacerbations. Keating *et al* (2011a) suggested that at that point there was a lack of evidence regarding the barriers to attending Pulmonary Rehabilitation. However, since their paper was written there have been numerous studies looking into the barriers and facilitators to attending Pulmonary Rehabilitation.

The value of Pulmonary Rehabilitation is well documented and evidenced. It is the highest value treatment for COPD but there are also the issues surrounding attendance and adherence. Despite this there is limited capacity on programmes but at the same time only a relatively small proportion of patients are referred into programmes (McCarthy *et al*, 2015). These aspects pose scope for development in Pulmonary Rehabilitation literature. Following the National Asthma and Chronic Obstructive Pulmonary Disease Audit Programme (NACAP) snapshot audits and now the continual audit, there is a demand for improved quality and rate of referrals, increased knowledge of Pulmonary Rehabilitation from the referrers, discovering alternative ways of delivering Pulmonary Rehabilitation to improve access for patients as well as recognising that one size does not fit all. Research questions in Pulmonary Rehabilitation are no longer focussed on the effectiveness of Pulmonary Rehabilitation but more associated with 'how should Pulmonary Rehabilitation be delivered to patients with COPD?' and 'which components form the basis of the success of Pulmonary Rehabilitation programmes?' (Troosters *et al*, 2005, p. 20). Building upon this new direction for Pulmonary Rehabilitation research, a key aim for research within this field is to bridge the gap between the strong evidence base for its effectiveness and the issues associated with its implementation in clinical practice (Steiner and Roberts, 2016). A recent systematic review (Wageck *et al*, 2021) explored the

characteristics of Pulmonary Rehabilitation programmes, primarily focussed on post-exacerbation Pulmonary Rehabilitation. Forty-three percent of studies included in this review delivered exercise alone, this was shown to be associated with a higher chance of readmission compared to programmes which included education as well as exercise components. There was minimal consideration to the content and delivery of the education in the studies reviewed. It is suggested that self-management education should form part of the educational content but it was not clear if behaviour change interventions were included as part of the Pulmonary Rehabilitation programme. This review recognises that the inclusion of education on self-management is an important factor in reducing hospital readmissions but there is a lack of analysis of the educational content of those studies included in the review which have education as part of the Pulmonary Rehabilitation programme. This demonstrates that there are still difficulties in defining the content and delivery of self-management education as well as implementing behaviour change interventions. This systematic review recognises that the studies used within the review were too heterogenous to be able to conduct a meta-analysis on defining the characteristics which influenced a positive outcome following Pulmonary Rehabilitation. This therefore contributes to the understanding that components and characteristics of Pulmonary Rehabilitation vary significantly in clinical practice which makes analysis difficult.

2.4. The Interpretation Phase:

The themes of adherence, self-management and behaviour change have been apparent from the outset and inception of this thesis. These areas shaped the development of this thesis and reflect the journey of investigation. Initial observations in clinical practice centralised around problems associated with adherence, therefore the literature search began with a focus on adherence. This quickly progressed to recognising the impact of adherence problems on self-management which consequently led to understanding the inherent links between behaviour change and self-management. Therefore, the literature from all the searches will now be presented in relation to key areas of adherence, self-management, and behaviour change.

2.4.1. Theme 1: Adherence

Cox *et al* (2017) provided a summary of the relevant literature with their large systematic review using 48 studies, including qualitative (12), quantitative (18), survey based (14) and mixed methods studies (4) from a global representative sample. The findings from this systematic review focussed on the barriers and enablers of referral, uptake, attendance and completion of Pulmonary Rehabilitation for people with COPD. There have been previous studies into the factors affecting adherence and successful completion of Pulmonary Rehabilitation. However, this is the first systematic review to look purely at the barriers from a system, policy and patient/provider point of view. They mapped their findings to the Theoretical Domains Framework (Atkins *et al*, 2017). The Theoretical Domains Framework synthesises several behaviour change theories including common aspects such as knowledge, skills, beliefs, goals and behavioural regulation as well as aspects related to social and environment influences. They found that the 'environment' including aspects such as waiting time, burden of illness, travel, transport and health system resources were the most cited issues related to barriers and enablers to successful Pulmonary Rehabilitation. Other commonly cited influences included 'knowledge' which includes clinician knowledge of the referral process and patient understanding of Pulmonary Rehabilitation and 'beliefs about consequences' were also cited including aspects related to beliefs regarding the role and safety of exercise and expectations of rehabilitation outcomes. This systematic review is significant to outline the key issues related to barriers and enablers to successful Pulmonary Rehabilitation. It confirms aspects from the previous literature relating to barriers from both the patient and healthcare professionals and highlights the need for further investigation into developing interventions targeting behaviour change. This review was particularly pivotal in developing understanding regarding barriers and enablers in Pulmonary Rehabilitation as it included both qualitative and quantitative studies therefore the data included in this systematic review is from a strong evidence base.

Issues with adherence have been recognised for many years, an early example of this is in a paper addressing adherence problems in both Cardiac and Pulmonary Rehabilitation. Emery (1995) investigated adherence in Cardiac and Pulmonary

Rehabilitation and considered strategies to improve adherence. The paper highlights that there are three areas to focus on, these include: patient characteristics, programme characteristics and environmental factors. Particularly in relation to environmental factors, the influence of 'addictive behaviours' such as smoking, drinking alcohol and overeating on success during rehabilitation are noted. These addictive behaviours, particularly smoking in the COPD patient population have an impact on the patients' likelihood of completing Pulmonary Rehabilitation. The education sessions within the Pulmonary Rehabilitation programme are designed to empower self-management and there is an emphasis on smoking cessation which generally starts at the first assessment and continues throughout the programme. The Pulmonary Rehabilitation programme is an ideal time to stop smoking as they receive twice weekly support when attending the group which could help facilitate success. Literature as well as clinical practice in Pulmonary Rehabilitation still recognises these barriers and there remain challenges with implementing behaviour change.

To explore the factors associated with adherence problems within the literature, themes were generated to conceptualise the key issues. In relation to adherence literature, the key themes included the psychological influence of COPD, health status including disease severity and social factors including support networks.

2.4.1.1 Subtheme: The Psychological Influence of Chronic Respiratory Disease

Within the earlier literature surrounding adherence, the influence of anxiety and depression was commonly cited as a barrier to attending and completing Pulmonary Rehabilitation. Keating *et al* (2011b) completed a systematic review to investigate reasons for poor attendance in Pulmonary Rehabilitation. Eleven studies were included in the review but with a bias towards quantitative research methods which was not uncommon at this time-point within the Pulmonary Rehabilitation research literature. A quantitative bias limits an in-depth exploration of the patient's voice and is less aligned with a psychosocial model of healthcare. Two of the eleven studies indicated that depressed patients were more likely to drop-out of pulmonary rehabilitation and that depression had been used to predict non-completion in some

patients. On reviewing one of these studies by Sabit *et al* (2008), the influence of depression is not actually discussed in detail. Although, their retrospective analysis of patients who attended on the Pulmonary Rehabilitation course did use the St George's Respiratory Questionnaire to assess depression. Within the article there is no reference to the influence of depression among the non-attender population. In addition, the other study by Fan *et al* (2008) assessed depression and found that depressed and anxious patients were less likely to complete rehabilitation. Fan *et al* (2008) also found that patients even with mild depressive symptoms were less likely to complete the Pulmonary Rehabilitation programme. This highlights that anxiety and depression have an influence on adherence irrespective of the extent of the anxiety and depression. In their systematic review, Keating *et al* (2011b) attribute many of the themes associated with non-attendance in Pulmonary Rehabilitation to objective issues such as transport, class timings and locations as well as factors such as anxiety and depression. These issues are in keeping with previous research into the barriers to attendance at Pulmonary Rehabilitation, such as living alone, smoking status and disease severity which influence the individual's ability to access a Pulmonary Rehabilitation course (Hayton *et al*, 2013). Further advancement in the literature is required to be able to explore the individual patient factors such as knowledge, beliefs, experience and perceptions of both patients who attend or drop-out of a Pulmonary Rehabilitation programme.

In keeping with previous early literature into depression and its impact on adherence, Garrod *et al* (2006) investigated characteristics of patients who complete Pulmonary Rehabilitation compared to those who dropped out. The aim of this study was to identify features of COPD which were prognostic with short and long-term success or failure in Pulmonary Rehabilitation. The findings suggest that depression was a risk factor and indicator of poor attendance and dropping out and patients with depression were twice as likely to drop out of Pulmonary Rehabilitation as patients who were not depressed. In addition, Heerema-Poelman *et al* (2013) discuss how depression at baseline assessments can be an indicator of poor attendance at Pulmonary Rehabilitation. They note that depression can be associated with a lack of interest and poor motivation to engage in exercise, which is therefore a predictor of poor or non-adherence. On the other hand, Bjoernshave *et al* (2011) used a prospective

follow-up study to investigate how baseline characteristics influenced Pulmonary Rehabilitation completion. They found a higher percentage of patients had depression in the completer group compared to the drop-out group. They attribute this to that fact that some patients envisage that Pulmonary Rehabilitation will improve their depression. Although it should be noted that the percentage of patients reporting depression in the completer group compared to the drop-out group was not statistically significant.

Arnold *et al* (2006) interviewed twenty COPD patients who either attended or did not attend the Pulmonary Rehabilitation programme to explore their experiences on being referred to Pulmonary Rehabilitation programmes. This was to determine reasons for poor uptake. One of the prime findings of this study focussed on the influence of the referring clinician on the successful outcome of attending Pulmonary Rehabilitation. A secondary finding was that some people found improvement in their depression from attending the programme. They recognised that many people with COPD have depression and that this can be improved during the programme by the sense of achievement from exercising beyond their baseline exercise capacity. Exercise can improve 'self-efficacy' which can empower the patient to continue to exercise and improve their exercise tolerance and even lower mortality rate. This study began to look at the influence of the referring clinician on the successful outcome in Pulmonary Rehabilitation. The influence of the referring clinician has been explored further (Cox *et al*, 2017) and now forms part of the understanding of the complex web of interactions between Healthcare Professionals and patients in relation to successful behaviour change in Pulmonary Rehabilitation, particularly at the point of referral.

Bulley *et al* (2009) interviewed patients who had accepted the referral to the Pulmonary Rehabilitation programme but who had not yet attended. Although the data from these interviews provides valuable information, it is necessary to consider the selection bias of the sample in that these patients had accepted a referral. The patients interviewed had feelings of fear and panic at the thought of exercise which increased their anxiety and depression. Therefore, it is important to explain the role of exercise in Pulmonary Rehabilitation and reassure the individual before they start

rehabilitation to reduce anxiety and depression. A component of Pulmonary Rehabilitation is teaching patients about breathlessness, how to cope with it and how to pace themselves so they can manage their breathlessness. Education plays a key role in Pulmonary Rehabilitation (Effing *et al*, 2007 and Blackstock *et al*, 2018), particularly in breathlessness management which in turn will have an influence on the patient's anxiety and depression. Anxiety and depression has been investigated more recently in a systematic review by Gordon *et al* (2019). This systematic review reviewed randomised controlled trials comparing levels of anxiety and depression with patients with COPD who attended Pulmonary Rehabilitation compared to usual care. The main findings were that Pulmonary Rehabilitation has a significant impact on reducing levels of anxiety and depression in patients with COPD. Anxiety and depression in COPD can be influenced by symptoms such as breathlessness which impacts an individual's physical activity levels. This systematic review suggests that Pulmonary Rehabilitation can positively influence anxiety and depression but it is not clear which components of the Pulmonary Rehabilitation programme influence the improvement in anxiety and depression scores. Pulmonary Rehabilitation programmes across the United Kingdom vary in content and delivery. The Pulmonary Rehabilitation accreditation scheme aims to improve consistency and quality of Pulmonary Rehabilitation programmes but many of the studies included in the Gordon *et al* (2019) systematic review were conducted prior to the introduction of the Pulmonary Rehabilitation accreditation scheme. This systematic review, by nature, only includes randomised controlled trials which are likely to be more quantitatively-led so there is a potential that there is a lack of quantitative data regarding the patient experiences of anxiety and depression.

Harris *et al* (2008) interviewed patients with COPD to see what their opinions were on attending Pulmonary Rehabilitation, only one of the patients had previously attended a course. They found that those with a higher Hospital Anxiety and Depression Score (HADS) (Zigmond and Snaith, 1983) were likely to be more breathless and have a greater fear of exercise which could influence their decision to attend a Pulmonary Rehabilitation course. The patients who scored higher on the HADS did not necessarily have more severe disease. Fear avoidance is a common problem in patients with COPD and education on managing their fears plays a key role in

promoting exercise. This is further explored by Harrison *et al* (2017) in a mixed methods study investigating the self-conscious emotions among patients with COPD. Key themes include grief and loss, blame, concealment and worry about the future. These themes encompass elements which contribute to anxiety and depression in COPD and the impact upon how an individual experiences the world with their condition.

Hogg *et al* (2012) also found that depression was a predictor of poor attendance and drop-out, but this was further increased by deprivation and worse disease severity. Social deprivation and poverty have also been attributed to worse disease severity or poorer outcomes (Porta *et al*, 2018). They note that although depression was an indicator, it only accounted for 10% of their drop-outs and there needs to be further analysis into reasons for poor attendance from a patient's perspective. This further demonstrates the need for and value in exploring patient's thoughts and views, particularly among those who don't accept a referral into Pulmonary Rehabilitation. Anxiety and depression play a key role in influencing the patient's ability to attend and complete a Pulmonary Rehabilitation programme. It is a recognised barrier to success in Pulmonary Rehabilitation. There is an association between anxiety and depression and behaviour change. Anxiety and Depression influences a patient's ability to successfully complete Pulmonary Rehabilitation therefore they are less likely to be supported with behaviour change for self-management. Therefore, more time should be invested into methods of assessing and treating anxiety and depression in relation to exercise among patients with COPD.

Milner *et al* (2018) conducted a literature review into the rate of referral to Pulmonary Rehabilitation by Healthcare Professionals and the barriers and enablers to referral perceived by Healthcare Professionals. Previous research had focussed on barriers from a patient and organisational point of view but the systematic review by Cox *et al* (2017) paved the way for further focus on the importance of investigating the influence of Healthcare Professionals' behaviours and in particular the quality of the referrals from the start of the patient journey in Pulmonary Rehabilitation. Cox *et al* (2017) focussed on the barriers and enablers from a Healthcare Professional point of view at

the point of referral. Enablers presented in this study included having training in Pulmonary Rehabilitation as well as knowledge and experience in Pulmonary Rehabilitation clinics as well as local awareness sessions and effective referral processes. Many of the barriers highlighted within this study were around factors such as lack of knowledge of Pulmonary Rehabilitation or the referral process, as well as low awareness of local Pulmonary Rehabilitation services. The influence of the referring clinician on the outcome of Pulmonary Rehabilitation has been cited as an influencing factor. A key finding was a lack of belief that patients could successfully gain benefits from Pulmonary Rehabilitation and that some would be unable to change their behaviour and take responsibility for their own self-management. The influence of Healthcare Professionals' behaviours is a key starting point in understanding the complex phenomenon of behaviour change with self-management, this study highlights issues from the point of referral but a necessary next step is to understand the influence of Healthcare Professionals' behaviours within Pulmonary Rehabilitation services. This systematic review shows a representative sample of papers ranging from 1999 to 2016 from globally diverse countries.

2.4.1.2 Subtheme: Health Status including Disease Severity

This section will refer to the literature on the impact of exacerbations, health status, and the influence of smoking and lung function on adherence to attending a Pulmonary Rehabilitation programme.

Exacerbations and hospital admissions are common in patients with COPD and account for poor attendance and drop-out from pulmonary rehabilitation programmes. Exacerbations of COPD account for the second largest cause of emergency hospital admissions. Patients admitted with COPD account for over 1 million 'bed days' per year (NICE, 2010). Many patients drop-out or are unable to complete Pulmonary Rehabilitation programmes due to an acute exacerbation and / or hospital admission. Pulmonary Rehabilitation programmes are designed to facilitate self-management and recognition of exacerbations to reduce healthcare utilisation (BTS, 2013).

Strategies to influence attendance and drop-out were previously investigated by Graves *et al* (2010). They compared a 'group-opt in' cohort to a non-'group-opt in' cohort and found that a similar number of patients dropped out due to illness this ranged from 6.8%-8.5%. The group-opt in session was aimed at reducing drop-out rates by using a face-to-face contact with a Physiotherapist and Clinical Psychologist. Their role was to introduce the importance of self-management but in a group environment alongside an explanation of the course. Their findings suggest that the group-opt in session did not change the exacerbation rate so did not reduce the number of patients dropping out due to illness, but they did improve upon the drop-out rates for other reasons such as declining attendance and did not attend (DNA) rates. This suggests that the treatment burden for COPD is often high which can influence their ability to commit to a Pulmonary Rehabilitation course. Exacerbations can influence adherence in Pulmonary Rehabilitation even in motivated patients. However, it has also been shown that by attending Pulmonary Rehabilitation can improve an individual's knowledge base on self-management strategies such as recognising an exacerbation and commencing on treatment as per their personal action plan (Bourbeau *et al*, 2004).

Keating *et al* (2011a) interviewed patients who had dropped out of the Pulmonary Rehabilitation programme and found that 24 out of 37 patients dropped out due to illness. Eight of these were due to COPD related illness and exacerbations and the remaining were due to other medical co-morbidities. This also highlights the fact that many patients who attend Pulmonary Rehabilitation have other co-morbidities which may limit their ability to participate. Keating *et al* (2011a) discuss the importance of allowing flexibility to the patients who drop out due to illness to allow them to continue or re-start the programme in the future. This suggests that a different programme structure, such as the rolling programme model would benefit this patient group.

Keating *et al* (2011b) also conducted a systematic review of the literature into what prevents people attending Pulmonary Rehabilitation. They evaluated research studies into two categories of non-attendance and non-completion. Eight of the eleven studies found reported that illness and co-morbidities were associated with poor

completion rates. These studies were a mixture of qualitative and quantitative studies. A common topic of discussion within the literature regarding what constitutes the definition of completion. There doesn't appear to be a consensus on how many sessions a patient should have attended to be deemed as 'completed' or conversely how many sessions missed would be considered as a 'drop out'. Selzer *et al* (2012) used a 50% cut off as being classed as a drop out if they attended less than 50% of the sessions. There is a large body of literature studying the predictors or barriers to completion, but they often don't include a definition of what constitutes completion (Hogg *et al*, 2012). It is difficult to draw conclusions within the adherence literature when it is unclear on how 'completion' or 'drop out' are defined.

Sabit *et al* (2008) completed a retrospective analysis of case notes for patients on the Pulmonary Rehabilitation programme. One of their parameters of data collection was to investigate number of COPD exacerbations requiring hospital admission in the preceding 12 months. This showed a positive correlation between less hospital admissions and better attendance rates. Selzer *et al* (2012) shows the high impact of exacerbations on completion rates. They retrospectively evaluated baseline data from 814 patients who were referred for Pulmonary Rehabilitation. Six hundred and seventy-eight patients completed the programme and 136 were non-completers. Of these 136 non-completers; 27% were due to respiratory illness and 28% were due to non-respiratory illness/injury. Therefore, 55% of the non-completers were due to illness of some kind.

Similarly, an early example of recognising issues surrounding adherence and behaviour change was Young *et al* (1999) who compared the 'adherent' group and 'non-adherent' group within a four-week pulmonary rehabilitation programme. They found that 55 patients were 'adherent' compared to 36 patients who were 'non-adherent'. This group comprised of patients who either declined or who started the programme and dropped out. Of the 36 patients in the 'non-adherent' group 30 declined to take part and 6 dropped out. Six of the 36 in the 'non-adherent' group were due to either exacerbation of COPD, other medical conditions or they considered themselves too ill to be able to participate. Young *et al* (1999) indicate that patients

who are poorly adherent to Pulmonary Rehabilitation are also likely to be poorly adherent to other health and behavioural management interventions. This suggests that to improve outcomes of adherence and completion in Pulmonary Rehabilitation, a deeper understanding of the behavioural elements is required.

These studies indicate that respiratory illness and other comorbidities can significantly affect the patient's ability to either start a Pulmonary Rehabilitation programme or to be able to complete the course. It suggests that strategies at Pulmonary Rehabilitation assessment should be directed towards improving respiratory health and assessing the patients' ability to participate in Pulmonary Rehabilitation with regards to other health conditions. Patients with COPD commonly have other chronic conditions and it has been suggested within some of these papers that other approaches to Pulmonary Rehabilitation should be considered to accommodate these patients and support them through Pulmonary Rehabilitation. Examples of these strategies include a different programme structure to allow for illness such as the rolling programme structure or home-based Pulmonary Rehabilitation with supervision and remote monitoring.

Fischer *et al* (2009) studied drop-out rates and attendance at Pulmonary Rehabilitation and to consider how patient's perceptions of their illness could influence their potential to drop-out or have poor attendance. They found that patients who were current smokers, lived alone and were female were more likely to have poor attendance. Both Fischer *et al* (2009) and Young *et al* (1999) support the theory that patients who are poorly adherent to a Pulmonary Rehabilitation programme are likely to be poorly adherent to other management interventions such as stopping smoking as well as medical management. Young *et al* (1999) completed a cross-sectional study of COPD patients referred for Pulmonary Rehabilitation and found that 28% of the non-adherent group of patients were current smokers compared to only 8% of the adherent group. This was alongside other variables such as living alone, living in rented accommodation, and being widowed or divorced. Garrod *et al* (2006) also found that patients with a higher smoking history were more likely to drop out of Pulmonary Rehabilitation. These elements suggest a 'type' of patient who are less likely to

succeed on a Pulmonary Rehabilitation programme; those who continue to smoke, those who live alone and those with a lower socioeconomic background. These are important elements to consider when thinking about supporting behaviour change.

Keating *et al* (2011b) completed a systematic review of the literature which found two studies which support the theory that current smokers were more likely to be poor attenders. Sabit *et al* (2008) completed a retrospective study of patients who were attending a pulmonary rehabilitation programme. They found that current smokers were more likely to be poor attenders and not complete pulmonary rehabilitation. Fifty-seven percent of poor attenders were smokers, compared to 18% of attenders. In their discussion they attribute this finding to the theory that people who continue to smoke are less pro-active and are poorly motivated with self-management. They also consider that heavy smokers may find it difficult to refrain from smoking for the duration of the session. Selzer *et al* (2012) analysed data from patients attending pulmonary rehabilitation. They also found that there was a higher percentage of patients who smoked in the drop-out group compared to the completer group. Twenty-six percent of completers were smokers, compared to 49% of drop-outs. Smoking status appears to be a strong indicator of both poor attendance and drop-out rates. Some studies have suggested that this is linked to the behavioural aspect of smoking and the patient's poor ability to adapt to change and adhere to self-management strategies. Pulmonary rehabilitation programmes emphasise and support smoking cessation, although stopping smoking is not an inclusion criteria for attending Pulmonary Rehabilitation.

Spirometry is used with COPD patients to analyse lung function and determine disease severity and influences medical management. Patients with a lower FEV₁ (forced expiratory volume in the first second of exhalation) is a common indicator of disease severity. Patients should have their lung function assessed regularly and it is commonly part of the pre-course assessment. The Medical Research Council (MRC) scale of breathlessness is also used to determine disease severity. The British Thoracic Society (BTS) Pulmonary Rehabilitation guidelines (2013) suggest that patients with an MRC of 3 and above should be referred for pulmonary rehabilitation.

However, some patients with an MRC of 1-2 are often considered if their breathlessness is affecting their daily life.

Bjoernshave *et al* (2011) completed a prospective follow-up study of COPD patients and found that patients who were not offered Pulmonary Rehabilitation had a higher forced expiratory volume in one second (FEV₁) compared to those who completed Pulmonary Rehabilitation. This is because only patients with a FEV₁ less than 50% of their predicted values were offered Pulmonary Rehabilitation. Despite the lower FEV₁ in the Pulmonary Rehabilitation group, their six-minute walk test distance was longer than the COPD patients who were not offered Pulmonary Rehabilitation. This indicates that patients with poorer lung function can benefit from Pulmonary Rehabilitation in terms of increasing their exercise capacity and dyspnoea.

Fischer *et al* (2007) conducted interviews with patients who attended the Pulmonary Rehabilitation programme. The patients who were interviewed were asked about their beliefs and goals with regards to Pulmonary Rehabilitation and they were also asked about potential reasons why people may drop out of the course. The patients had completed Pulmonary Rehabilitation and therefore their reasons for drop-out are hypothetical. However, they found that adherence was higher in patients who perceive their illness to be more severe. The individual beliefs and goals are important to understand when supporting patient-centred behaviour change in self-management. They attribute this to patients wanting to take action to improve their symptoms and therefore, if their disease is more severe or if they perceive it to be then they are more likely to complete the Pulmonary Rehabilitation programme. Selzer *et al* (2012) also found that patients with a higher FEV₁ were more likely to complete Pulmonary Rehabilitation. They suggest that exercise impairment and disease severity does not necessarily impact upon adherence, but the patient's perception of their illness has a larger influence on whether they complete the Pulmonary Rehabilitation programme.

Heerema-Poelman *et al* (2013) investigated adherence to a maintenance Pulmonary Rehabilitation programme and found that FEV₁ was one of the key indicators of poor adherence. It is thought that alongside greater disease severity, FEV₁ indicated that patients were more limited by their breathlessness and were therefore more likely to drop out of Pulmonary Rehabilitation. If patients are more limited by their breathlessness, they are more likely to have a greater impairment to exercise and are expected to have more frequent exacerbations. In contrast Young *et al* (1999) found that physiological parameters such as FEV₁ did not influence the likelihood of the patient being non-adherent. In their study, most of the patients had severe impairment in their lung function and this was not associated with an increase in poor adherence. The limiting factors within this study were more related to social isolation and less compliant with other healthcare activities. One of the key differences with these studies is that the Heerema-Poelman *et al* (2013) study investigated a maintenance programme compared to the Young *et al* (1999) study which investigated a 4 -week Pulmonary Rehabilitation programme. Patients with more severe disease may experience difficulties in continuing a maintenance programme for a longer duration compared to the shorter duration of the 4-week intervention in the Young *et al* (1999) study.

2.4.1.3 Subtheme: Social Factors and Support Networks

Other factors which have been shown as indicators of poor adherence include transport, lack of social support/living alone and the influence of the referrer. It has been thought that living alone and having a lack of social support are associated with poor adherence to Pulmonary Rehabilitation as well as other medical interventions (Young *et al*, 1999). Keating *et al* (2011a) discuss that some patients would prefer a home exercise programme compared to a community exercise group as it avoids problems with transport and patients often feel more secure in their home environment. Some studies have found a greater impact upon a patient's perceptions of the value of Pulmonary Rehabilitation from the influence of the referrer. Arnold *et al* (2006) interviewed patients who had been through the Pulmonary Rehabilitation programme and found that the patients generally had a positive perception of Pulmonary Rehabilitation from their referrer. However, some found negative

influences from the referrer as they were given the impression that it was a last attempt to help them or that it may or may not help them. Bulley *et al* (2009) also appreciate the value of positive enthusiasm from the referral and consider how knowledge and information on the benefits of Pulmonary Rehabilitation are key to improving patient adherence.

COPD is a chronic condition which often involves family members to support the patient in their daily lives. Healthcare Professionals must also recognise the impact of the disease upon the family members. Within adherence to self-management, the relationship between the patient and Healthcare Professional is important to understand but it is also crucial to understand the relationship between the patient and their family members or carers or social support group. Some family members may inadvertently influence the patient's independence and therefore their sense of self-efficacy but doing daily tasks for them rather than supporting effective adaptations so that the patient can still complete tasks themselves (Bourbeau *et al*, 2004). (Bourbeau *et al* (2004) advocate that Healthcare Professionals should tailor educational content so that the patient can develop and strengthen their sense of self-efficacy. It is not only the patient's sense of self-efficacy but also the influence of the social support mechanisms and their view of their abilities. These specific mechanisms warrant further investigation.

The landscape of issues surrounding adherence has evolved over the past 10-15 years. Initial studies investigating adherence problems identified barriers relating to the patient as the cause of the problem such as addictive behaviours, transport, location and exacerbations. Whilst these issues are still relevant, the literature within this area has evolved to focus more on a deeper understanding of the individual perspectives in relation to attending Pulmonary Rehabilitation. However, it is important to bear in mind that the literature surrounding adherence problems and initial studies into service models such as rolling programmes and home Pulmonary Rehabilitation were conducted before the COVID-19 pandemic. The landscape of healthcare has changed considerably in the last 2 years and research into the area of adherence and success of Pulmonary Rehabilitation should be revisited considering

a post COVID-19 world in healthcare. For example, home-based Pulmonary Rehabilitation has previously been investigated (Hunter *et al*, 2006, Bollen *et al*, 2014 and Donesky-Cuenca *et al*, 2007) but often the outcomes weren't superior to centre based Pulmonary Rehabilitation and they didn't have lasting effects. However, due to the COVID-19 pandemic services were forced to run on remote delivery models which allowed for improved access into services due to reducing the impact of barriers such as transport, work or social commitments and constraints in service models regarding class times and availability. This meant that services eliminated some of the common barriers to adherence in Pulmonary Rehabilitation. Literature relating to the impact of COVID-19 will be revisited within the Discussion and Conclusion chapter.

The impact of living alone, a lack of support networks as well as lower socio-economic status has been shown to impact upon adherence and consequently successful Pulmonary Rehabilitation. There has been a range of literature recognising the barriers to attending Pulmonary Rehabilitation with some suggesting solutions such as programme structure such as a rolling programme and different models such as home-based Pulmonary Rehabilitation. For the past 10 or more years home-based Pulmonary Rehabilitation has been suggested as an alternative model to improve adherence issues (Holland *et al*, 2011). Home-based Pulmonary Rehabilitation and tele-health have previously been trialled and investigated but often not showing long-term benefits or solutions (Horton *et al*, 2018, Hansen *et al*, 2020, Bollen *et al*, 2014 and Donesky-Cuenca *et al*, 2007). Nolan *et al* (2019) compared traditional Pulmonary Rehabilitation to home-based Pulmonary Rehabilitation and found that the traditional model showed significantly higher improvements in physical outcomes but both improved breathlessness. This was one of the first studies which compared home-based Pulmonary Rehabilitation to the traditional centre-based programmes. However, there has been a growing body of evidence into the effectiveness of home-based Pulmonary Rehabilitation, especially following the COVID-19 pandemic. A recent systematic review by Cox *et al* (2021) reviewed the evidence on tele-rehabilitation for chronic respiratory disease. It is well recognised and evidenced that social factors such as transport, location of community-based venues as well as days and times for classes, symptom severity and disruption to daily routines are barriers to attendance and adherence to successful Pulmonary Rehabilitation programmes

(Hansen *et al*, 2020). Home-based programmes have been used in the past, but the COVID-19 pandemic forced programmes nationally as well as globally to adopt home-based programmes using digital packages and remote monitoring. Historically there has been a lack of robust evidence to prove that home-based programmes are comparable to centre-based programmes in relation to treatment outcomes such as health related quality of life, exercise capacity and symptom control (Horton *et al*, 2018, Hansen *et al*, 2020, Bollen *et al*, 2014 and Donesky-Cuenca *et al*, 2007). Cox *et al* (2021) completed a systematic review to determine these outcomes. In this systematic review, it is suggested that tele-rehabilitation provides similar outcomes to traditional centre based Pulmonary Rehabilitation. However, there were few studies discussed and they had small sample sizes, so it is difficult to determine the accuracy of the outcomes. The National Asthma and Chronic Obstructive Pulmonary Disease Audit Programme (NACAP) (2020) reports that 98% of services were centre-based in their 2019 audit. This suggests that home-based Pulmonary Rehabilitation is less commonly used compared to centre-based programmes.

The National Asthma and Chronic Obstructive Pulmonary Disease Audit Programme (NACAP) are guided by the current quality standards and Pulmonary Rehabilitation guidelines which suggested that centre-based Pulmonary Rehabilitation is more effective than home-based Pulmonary Rehabilitation. There is a growing evidence-base for the quality and effectiveness of home-based Pulmonary Rehabilitation. Holland *et al* (2022) have recently published a protocol for a randomised control trial comparing centre-based and home-based Pulmonary Rehabilitation. The aim of this randomised controlled trial was to examine the effects of offering patients a choice of location (home or centre-based) for Pulmonary Rehabilitation, compared to the traditional model of only centre-based. Further aims include investigating the clinical outcomes, acceptance and completion of Pulmonary Rehabilitation and also the cost implications and sustainability of offering a choice of location. This results of this trial will have implications of future models of Pulmonary Rehabilitation delivery and offer some evidence-base to base future delivery models upon. The Association of Chartered Physiotherapists in Respiratory Care (ACPRC) specialist interest group formulated a document entitled 'Statement and considerations on remote Pulmonary Rehabilitation services during the COVID-19 pandemic' (2020). This document

included resources for the adaptation of Pulmonary Rehabilitation services into remote and / or digital format. Some key issues were related to using remote delivery models including, risk assessment particularly in relation to exercise testing and physiological parameter monitoring, supervision of correct technique and patient safety during exercises, governance issues related to the use of digital technology as well as issues relating to digital literacy of both staff members and patients as well as ensuring the programmes met the standards for Pulmonary Rehabilitation set out by the British Thoracic Society (2014).

Adherence to pulmonary rehabilitation is a complex phenomenon in which there are many variables. It is important to appreciate these influences when striving to improve adherence and to consider implementing strategies to improve some of the barriers to completion of Pulmonary Rehabilitation. A key aspect to consider in relation to adherence in Pulmonary Rehabilitation is the issues surrounding self-management. Literature surrounding adherence and attendance in Pulmonary Rehabilitation has often focussed on quantifying numbers of drop-outs and possible reasons for poor adherence but there has been less focus on the qualitative exploration of those who drop-out.

2.5. Quality Assessment

Quality assessment is an important part of critical appraisal but there is debate on how to critically appraise qualitative literature (Williams *et al*, 2020). Often critical appraisal tools are focussed on quantitative research methods with greater focus of quality directed towards research conducted in 'gold-standard' quantitative methods. Checklist style approaches to critical appraisal have been considered to align with a more positivist paradigm whereas framework approaches focus on determining overarching key themes within the literature (Williams *et al*, 2020). This literature review comprises both elements, development of overarching key themes in the initial exploration phase and then a more detailed review of the literature surrounding self-management and behaviour change.

Key papers surrounding the issues of self-management and behaviour change were selected by the inclusion criteria of being in full-text, English language and within one or more of the key words: Pulmonary Rehabilitation, adherence, COPD, completion, behaviour, behaviour change and self-management. A quality assessment was carried out using the Critical Appraisal Skills Programme (CASP) appraisal templates due to several systematic reviews being included. Table 2.1. shows a selection of key papers surrounding self-management and behaviour change. There is often a focus on the hierarchy of evidence with randomised controlled trials and systematic reviews considered higher quality. Several of these key papers in Table 2.1 are systematic reviews, these were not selected by choice as being higher quality evidence, but it merely represents the study types of the available evidence.

Table 2.1. Key papers summarised with quality assessment:

Author (s) / Year	Title	Study Type	Findings	Conclusions	Quality Assessment CASP Score 0= no 1= partly 2= yes	Limitations
Keating <i>et al</i> , 2011b	What prevents people with Chronic Obstructive Pulmonary Disease from attending Pulmonary Rehabilitation? A Systematic Review	Systematic Review	Transport and travel were barriers to both uptake and completion Lack of perceived benefit influenced uptake and completion Current smokers and those who are depressed are likely to not complete PR	More information is needed on factors influencing patients' decisions on attending PR	2	Some studies included had small sample sizes Varied definitions on completion Lack of quality assessment tool to assess quality
Milner <i>et al</i> , 2018	Rate of, and barriers and enablers to, Pulmonary Rehabilitation referral in COPD: A Systematic Review	Systematic Review	Barriers included: low knowledge of benefits of PR and referral process Enablers included: PR training, experience in PR, reminders and prompts on referral process	Further development is required on specific interventions to improve referral rates	1	No quality assessment
Cox <i>et al</i> (2017)	Pulmonary Rehabilitation referral and participation are commonly influenced by	Systematic Review	'Environmental context and resources' were a strongly represented domain followed by 'knowledge' and	Highlights the complex interaction between the patient and healthcare system factors that influence feelings, attitudes and	2	Need to map the studies to the pre-determined descriptions of the domains but based only on the data

	environment, knowledge, and beliefs about consequences: a Systematic Review using the Theoretical Domains Framework		'beliefs about consequences' The least represented domain was 'social and professional role and identity'	behaviours associated with referral uptake, attendance and completion of PR		available in the papers
Jordon <i>et al</i> , 2015	Supported self-management for patients with moderate to severe COPD: An evidence synthesis and economic analysis	Evidence Synthesis and economic analysis	Few studies identified the components of self-management interventions, but the most effective ones included an exercise component. Those including exercise showed significant improvements in health-related quality of life. A clear framework for describing and classifying self-management interventions is required	Little evidence to suggest that providing self-management interventions after a hospital admission was beneficial. Future work should include qualitative studies to explore the barriers and facilitators to self-management including novel approaches to behaviour change	1	Only RCT's used within this review so a lack of qualitative studies
Mudge, <i>et al</i> , 2015	Who is in control? Clinicians' view on their role in self-management approaches: a	Qualitative Meta-synthesis	Delivering self-management in practice is a complex process. Healthcare Professionals discussed	Control is a key feature of how self-management is viewed by clinicians. Clinicians describe the challenges associated	2	Range of studies included in the review across a range of long-term conditions so not fully representative

	qualitative meta-synthesis		ways in which they exercised control over their patients as well as the control they expected patients to have over their condition. The need to transform practice regarding self-management interventions highlighted the need to change clinician views.	with a paradigm shift required to share or let go of control		of COPD patients and Healthcare Professionals in Pulmonary Rehabilitation.
Lenferink <i>et al</i> (2017)	Self-management interventions including action plans for exacerbations versus usual care in patients with Chronic Obstructive Pulmonary Disease	Systematic Review	Patients in the intervention group were less likely to be admitted to hospital compared to the control group, indicating that the self-management interventions contributed to this. Although, there was no significant difference between groups on length of stay once admitted	Due to a range of self-management programmes in the studies included in the review it was difficult to identify specific components of the self-management interventions. However, it was suggested that smoking cessation should be included in all programmes.	1	Only RCT's used within this review therefore a lack of qualitative evidence
Smalley <i>et al</i> (2021)	Can self-management programmes change healthcare utilisation in COPD?	Systematic Review	Skills and behavioural regulation were evidence throughout the studies reviewed	The review highlights the need to further explore the goals, design, and evaluation	1	Only RCT's used within the review therefore qualitative papers not used within the analysis so

	A Systematic Review and framework analysis		The most common outcome amongst the COPD patients was hospitalisation	of self-management programmes		lacking detail on patient perceived problems
Robinson <i>et al</i> (2018)	Facilitators and barriers to physical activity following Pulmonary Rehabilitation in COPD: A Systematic Review of qualitative studies	Systematic Review	Three main themes from the papers studied: beliefs, social support and environment including sub themes of: self-efficacy, feedback on capabilities and improvements, relationship with Healthcare Professionals, peer interaction, opportunities to engage in physical activity following Pulmonary Rehabilitation, and routine.	Recommend that future research should include mixed methods approach using qualitative methods within a RCT. The themes highlight the complexity of behaviour change	2	Papers not restricted to language or country of origin therefore there may be some variability in the cultural setting which could have impacted the results

2.6. Theme 2: Self-Management

Literature surrounding self-management in Pulmonary Rehabilitation has often focussed on outcomes relating to health status and healthcare services utilisation, particularly inpatient hospital stays (Bourbeau *et al*, 2004). However, it is becoming better recognised that to maintain improvements in health status, behaviour change in self-management behaviours is crucial. Understanding the patient as an individual and working collaboratively is an essential component of supporting behaviour change in relation to self-management. Research into self-management in relation to COPD and Pulmonary Rehabilitation has developed in recent years and it is now recognised as a key component of disease management (Jordon *et al*, 2015). NICE (2013) state that all patients with COPD should have a comprehensive and personalised management plan including support with behavioural change in relation to smoking cessation and exercise. But it is apparent that evidence is lacking in relation to the specific recommendations on the exact elements to be included in behaviour change in self-management (Jordon *et al*, 2015). Traditionally self-management interventions are focussed on education but in long-term conditions management, there are complex needs surrounding medical, emotional and social aspects which require more than education alone. Behaviour change is necessary to be able to manage the complexities of chronic diseases (Rice *et al*, 2014).

Following on from a large body of evidence investigating adherence issues, there was a shift in focus within the literature to investigate aspects associated with and the role of self-management in Pulmonary Rehabilitation. The association between self-management and behaviour change started to be appreciated. An early key paper in recognising the interaction of self-management and behaviour change in COPD is by Bourbeau *et al*, (2004). This key paper was trailblazing in investigating the association of behaviour change and self-management as there were few studies at that time which associated self-management and behaviour change. The role of self-efficacy is discussed in relation to the relationship with self-management in that patients need to improve their confidence in their own abilities in managing their own condition by increasing their self-efficacy. Bourbeau *et al*, (2004) suggest that 'there is sufficient

empirical evidence to support the notion that behavioural performance and patient's belief in their ability to perform in varied situations and disease states are linked by self-efficacy (Bourbeau *et al*, 2004, p.272). This is particularly important in explaining health behaviours. Providing patients with the knowledge and tools to be able to manage their own condition is the starting point and has been described as important as writing the correct prescription (Bourbeau *et al*, 2004, p.276). However what is required is further investigation into how the knowledge and tools are applied by the individual to achieve behaviour change.

Some years after Bourbeau's 2004 paper acknowledging the importance of behaviour change in self-management, Kendall *et al* (2011) reflected on the differences between the terms 'self-managing' and 'self-management'. Literature supporting self-management has grown over the past 10 years to move away from a less patient-centred model of care. Self-management has often been referred to as an essential component of chronic disease management and implies that it is a process of educating the patient and the patient is described as 'in need of instruction' (Kendall *et al*, 2011, p.87). This view on self-management fails to appreciate that each patient has their own individual life that is important to them in their own way. Traditional self-management models focus on the role of education and instruction to complete certain tasks to improve outcomes, but it is essential to acknowledge that people are individuals with their own set of beliefs and personal circumstances; one approach doesn't suit everyone. Kendall *et al* (2011) go on to suggest that the 'it is the complex sociocultural, political and economic contexts which it is embedded and the relationships that make self-management possible' (p.87). In addition, it is often described as a problem with patients adopting self-management behaviours but Rice *et al*, (2014) highlight that the challenge is also among the Healthcare Professionals in which there are individual challenges such as knowledge deficits and skills but also the healthcare systems in allowing an environment for behaviour change.

Self-management is considered an essential component of COPD management and Pulmonary Rehabilitation but there remains a gap in the literature on how to facilitate patients in self-managing their own condition within the realms of their individual

circumstances rather than the prescriptive process of educating patients on self-management. This involves detailed consideration into how the behaviours of both Healthcare Professionals and patients can influence successful behaviour change in relation to self-management. Kendall *et al* (2011) conducted a critical review of the literature surrounding self-management and reviewed the varying definitions. They defined three descriptions of self-management: 'Self-management as a cost-cutting mechanism', 'Self-management as the domain of Healthcare Professional experts' and 'Self-management as emancipation' (p. 92). A key suggestion from this paper is that 'the meaning of the term 'self-management' has changed from being used as a verb (i.e. a process or activity in which consumers engage) to that of a pre-packaged noun (i.e. a thing that it imposed upon consumers or an external entity that can remain separate from themselves)' (Kendall *et al*, 2011, p. 95). This requires further investigation into whether self-management is something that we 'do' to patients or something that we 'give' to patients compared to a process that patients are able to actively engage with. By understanding the mechanisms involved in support for self-management, this thesis will enable a deeper understanding of the concept of self-management.

National and international guidelines including The GOLD guidelines, The NICE guidelines for COPD, The American Thoracic Society/European Thoracic Society (ATS/ERS) as well as The Canadian Thoracic Society all recommend self-management and the role of education as part of disease management in COPD (Bourbeau, 2009). Pulmonary Rehabilitation service delivery has a strong influence on the success of support for self-management, as it dictates the level of staffing, funding and support for staff to be able to be adequately trained and supported to become 'experts' in behaviour change within their clinical area. The National agenda for Pulmonary Rehabilitation within the context of Long-Term conditions may have an influence on the quality and delivery of services in the future. For example, the Pulmonary Rehabilitation Accreditation Scheme may allow for more investment to ensure Pulmonary Rehabilitation Services are quality assured.

Self-management is often referred to as a skill that patients need to be educated on. Healthcare Professionals tend to adopt quite a didactic style approach to disease management. It is however becoming more widely recognised that self-management education requires collaborative learning and teaching, to allow the patient to acquire and practice skills required as well as assessing progress and problems and goal setting (Bourbeau, 2009). Education alone in self-management isn't sufficient to achieve behaviour change but in supporting patients through learning and practice it improves their knowledge, increases their self-confidence, and also improves self-efficacy. 'The pivotal objective of self-management programs is to change patients' behaviour' (Bourbeau, 2009, p. 702). Despite a move towards collaborative support for self-management, the concept of control remains a challenge in achieving this. The traditional biomedical model approach to healthcare is associated with an approach to self-management where the clinician is in control and adopting a didactic model of care. To effectively support behaviour, change in relation to self-management, it has been suggested that clinicians review how they use control in their patient interactions as well as how they expect patients to have control over their own condition (Mudge, *et al*, 2015). There is a call for a move away from the biomedical model within healthcare which requires Healthcare Professionals to examine their approach to support for self-management and behaviour change. Mudge *et al* (2015) recommend that motivation is a key component in disease management. It is suggested that education and instruction are key elements in motivation.

Jordan *et al* (2015) conducted a systematic review to review the effectiveness of self-management interventions following a hospital admission for an exacerbation of COPD. They found that there were a wide and varied range of self-management interventions therefore they were unable to recommend a specific intervention. Further research was recommended into specific interventions with a particular focus on behaviour change and self-efficacy. Self-management interventions are likely to be varied but Jordan *et al* (2015) note that it is important to consider the goal of self-management interventions; these are likely to be different from different perspectives, for example, patients and Healthcare Professionals may have different aims for treatment outcomes. This why a collaborative conversation is essential when planning appropriate self-management interventions. The purpose of the systematic review by

Jordan *et al* (2015) was to determine which self-management interventions and what specific components were recommended due to a lack of clarity in the existing literature.

Lenferink *et al* (2017) conducted a systematic review on self-management interventions, particularly relating to action plans associated with exacerbation management. They found that self-management interventions, particularly the use of action plans following an exacerbation improved health related quality of life and reduced subsequent hospital admissions. They noted that the use of action plans could have potentially triggered earlier contact with Healthcare Professionals during an exacerbation which could have led to more hospital admissions but largely there was a reduction in hospital admissions. Alongside action plans, goal setting is a key component of self-management. Cheng *et al* (2017) published their protocol for a randomised controlled trial investigating using guided goal setting in relation to reduce sedentary behaviour in patients with COPD. They planned to use the COM-B model to diagnose which elements patients were struggling with on an individual basis and then apply this COM-B diagnosis to the behaviour change wheel to select appropriate behaviour change techniques to be able to effectively achieve their goals.

Goal setting is also a key component of Pulmonary Rehabilitation as outlined in the British Thoracic Society (BTS) Guidelines for Pulmonary Rehabilitation (2013). There is a lack of evidence to be able to quantify 'Goal-Setting', but it was recognised that it should be individualised with each patient. Professional standards and guidelines outline the importance of shared and patient-centred goal setting. There is a lack of evidence to suggest the most appropriate method for goal setting discussions with patients with long-term conditions. Goal setting is often poorly documented and requires regular follow-up and review for successful achievement.

Self-Efficacy is specifically outlined within the British Thoracic Society (BTS) guidelines for Pulmonary Rehabilitation (2013) as a component to include within the education programme. Self-efficacy is also listed as a Behavioural Change Technique

and can be a predictor of health behaviours. Self-efficacy explores emotional functioning and coping skills. Therefore enhancing self-efficacy is an important aspect to consider when supporting patients' self-management. Vincent *et al* (2012) developed the Pulmonary Rehabilitation Adapted Index of Self-Efficacy (PRAISE) tool which is an adapted version of the General Self-Efficacy Scale (GSES).

Pulmonary Rehabilitation is a window of opportunity to support patients with behaviour change, particularly in relation to self-management. Typical Pulmonary Rehabilitation programmes last for 6-8 weeks, and patients usually attend twice weekly, this is a golden opportunity to be able to support patients to achieve behaviour change with a structured mechanism. However, often Pulmonary Rehabilitation programmes tend to focus on education and less on evaluating and ensuring behaviour change to maintain the improvements gained in Pulmonary Rehabilitation (Bourbeau, 2010).

2.7. Theme 3: Behaviour Change

Following developments in the literature with regards to the role of self-management there has been an expansion in the literature using novel approaches to evaluating self-management interventions and behaviour change. This thesis will explore behaviour change in self-management using the Behaviour Change Wheel and the Theoretical Domains Framework. Notably, the Behaviour Change Wheel and The Theoretical Domains Framework have been used more recently to explore self-management interventions. For example, intervention-based studies and systematic reviews using models such as the Theoretical Domains Framework have been used to evaluate and categorise behaviours. For example, Smalley *et al* (2021) conducted a systematic review and framework analysis using The Theoretical Domains Framework to develop a broader understanding of the elements surrounding behaviour change and to categorise self-management interventions. This is particularly valuable when considering a move away from the traditional biomedical model approach to disease management in COPD and a move towards more patient-centred care in long-term conditions. Twenty-six studies were included in this systematic review, including 19 self-management programmes. Findings from this systematic review concluded that they couldn't establish a link between self-

management interventions and healthcare-seeking behaviours amongst people with COPD. This highlights the need to further investigate the missing link between existing self-management interventions and behaviour change. This thesis will explore the mechanisms which underpin self-management, particularly in relation to Pulmonary Rehabilitation. This approach of going back to basics will allow for a deeper exploration of the mechanisms associated with behaviour change. Blackstock *et al* (2018) suggest exploring the role of education in tackling adherence problems. Whilst education is an essential component in Pulmonary Rehabilitation, it should be recognised that behaviour change interventions including education have multiple layers of complexity. The interplay between the social, cultural and environmental context influences the ability of the individual to engage successfully with behaviour change in self-management (Smalley *et al*, 2021).

The Behaviour Change Wheel and COM-B Model have also been used to evaluate sedentary behaviour in COPD (Cheng *et al*, 2017 and 2020). These models were used to investigate if a six-week intervention including education, goal setting and feedback improved outcomes in patients with COPD awaiting a Pulmonary Rehabilitation programme. Outcomes were poor and found that behaviour change intervention did not improve sedentary behaviour. This suggests that either the intervention wasn't effective, or it could be that the intervention required deeper understanding of the inherent mechanisms which could bring about change in behaviours. This thesis will explore the mechanisms associated with behaviour change in self-management to be able to determine key elements.

Robinson *et al* (2018) conducted a systematic review into the barriers and facilitators to continuing exercise after Pulmonary Rehabilitation. Fourteen studies, comprising 12 published studies and 2 theses were included in their review. Twelve were qualitative studies and 2 were mixed methods design. Data collected from the studies included in the review were primarily from interviews and focus groups. A key feature to note with this review is that it focussed only on patient reported barriers and facilitators. Whilst this is an important aspect to investigate, it must also be appreciated that the relationship between the patient and Healthcare Professional can influence outcomes in Pulmonary Rehabilitation. The main findings were grouped into three main themes: beliefs, social support and the environment. They found that

exercise alone was not sufficient to improve outcomes and maintain physical activity in COPD following a course of Pulmonary Rehabilitation. Although 'intentions' were a common theme, they found that intentions didn't always lead to successful behaviour change. This thesis will begin to investigate the components associated with behaviour change. A positive environment for successful behaviour change included beliefs and self-efficacy, a good relationship with the Healthcare Professional, peer interaction, having opportunities for maintenance exercise and being able to establish a routine. The interaction between beliefs and self-efficacy are key to be able to support behaviour change.

Bourbeau *et al* (2016) conducted a multicentre randomised controlled trial using a behaviour change intervention using case managers to support self-management. This was part of a wider trial investigating the effects of inhaled medication with or without physical activity training. The self-management behaviour change intervention using case managers were used with all participant groups. The case managers aimed to assess physical activity, support with education, discuss goal setting and use coaching skills to support the patient with individual behaviour change. The benefit of using case managers was to ensure that each patient had an individually tailored support intervention. Individual patient-centred support has been recommended previously (Bourbeau, 2010) and is associated with improved outcomes in relation to self-management and behaviour change. Despite this individually guided approach, the main method of supporting behaviour change was through education. To maintain successful behaviour change it is a more complex process than solely providing the patient with education. This thesis will investigate further the mechanisms associated with behaviour change in self-management and considering more than solely education as an intervention.

The topic of poor adherence is well documented as a barrier to successful behaviour change, particularly in relation to self-management. There is a stigma associated with poor adherence, Healthcare Professionals often think that patients fail to adhere to treatment advice but often neglect to consider the reasons behind the adherence problems. Therefore, there have been several studies to explore reasons for

adherence problems. However, the next step is to investigate the mechanisms underlying the adherence problems, particularly in relation to behaviour change. There are a multitude of reasons why patients may not adhere to treatment advice, ranging from a lack of understanding, or they may be unable to follow treatment advice due to physical, emotional or cognitive barriers (Blackstock *et al*, 2016). It is therefore suggested that not only patient's behaviours that need to change, but Healthcare Professionals too. The interplay between patient and Healthcare Professionals behaviours is a complex phenomenon which warrants further investigation. There is often a conflict of view on Healthcare Professionals support in Pulmonary Rehabilitation. Patients often rely on Healthcare Professionals to maintain commitment to exercise during and following Pulmonary Rehabilitation (Robinson *et al*, 2018). On the other hand, Healthcare Professionals appear to aim to provide patients with self-management skills and education for them to be able to self-manage independently (Blackstock *et al*, 2016). This thesis will explore behaviour change from both Healthcare Professional and patient perspectives to gain a deeper understanding of the mechanisms associated with behaviour change in Pulmonary Rehabilitation.

In their systematic review, Jordan *et al* (2015) note that behaviour change techniques were poorly defined, so it was difficult to suggest specific behaviour change interventions. Self-management interventions often focus on education, but education alone is not sufficient to change health behaviours. In this review they highlighted the role of self-management interventions that 'teach skills that promote health behaviour modification with the aim of increasing self-efficacy' (p.3).

Healthcare Professionals continue to demonstrate a lack of understanding on how to integrate behaviour change techniques into rehabilitation programmes (Whittaker *et al*, 2022). There continues to be a focus on quantitatively-led research investigating outcomes during Pulmonary Rehabilitation. A recent study by Armstrong *et al* (2022) investigated primarily quantitative outcomes using a behavioural intervention as well as cognitive behavioural therapy. The focus on the behavioural considerations by using cognitive behavioural therapy shows that there is advancement in behaviour change literature with the consideration to the impact of behaviour on outcomes.

However, this study is primarily focussed on quantitative objective markers of outcome using an accelerometer to determine physical activity levels, but with less focus on the behavioural modification. It does demonstrate that support during Pulmonary Rehabilitation alongside behaviour modification leads to improved outcomes and aligns with previous literature that supporting self-management increases the likelihood of lasting behaviour change in self-management (Wageck *et al*, 2021). Pulmonary Rehabilitation is an ideal setting to be able to effectively support self-management. Self-management continues to be shown to improve following a course of Pulmonary Rehabilitation (Janssen *et al*, 2021). The existing literature in Pulmonary Rehabilitation including the national focus within the National Asthma and COPD audit and the Accreditation Scheme are dominated by primarily quantitatively-led research methods which contradicts the contemporary nature of the complexities associated with self-management and behaviour change in Pulmonary Rehabilitation which requires a qualitatively-driven focus. Considering the individual needs of both the patient and Healthcare Professional are key to be able to influence long-lasting behaviour change. But, in order to achieve this, Healthcare Professionals need to be equipped with the relevant training and knowledge in behaviour change interventions which is an area for further development in modern Pulmonary Rehabilitation programme delivery (Whittaker *et al*, 2022).

2.8. Communication Phase

This literature review presents the complex relationship between adherence, self-management, and behaviour change. This interplay between these elements opens the opportunity to develop understanding on the mechanisms involved in achieving behaviour change in self-management. This literature review has presented contemporary literature surrounding these themes and it is apparent that there is a journey on the timeline of research within the field of Pulmonary Rehabilitation. Initial studies were very much focussed around demonstrating outcomes and effectiveness and were mainly quantitative and robust in their methodologies to evaluate aspects such as duration of programmes, validity of exercise tests such as the incremental shuttle walk and 6-minute walk test, exercise prescription and programme content. Once the evidence base for the effectiveness of Pulmonary Rehabilitation had been

well established in clinical research and documented in guidelines and standards the research focus moved onto investigating issues surrounding adherence to programmes and identifying reasons for poor adherence. Many of the research methodologies were focussed on more qualitative structured interviews and focus groups. There have been several studies which have identified barriers and facilitators to adherence in Pulmonary Rehabilitation. Despite this there remain issues with adherence in clinical practice. The concept of self-management has been well documented in the literature and it is incorporated into several of the COPD and Pulmonary Rehabilitation guidelines and standards. Nonetheless, the specific content and approaches to self-management remain vague. Self-management as an intervention is multifaceted. Traditional models of self-management are quite didactic in nature and many Healthcare Professionals continue to adopt this approach with patients. Some patients respond well to this approach and seek continual support from Healthcare Professionals. Consequently, a biomedical model of care is reinforced which jeopardises the underlying principles of self-management for patients to be able to manage their condition themselves. This discourse in approaches to self-management paved the way for further research into behaviour change in relation to patients with COPD in Pulmonary Rehabilitation. Much of the literature surrounding behaviour change focuses on the requirement for patients to change their health behaviours. There is less reference to Healthcare Professionals behaviours and the impact that their behaviours have on successful behaviour change in patients. The issues surrounding behaviour change in self-management are well recognised but further investigation is required into the mechanisms influencing its success in clinical practice. Key recommendations from the literature which influenced the planning and conduct of this thesis are outlined in Table 2.1:

Table 2.2. Recommendations from the literature related to key themes:

Adherence	Self-Management	Behaviour Change
<p>Blackstock <i>et al</i> (2018) recommend exploring the potential role of education to promote adherence in Pulmonary Rehabilitation and ensuring the proper implementation of education in Pulmonary Rehabilitation to be able to influence behaviour change.</p>	<p>Jordan <i>et al</i> (2015) recommend that future research should focus on exploring the barriers and facilitators to self-management, particularly post exacerbation as well as novel approaches to affect behaviour change tailored to the individual and their circumstances. Further research is required to identify the most effective components of self-management interventions. A clear framework is required for describing and classifying self-management interventions.</p>	<p>Robinson <i>et al</i> (2018) recognise that future research should focus around developing interventions which promote the value of social support and optimise opportunities for individuals to recognise their own improvements to boost self-efficacy. Future research should also recognise that patients are unique in their presentation so a ‘one-size fits all’ approach to support lasting behaviour change should be avoided.</p>
	<p>Lenferink <i>et al</i> (2017) suggest that future work should be directed towards defining the content of self-management interventions.</p>	<p>Rice <i>et al</i> (2014) recommend that larger longer-term studies are required using well-described self-management interventions aimed at behaviour change.</p>

These key studies suggest that further research is required into developing understanding of the content and methods of delivery for behaviour change in self-management. To be able to do this, this thesis will explore further the barriers and facilitators to adherence and self-management in Pulmonary Rehabilitation from varied perspectives. The mechanisms associated with behaviour change in self-management will also be investigated. The content of self-management in Pulmonary Rehabilitation will be considered from a Physiotherapist's perspective to determine how self-management is approached in clinical practice. This will enable a deeper understanding of the factors associated with self-management to better understand how to achieve behaviour change. This thesis will consider how current practice of support for self-management is approached by Physiotherapists and begin to understand how this may impact upon successful behaviour change. Patient-centred care models will be reviewed, and these approaches will be considered in relation to the theoretical and philosophical underpinnings of the research.

2.9. Chapter Summary

Factors associated with adherence to Pulmonary Rehabilitation have been well documented. Objective examples such as transport and accessibility of programmes, psychological factors such as fear and anxiety, acute exacerbations, and disease severity as well as knowledge of the benefits and the influence of the referring clinician have been shown to influence adherence. Despite this, there remains a gap in the evidence-base regarding the underlying issues related to these issues. The COVID-19 pandemic demanded an expansion in the evidence-base for home-based and remote Pulmonary Rehabilitation models due to the requirement to adapt services. The expansion in the literature focussed on safety and feasibility of remote and / or digital Pulmonary Rehabilitation. However, there remain issues relating to adherence and in particular behaviour change.

There has been a growing body of evidence into the understanding of the meaning and the role of self-management. The importance of behaviour change is becoming well recognised but further research is required into specific behaviour change techniques already used in Pulmonary Rehabilitation and which may be most effective. Behaviour change is a complex phenomenon alone and behaviour change in an

already complex chronic respiratory disease such as COPD in relation to self-management is a necessary but complicated area for investigation. Pulmonary Rehabilitation as an intervention, irrespective of whether it is a face-to-face or remote models, requires specific attention to support for self-management and behaviour change. It has been recognised that the approaches to support for self-management by Healthcare Professionals is varied and that their behaviours can affect the patient outcomes. Gaps exist in the literature in understanding the components of self-management and how this influences successful behaviour change. Existing literature focuses on patients' behaviour change and there are limited studies exploring behaviour change among Healthcare Professionals. This thesis aims to investigate the influences of both Healthcare Professionals and patients' behaviours on the success of behaviour change in self-management.

Chapter 3: Methodology

3.1. Overview of chapter

This chapter will outline the overarching research aim and objectives underpinning the current study. The philosophical paradigm and methodological assumptions will be presented as well as the research methods used. A critical realist approach will be discussed in relation to the ontological and epistemological features associated with mixed methods research. The value and role for qualitatively-driven mixed methods research will be presented and discussed with reference to Critical Realism. The unique perspective of a researcher-practitioner approach to the research will be outlined and presented in relation to the approach to the research.

3.2. Research Aim

To explore the opportunities and challenges associated with behaviour change in self-management within the context of Pulmonary Rehabilitation from a Critical Realist perspective.

3.3. Research Objectives

1. To compare and contrast how behavioural factors associated with self-management in Pulmonary Rehabilitation influence successful behaviour change amongst different stakeholder groups including from a patient, service user and Healthcare Professional perspective.
2. To determine how Physiotherapists behaviours influence patient behaviours and abilities to self-manage in Pulmonary Rehabilitation.
3. To develop an enhanced conceptual understanding of the causal mechanisms influencing behaviour change in self-management among patients and

Healthcare Professionals, with a particular focus on Physiotherapists to provide recommendations for clinical practice.

3.4. Clarification on terminology

Definitions will now be described for key terms used within this chapter. The philosophical paradigm refers to how the individual set of beliefs or assumptions which the research questions are based and can influence the direction of the research (Bowling, 2002). The philosophy refers to the method of investigation chosen and depends on the investigator's assumptions about society (Bowling, 2002). The overarching research philosophy is considered a 'net that contains the researcher's epistemological, ontological, and methodological premises' (Denzin & Lincoln, 2007 p. 13). Roy Bhaskar (2008) refers to ontology as the theory of being whilst epistemology refers to the theory of knowledge.

3.5. Methodological Strategy for the current study

The research processes are related to the methodological strategy within table 3.1 to allow the reader to have an overview of the methodological approach.

Table 3.1: Methodological Strategy

Research Process	Methodological Strategy	Thesis Section
Philosophical Paradigm	Critical Realism	3.6
Research Approach / Methodology	Qualitatively driven mixed methods	3.8
Methods	Focus Groups	4.3
	Survey	4.7
	Conceptualising behaviour change in self-management	4.13
Data	Qualitative Focus Groups	5.4
	Qualitative and Quantitative Survey	6.4
	Conceptualising behaviour change in self-management	7.3
Data Analysis	Thematic Networks Tool (Focus Groups)	5.4
	Graphical presentation of data and Framework Analysis (Survey)	6.4
	Theoretical Domains Framework Behaviour Change Wheel and COM-B models	7.5, 7.6, 7.7

3.6. Philosophical Paradigm

It is essential to complement appropriate research methodology with suitable philosophical underpinnings of the study to enhance rigour of the research (Wilson and McCormack, 2006). The results of a study are influenced by not only the research methods used but also by the theoretical framework employed (Bergman, 2011). Bergman (2011) also argues that ‘nothing can be studied empirically in the absence of theory and research methods’ (Bergman, 2011, p.99). This section will introduce Realism with a particular focus on Critical Realism as the research philosophy

underpinning the current study. Understanding behaviour change in self-management within the context of Pulmonary Rehabilitation requires consideration of the influences from individual perspectives. With this in mind, using Critical Realism as a philosophical framework for this thesis allows for exploration of the underlying mechanisms associated with behaviour change and self-management as a complex intervention.

Realism is the belief in the existence of independent reality and has been defined as:

“the view that entities exist independently of being perceived, or independently of our theories about them” (Phillips, 1987, p.205).

In addition, Scientific Realism is defined as:

“the view that theories refer to real features of the world” (Schwandt, 2007, p.133)

Realism, considered as a model of scientific explanation, has a focus on the mechanics of explanation and is positioned between the polarising approaches of positivism and relativism (Pawson and Tilley (1997). ‘Realism transcends the qualitative and quantitative divide, or the epistemological divide between empirical and interpretivist approaches’ (Kazi, 2003, p. 6). Realism allows for the opportunity to investigate the complexities associated with self-management and behaviour change within Pulmonary Rehabilitation. Using a mixed methods approach allows for an in-depth exploration of complex, broad and multifaceted issues relating to behaviour change and self-management from individual perspectives.

In Scientific Realism, the principles of scientific theories are often referred to as the truth. In contrast, Critical Realism is commonly referred to as sitting within emancipation (Chernoff, 2007). Mukumbang (2021) notes that there is a definite relationship between Scientific Realism and Critical Realism, some believe that they share similarities but remain separate whilst others consider Critical Realism to sit

within Scientific Realism. This has been the topic of much debate within the scientific realist community (Chernoff, 2007). Scientific Realism claims that the principles of scientific theories are true and must be accepted whereas Critical Realism allows for exploration which recognises that the social world can be experienced differently by different people. Critical Realism within this thesis allows for the complex intervention of Pulmonary Rehabilitation to be explored through considering the influence of the social structures influencing adherence and completion as well as the thoughts and actions of both Healthcare Professionals and patients. Scientific Realism wouldn't offer an in-depth exploration of individual experiences in Pulmonary Rehabilitation but Critical Realism allows for underlying mechanisms to be explored.

Social reality is inherently challenging to investigate due to the complex components associated with its human constitution (Archer, 1995). Social reality exists and is dependent upon the human components which presents a problem of the relationship between individuals and society (Archer, 1995). In relation to this thesis, the challenges associated with Pulmonary Rehabilitation demonstrate the complexities associated with research in this field. There are complexities which exist in the individual social worlds of both the Healthcare Professionals and the patients within Pulmonary Rehabilitation. There are additional levels of complexity when considering the relationship between the Healthcare Professionals and the patient. These all have an influence on their individual perceptions of illness as well as their ability to engage in Pulmonary Rehabilitation. Critical Realism offers greater opportunity for this exploration by recognising complexity and variation in experiences of social reality, compared to Scientific Realism in which it is assumed that all scientific theories are true (Chernoff, 2007).

In Realistic evaluation research the aim is often to construct explanations in relation to the context, mechanism and outcome, commonly referred to as CMO configurations (Pawson and Tilley, 1997). A key principle in Realistic evaluation when conducting social science research is to identify the mechanisms for change. Whilst this thesis doesn't employ a realist evaluation methodology per se, the underlying aim to identify and understand the mechanisms for change informed the development of the

approach to this thesis. Research can often focus on identifying what works with little consideration to the influence of behavioural interventions where individual and contextual differences can interact and influence the outcome (Hunter *et al*, 2022).

Realist thinking is made up of a series of open and overlapping systems which impact on one another. Thinking around open and closed systems from a Critical Realist perspective centralises around the concept of “regularities and irregularities in the flux of events or states of affairs” (Fleetwood, 2017, p. 41). Within Pulmonary Rehabilitation, the literature surrounding quantitative-based research such as exercise testing, exercise prescription and optimal duration of courses from a more biomedical ‘gold-standard’ approach are more aligned to closed systems such as cause and effect regularities. For example, improvements in outcome measures such as walking distance, health related disease questionnaires and breathlessness as a result of attending Pulmonary Rehabilitation. Comparatively, open systems tend to depend on the context of the social situation and are often associated with what mechanisms are activated or not and the individual’s interpretation of it (Sayer, 2000). Behaviour change research naturally sits within an open system in which there are varying contributing factors. For example, factors associated with a qualitative-based research approach may include: readiness to change, adherence and engagement in Pulmonary Rehabilitation.

3.6.1 Critical Realism

Critical Realism is an umbrella term used to define the philosophical paradigm by a range of philosophers. Roy Bhasker was a key influential philosopher in the early formulation of the theory of Critical Realism which has now become a well-defined philosophy of science. Bhasker suggested that things exist in the real world and act independently of our descriptions of them but that it is only through particular descriptions that we can understand them. Bhasker argued that science ‘....is the systematic attempt to express in thought the structures and ways of acting things that exist and act independently of thought’ (Bhasker, 1978: 250). Critical Realism is a philosophy of science based upon truths about the nature of the world (McEvoy and Richards, 2006). In relation to behaviour change in self-management, using a Critical

Realist approach allows for a conceptual understanding of the interaction between the natural and social worlds to identify associated causal mechanisms.

Critical Realism is a relevant philosophical paradigm to approach the current research into behaviours associated with self-management. Self-management is a complex phenomenon which has influences on how an individual perceives the world in which they live. Healthcare Professionals teach and promote self-management so individuals can gain better control over their long-term health condition but it is evident that there are several influencing factors associated with its' success. The psychological aspects of chronic respiratory disease have strong influences on an individual's ability to self-manage. Often anxiety and depression have an impact on individual's perspectives on their current health status. This, in turn will have an impact upon how they view the world in which they live. It is relevant to consider that people view the world in different ways and that these different perceptions of aspects such as chronic lung disease and its' implications can have a profound impact upon the outcome of interventions such as self-management in Pulmonary Rehabilitation. The purpose of this study is to view different people's behaviours associated with self-management in relation to chronic lung disease. Bergin *et al* (2008) note that research within the field of healthcare often fails to understand the inequalities within a complex social world. It is particularly important to note that the current study provides a unique opportunity to explore the causal mechanisms to gain a deeper understanding of their influence on self-management in chronic respiratory disease.

Critical Realism is the joining of ontological realism and epistemological constructivism. Maxwell (2012) describes that Critical Realists retain an ontological realism meaning that there is a real world that exists independently of our perceptions of it, whilst also accepting a form of epistemological constructivism and relativism and that our understanding of this world is often made up of our own perspectives. Historically, the mind and the physical world have been seen as separate entities however, Critical Realists retain the notion 'that mental and physical entities are interacting parts of a single real world' (Maxwell, 2012, p.16). Physical entities refers to concrete and inanimate things. This is reflected within the current research question

to identify barriers and facilitators to behaviour change in relation to self-management. In other words, there are influences from both the psychological and physical ability of the patient. Critical Realists see the psychological aspects as being directly involved in the causal processes that produce behaviour.

It is essential to acknowledge the role of causal mechanisms from a Critical Realist perspective. Sayer (2000) describes causality from a Critical Realist perspective as the process of 'identifying causal mechanisms and how they work and discovering if they have been activated and under what conditions (Sayer, 2000, p.14). Critical Realists strive to look beyond what is directly observable within the empirical domain. Critical Realists approach causality in relation to how structures influence mechanisms to bring about an event (Sayer, 2000), compared to a positivist method of cause and effect. Structures are described as 'a set of internally related elements whose causal powers, when combined, are emergent from those of their constituents (Sayer, 2000, p.14). To understand why certain causal mechanisms exist, the underlying nature of the structure needs to be understood. Explanation of causation depends on identifying the causal mechanisms and how they work as well as discovering if they have been activated (Sayer, 2000).

Self-management and behaviour change in relation to health behaviours are complex, especially within long-term conditions. Therefore, this thesis begins to explore the causal mechanisms associated with behaviour change in self-management. Bhaskar's work focussed on the development of an understanding of the causal level, this is especially important to decipher the inherent mechanisms that bring about events (Wilson and McCormack, 2006). For the purpose of this study it is important to consider this in the context of analysing the causal tendencies that take place within Pulmonary Rehabilitation and consider what the environmental and social behaviour influences may be. With this in mind it is key to be able to recognise that an individual's physical contexts have a causal influence on their beliefs and perspectives of their situation. The key question in relation to Critical Realism is 'how do certain causal mechanisms operating in particular circumstances create certain changes?' (Wilson and McCormack, 2006). In Critical Realism, understanding the mechanisms at play

and the contexts in which they operate provides a theoretical understanding of the phenomenon which can then be used to optimize the effects of an intervention by recognising and removing blocking mechanisms, or by changing the intervention so that it sits within the contexts in which achieve positive outcomes (Robson, 2002).

The philosophical and methodological underpinnings of this study allowed the researcher to explore Pulmonary Rehabilitation as a complex intervention. It is challenging to understand the underlying mechanisms due to the variances in Healthcare Professionals and patient opinions and views of what self-management means. There is currently limited knowledge of the underlying mechanisms associated with Pulmonary Rehabilitation as a complex intervention. A key component of Critical Realism is being able to identify the enduring entities of the causal mechanisms associated with an event. These underlying structures have a variety of forms, they can be either physical, social or conceptual and they hold their own powers and may act in certain ways which may or may not be observable (Mingers, 2013). In relation to Pulmonary Rehabilitation, there are many different components which influence an individual to be able to engage in Pulmonary Rehabilitation, these are also associated with the physical, social and conceptual understandings and practices of behaviour change and self-management. They have different ontological and epistemological characteristics which require a range of research methods to investigate, thus, a mixed methods approach to research design is often favoured in Critical Realism (Mingers, 2013).

The 'human' components of health especially those related to health behaviours and the influence of social and cultural aspects are complex and inherently challenging to investigate. Therefore, this thesis employs a mixed methods approach whilst using a Critical Realist lens to evaluate the elements of complex health behaviours in relation to behaviour change in self-management. By using a Critical Realist approach this thesis aims to acknowledge that despite commonly cited barriers and enablers, each individual conducts themselves due to their own beliefs about how they see the world.

Critical Realism is primarily concerned with ontology and generally starts with research questions about what actually exists. For example, this thesis begins by presenting the problem of adherence in Pulmonary Rehabilitation. Bhasker (1978) maintains that a philosophy of reality must begin with ontology (a theory of being) before moving onto questions regarding epistemology (the formation of knowledge). Critical Realism is based on three different ontological domains described by McEvoy and Richards (2006) as The Real (real objects and mechanisms that generate phenomena), The Actual (actual events that occur but may not actually be experienced) and The Empirical (empirical experiences and aspects of reality that can be directly or indirectly experienced). Modell (2009) argues that the Real domain is 'independent of our existence as individual human beings and thus displays a certain element of stability' and thus 'the properties of such mechanisms are only partially within the realm of human cognition' (Modell, 2009, p.212). Whilst Bergin *et al* (2008) describe the Real domain as 'the ontological gap between what we experience and understand, what really happens and the deep dimension where the mechanisms are which produce events' (p.171). The Real domain consists of all three ontological domains because we experience (Empirical) events (Actual) and mechanisms (Bergin *et al*, 2008).

Within the context of this thesis, these are described as follows:

- The Empirical – what happens as a result of implementing Pulmonary Rehabilitation and the experiences of Healthcare Professionals and patients as a result of delivering and participating in these programmes.
- The Actual – implementation of Pulmonary Rehabilitation in practice and events which may or may not be observed.
- The Real – the factors and mechanisms influencing self-management and behaviour change in Pulmonary Rehabilitation.

Social systems and practices are fundamentally complex in nature which means it is often difficult to determine key components and examine them individually (Sayer, 2000). Kazi (2003) also presents the notion that people are complex and that human interactions and outcomes are the result of complex interactions of different kinds of structures at different levels which cannot be explained by one causal link but suggest that several causal processes could be interacting at different levels. To grasp the complexities of the interaction between the Real, the Actual and the Empirical, this thesis approaches the concept of behaviour change in relation to self-management from multiple perspectives, utilising Healthcare Professionals, patients and Breathe Easy support group members.

In Critical Realism mental states and attributes are part of an individual's personal situation and from an ontological perspective the nature of meaning depends on the nature of mind and its relationship to the physical world. It is therefore especially important to address the psychological aspects of chronic lung disease and how this impacts upon daily life. Critical Realism rejects the idea of multiple realities but there are different valid perspectives on reality which means that each individual's perspective is important and personal to them.

3.7. Research Framework

To address the complexity of the issues surrounding adherence in self-management and in keeping with a Critical Realist approach, this thesis uses a qualitatively-driven mixed methods approach. The issues surrounding adherence in self-management in Pulmonary Rehabilitation are complex and the underlying issues require in depth investigation. With this in mind, this thesis begins with a qualitative approach using focus groups which required in depth analysis to generate themes associated with adherence in Pulmonary Rehabilitation. The themes from the focus groups then informed the development of the survey which uses both a qualitative and quantitative approach. The survey aimed to develop further understanding of the issues surrounding behaviour change in self-management which underpins the issues relating to adherence. These methods will be discussed in detail in Chapter 4.

Qualitative research within the field of health research offers great potential for investigation into health behaviours and ‘unravelling some of the messiness and complexity of health beliefs’ (Thorne, 2011, p.444). There is an increasing need for the future workforce to be able to facilitate behaviour change in long term conditions management.

Historically, Physiotherapists were more aligned with a scientific approach to their practice, using clinical reasoning and decision making based upon best available evidence, generally aligned with a more biomedical perspective (Kerry *et al*, 2008). However, more recently there has been an increasing emphasis upon appreciating the philosophy of science and exploring how this influences clinical practice. Thorne (2011) noted that ‘enthusiasm for qualitative health research has blossomed’ (p.443) and attributed value of qualitative research within healthcare as clinicians are ideally situated to be able to interpret clinical practice knowledge due to their repeated engagement with patients.

Pulmonary Rehabilitation comprises a complex interaction between adherence, self-management and behaviour change. Each element has an important role to play in an individual’s experience of Pulmonary Rehabilitation, but it is the interaction of all three elements together that increases the success of Pulmonary Rehabilitation. Adherence is often recognised as a problem, but this thesis begins to unravel the complexities surrounding adherence and its’ impact upon behaviour change in self-management. An individual’s adherence to a Pulmonary Rehabilitation programme influences their interaction with Healthcare Professionals who intend to support self-management education to facilitate change in health behaviours. This interaction requires consideration of the mechanisms involved with adherence, self-management and behaviour change from both the perspectives of the patient as well as Healthcare Professionals. Individuals with chronic respiratory disease, in particular those with Chronic Obstructive Pulmonary Disease (COPD) often experience both physical and psychological symptoms which interact with each other and influence the success of adherence, self-management and behaviour change. Recognising the mechanisms

involved is a necessary step towards understanding the complexity of behaviour change in relation to self-management among patients with chronic respiratory disease. Critical Realism is used as a lens to view perspectives on behaviour change and self-management and this thesis begins to identify the causal mechanisms associated with behaviour change in relation to Healthcare Professionals and patients within support for self-management in Pulmonary Rehabilitation.

Fundamentally, all forms of research derive from the researcher's desire to understand and make sense of the world (McEvoy and Richards, 2006). McEvoy and Richards (2006) describe that quantitative approaches employing standardised measures and statistical techniques are generally associated with a positivist paradigm which is based on 'the philosophy that our preconceptions need to be set aside to identify facts based on empirical observations' (McEvoy and Richards, 2006, p. 67). Whilst qualitative approaches based on non-numerical data are often associated with the interpretivist paradigm which has greater focus on the 'way in which the world is socially constructed and understood' (McEvoy and Richards, 2006, p.67). Methods associated with qualitative research are often focus groups, unstructured interviews and opinion-based data. Qualitative and quantitative approaches have traditionally been regarded as separate paradigms (McEvoy and Richards, 2006). However, Critical Realism offers an alternative approach to positivism and interpretivism. This thesis focusses on a mixed methods approach to the research allowing for a more complex understanding of phenomenon (Shannon-Baker, 2016). Critical Realism emphasises perspective taking and empowering the voice of others which is further enhanced by using a mixed methods approach. Christ (2013) suggests that there are many levels of objective truths in Critical Realism that can be constructed by investigating relationships and causal mechanisms. A mixed methods approach allows the researcher to identify causal mechanisms to theorise about a particular social phenomenon.

Positivism incorporates quantitative approaches using standardised methods and statistical measures, often situated within the natural sciences (McEvoy and Richards, 2006). Quantitative researchers usually employ large and random samples, reduce

complex occurrences to simple variables, test hypotheses, work deductively and generalize the findings (Bergman, 2011). Quantitative approaches aligned to a positivist paradigm include closed-response interviews and questionnaires, randomized controlled trials and systematic reviews (McEvoy & Richards, 2006).

Whilst an interpretivist paradigm is associated with qualitative approaches concerned about the way in which the world is socially structured and understood (McEvoy and Richards, 2006). Researchers conducting qualitative research typically employ small sample sizes, they are non-reductionist about their subject matter, the subjective experience is paramount, and they work inductively and study phenomena in their natural setting (Bergman, 2011). Participants are often selected on the basis of how useful they are likely to be for the pursuit of the research aim and the views of participants who are not representative of the general sample are actively sought out (Kitzinger 2006). Qualitative approaches associated with the interpretivist paradigm include focus groups, unstructured interviews, textual analysis and ethnographic case-studies (McEvoy & Richards, 2006). Critical Realism offers an alternative to positivism and interpretivism, whereby positivism fails to appreciate that the observable events are influenced by our perceptions of the reality and fail to recognise the influence of mechanisms and contexts in which they occur (McEvoy & Richards, 2006). In contrast, interpretivists focus on human discourse and perceptions which fail to recognise the influence of the social structures. Consequently, Critical Realism sits somewhere in between positivism and interpretivism, taking aspects from both to achieve an alternative view on causality.

An interpretative approach to Critical Realism was employed during the focus groups to view the concept of self-management and adherence from the different perspectives to further understand the reality of adherence to self-management in chronic respiratory disease. Behaviours and social practices in particular, are more suited to an interpretative paradigm with qualitative research methods. However, it is important to recognise that using purely qualitative approaches has its limitations. The qualitative data from the focus groups informed the development of the survey to respiratory physiotherapists with the aim to gain both qualitative and quantitative data from a more specific sample group.

Critical Realism offers the researcher an alternative to purely quantitative or qualitative methods whilst at the same time recognising the value of a constructivist approach. Bergin *et al* (2008) discuss that Critical Realism is more focussed towards constructivism. Constructivism allows the researcher to explore complex social realities and how the human interaction can influence the meaning in comparison to positivists where the focus is on a cause-and-effect relationship (Bergin *et al*, 2008). Bergin *et al* (2008) describes constructivism as when reality is 'socially constructed and what exists is dependent upon the person's interpretation and understanding of that reality' (Bergin *et al*, 2008, p. 171). It is also important to also appreciate that constructivism has its limitations. Often in healthcare, there are certain structural and organisational aspects which can influence individuals' perceptions and ultimately are independent of their own thinking (Bergin *et al*, 2008). The researcher used a constructivist approach to the research question. As previously highlighted, there is a correlation between the psychological impact of chronic respiratory disease on the individual's physical functioning and their ability to effectively self-manage their condition.

The value of Critical Realism is that it supports the value of using both qualitative and quantitative methods by working together to address the limitations of each method. A mixed methods approach within Critical Realism allows for varying perspectives on causal relationships (Shannon-Baker, 2016).

3.8. Methodology

The current study employed a qualitatively driven mixed methods approach using focus groups as the prime qualitative source and a survey using both qualitative and quantitative data. The nature of the research question requires a deeper understanding of the inherent mechanisms involved in behaviour change. From a critical realist perspective it is key to obtain data from multiple sources to gain a deeper understanding of the causal mechanisms involved in behaviour change and particularly from different perspectives. From a practitioner-researcher perspective, it

was valuable to be able to critically reflect on the data from multiple methods. Thorne (2011) advocates the use of mixed methods due to the risk of affecting the researcher's ability to critically reflect on the data when only one method is used.

Mason (2006) advocates a 'qualitative thinking' as a starting point rather than a definitive framework. The benefits of using mixed methods include triangulation which enhances the validity of findings, completeness which provides a more comprehensive picture of the research and mixed methods allow the researcher to investigate complex phenomena which are particularly apparent in real world complex situations. Pulmonary Rehabilitation is a complex intervention that has been well researched into its effectiveness, however, it is apparent that adherence to self-management is a complex aspect which needs further clarity. Therefore, the current study uses the value of a mixed methods approach to gain a deeper understanding of the complex nature of behaviour in relation to adherence to self-management using both qualitative and quantitative methods. There has been a wealth of research into the optimal type and duration of Pulmonary Rehabilitation with reference to the national audit and guidelines. However, from a clinician perspective and in a researcher/practitioner role it is evident that there remains a gap in the research into determining the causal mechanisms involved in adherence, self-management and behaviour change. Therefore, a Critical Realist mixed methods approach is an appropriate method to approach the research question. There are multiple aspects to behaviour change in self-management where causal mechanisms could influence to outcome. Therefore, this unique approach to the research question using influences from a researcher/practitioner approach with the benefit of clinical knowledge and experiences. As well as a Critical Realist approach utilising aspects of deeper understanding and appreciation of the impact of both physical and psychological aspects of chronic respiratory disease as well as using a mixed methods approach to view the data using different sources.

A qualitative approach allows for a deeper understanding of individual's thoughts and opinions and is therefore appropriate to understand the mechanisms of self-management in Pulmonary Rehabilitation. Qualitative focus groups were carried out

to provide insight into the factors associated with adherence and maintenance in Pulmonary Rehabilitation from different perspectives using patients, Healthcare Professionals and Breathe Easy support group members. Atkins *et al* (2017) suggest that qualitative interviews or focus groups are ideally used in the first instance, when there is less knowledge on the intervention implementation problem to develop theory and gain a deeper understanding of the problem. For example, there is ample evidence to suggest that Pulmonary Rehabilitation leads to successful outcomes, but there remains a problem with long-term successful behaviour change in relation to self-management. It is then recommended that survey methods are used once there is greater knowledge of the problem and are a useful tool to use to gain deeper understanding of particular behaviours influencing the problem. Therefore, a mixed methods survey was used to focus on Physiotherapists views on barriers and facilitators to successful self-management.

Initially an inductive reasoning approach was applied as focus group and survey data were analysed individually to be able to understand and become more familiar with the data. Following this, a more deductive approach was used to map the focus group and survey data to the 14 domains within the Theoretical Domains Framework, the COM-B system as well as the Behaviour Change Wheel with the view to conclude recommendations for future practice on behaviour change interventions within a wider stakeholder group. The value of using both inductive and deductive approaches allows for a richness in the data by understanding the key concepts from the raw data and then by using theoretical models it allows the data to be translated into meaningful information to be able to implement change in clinical practice (Atkins *et al*, 2017). This thesis explores the issues surrounding behaviour change and self-management by comparing data with data and following this, then comparing data with theory. In Critical Realist approaches to research, both inductive and deductive methods are necessary but not sufficient for theory development without retrodution or abductive inspiration (Patomaki & Wight, 2000). Abductive inspiration is a creative form of reasoning which takes place retrospectively as mechanisms are proposed in relation to certain phenomena (McEvoy and Richards, 2003). In the current study, the findings from the focus groups and survey data were used to develop understanding of the causal mechanisms associated with behaviour change and self-management which

stimulated the retroductive reasoning which led to the development of the recommendations for practice.

Self-management is commonly taught by Healthcare Professionals with a biomedical model approach, including advice on exacerbation management and exercise prescription. Many patients with long-term conditions have a medicalised approach to self-management and are often lacking in support for behaviour change which would help them with longer term success of self-management. The value of using a mixed methods approach allows the researcher to delve deeper into the mechanisms involved from multiple perspectives to be able to determine what the current practice of support for self-management is and to be able to recommend ways to enhance behaviour change.

Self-management is a key aspect of Pulmonary Rehabilitation. However, it is a complex behaviour and the delivery and content of support for self-management varies among Healthcare Professionals and services nationally. Patient's ability to practice and succeed at self-management also varies considerably. Self-management should be seen as an overarching description of a number of interventions which may be used together or separately. There are several opportunities within Pulmonary Rehabilitation where support for self-management occurs and these are all opportunities to improve on the delivery and content of support for self-management to improve its success. Self-management is a continual thread within Pulmonary Rehabilitation. Healthcare Professionals strive to support self-management through exercise prescription and providing guidance within the exercise component as well as through the individual education sessions on topics ranging from disease education and medical management through to psychological and emotional aspects of disease management. The success of behaviour change is influenced by the quality of the support for self-management from Healthcare Professionals but also by the ability of the patient to successfully change their health behaviours to be able to self-manage their condition. Self-management as a concept is very broad in nature and encompasses a range of interventions so is therefore difficult to quantify or establish

its success. Therefore, an essential first step is to determine factors influencing behaviour change in self-management.

Social and lived experiences are multi-dimensional and our understandings are likely to be inadequate if viewed using a single methodological approach. Critical Realism, using a mixed methods approach offers a perspective that emphasises diversity and explores the relationships between people and events (Shannon Baker, 2016). The current research focus on behaviours within a complex intervention such as Pulmonary Rehabilitation requires a mixed methods approach to allow for the nuances associated with the complexities and multi-dimensional influences of the lived experience with chronic respiratory disease. Complex interventions are inherently challenging to investigate as they are often made up from several interconnecting components which may act independently or interdependently (Campbell, 2007). Complex interventions are commonly used within healthcare. However, they often pose difficulties due to the multiple interacting components (MRC, 2000).

Critical Realists maintain that the choice of research methods should be decided by the nature of the research question, often suggesting that a combination of qualitative and quantitative methods is an appropriate way forwards (McEvoy and Richards, 2006). Robson (2016) describes the movement towards mixed methods research as evolving after the quantitative-qualitative paradigm wars where a positivist quantitative approach was dominant, closely followed by a move towards a qualitative interpretivist / constructivist research paradigm. It is thought that there are now three methodological research paradigms: quantitative, qualitative and mixed methods.

Mixed methods research allows the researcher to 'think outside the box' which opens up vast scope for exploring new perspectives of social science. This study investigates those with chronic respiratory disease and has particular reference to their interactions within society and their lived experience.

3.9. Methodological Triangulation

A mixed methods approach to the research allowed the researcher to view the concept of behaviour in relation to adherence to self-management from different perspectives. This is a concept described by Mason (2006) in which mixed methods triangulation allows the researcher to use each element of each method and form of data to tell a specific part of 'the picture' as well as allowing the researcher to view the picture from different angles. Once the different perspectives have been explored the data can then be consolidated alongside the overarching 'world view' to be able to conceptualise 'the picture' (Mason, 2006). Methodological triangulation can enhance validity. However, it can pave the way for discrepancies and variances between different methodological sources (Robson, 2016). Qualitative data from the focus groups required in depth analysis to determine themes. This then complimented the design, conduct and analysis of the survey. The survey required both quantitative and qualitative analysis.

Risjord *et al* (2002) suggest that qualitative and quantitative data may be triangulated for the purpose of completeness to obtain complementary perspectives, and a greater level of detail than could be gained from either data source alone. Critical Realism offers a framework to allow for mixed methods approaches as researchers can use both qualitative and quantitative methods to investigate a particular phenomenon. In particular, Critical Realism allows for triangulation of the data to enhance the insights into a particular research question with the aim of increasing the validity of the data obtained (Modell, 2009). It allows the researcher to use different research methods to explore social phenomena to determine the underlying mechanisms at play. Triangulation offers a way to achieve a more complete understanding of the data obtained from different sources (McEvoy and Richards, 2003). This thesis is unique by using a Critical Realist approach with regards to health behaviours from varying perspectives of patients and Healthcare Professionals to be able to triangulate perspectives on behaviour change within the context of Pulmonary Rehabilitation.

Interventions and specific components of the intervention need to be targeted to improve the success of behaviour change (Richardson *et al*, 2019). The process of triangulation of the data by using the 14 domains of the Theoretical Domains

Framework, the COM-B system and the Behaviour Change Wheel allows the researcher to identify those who are involved in the intervention to successfully change behaviours as well as key interventions targeted at behaviour change. Triangulation allows the researcher to view the problem from different perspectives and within this thesis, these include participants from different participant groups which enhances the rigour of the research.

McEvoy and Richards (2006) describe that methodological triangulation is often employed for three main reasons: confirmation, completeness and 'abductive inspiration'.

3.9.1. Confirmation

Confirmation is primarily used to demonstrate the reliability and validity of the research findings by using both qualitative and quantitative data to support a more robust conclusion compared to using one data source only (McEvoy and Richards, 2006). The current study used data from both the focus groups and survey which provided insights into the barriers and facilitators influencing adherence to self-management in chronic respiratory disease. The data from the focus groups allowed for confirmation of the barriers to adherence to Pulmonary Rehabilitation outlined within the literature, as well as adding value to the findings by having perspectives from a range of participant groups. This was further confirmed with the survey findings which elaborated on specific barriers and facilitators in relation to behaviours and behaviour change within self-management in Pulmonary Rehabilitation.

3.9.2. Completeness

Completeness allows for a greater level of detail by using data from both quantitative and qualitative methods compared to what can be obtained from one source. McEvoy and Richards (2006) describe that the goal of completeness can be more ambiguous than confirmation. From a positivist viewpoint, 'the goal of completeness may be to reveal different aspects of a phenomenon' whilst from an interpretivist viewpoint 'it may be to provide a wider range of perspectives' (McEvoy and Richards, 2006, p. 72). The

current research leans more towards an interpretivist viewpoint, as the focus groups and survey allowed the researcher to view the influence of behaviours on self-management from different perspectives: Healthcare Professionals, Breathe Easy support group members, patients as well as respiratory specialist Physiotherapists.

3.9.3. Abductive Inspiration

The current study started by identifying factors associated with adherence to self-management in which behaviours were a prominent theme which led to the survey to identify specific barriers and facilitators to successful self-management. Although the current study investigated behaviours towards self-management as a source of causal mechanisms, it is also key to acknowledge that it is often within the social relations and organisational structures that causal powers reside. Abductive inspiration allows for enhancing knowledge by looking at the fundamental properties of a phenomenon and examining data focussing on causal relationships and meanings at a deeper level of the Real and the Actual (Christ, 2013). Risjord *et al* (2002) describe abductive inspiration as using one method to generate ideas that are then further tested by another method to determine a new explanation for a phenomenon.

Kazi (2003) recognises that people are complex and interactions among different structures particularly within individuals are inherently complex which in turn means that there is never usually one causal link. Therefore it is appropriate to consider the wider perspective of self-management within the context of the national agenda for long-term conditions management and current policy related to Pulmonary Rehabilitation. Whilst, not forgetting the inherent clinical pressures among Healthcare Professionals and how this may impact their behaviours towards self-management particularly in chronic respiratory disease.

3.10. Thesis Approach: Practitioner - Researcher Role

This section is a personal reflection on the researcher's unique and personal approach to the thesis and thus will be presented in the first person.

As an advanced clinical specialist Physiotherapist in Pulmonary Rehabilitation and Chronic Respiratory Disease, I embraced this thesis with a practitioner – researcher approach. A practitioner – researcher is described as ‘someone who holds down a job in some particular area and is, at the same time, involved in carrying out a systematic enquiry which is of relevance to that job’ (Robson, 2002 p. 534). It is important to outline the intent of the research when using a practitioner-researcher approach (Fox *et al*, 2007). By adopting a practitioner-research role, the current study was underpinned by my background clinical knowledge and experience within the field of Pulmonary Rehabilitation and Chronic Respiratory Disease which ensured the aims and objectives were clinically relevant and contemporary. On reflection, this approach was more practitioner-led, which could have influenced the direction of the research. Although this approach offers a valuable stance on contemporary clinical issues, there remain risks to influencing the ethical and methodological quality of the research due to previous or existing relationships between the researcher and participants. This will be discussed more within the Discussion and Conclusion Chapter.

A practitioner-researcher allows for greater richness and relevance to the research study at all stages. For example, particularly in the planning stages such as developing the research question, it is especially important to have a sound clinical background to base a relevant research question. However, Reed and Procter (1995) argue that a practitioner’s experience can be seen as not ‘scientific’ which could therefore jeopardise the quality of the research as they cannot be distanced from their subjective opinions and impressions. This is where the term ‘applied research’ derives from, meaning that research is not conducted to develop methodology and theory but to develop practice.

In Critical Realism, reality is experienced and interpreted in an individual subjective way, but reality exists independently of these subjective values and experiences. If the researcher ignores their role and position in the research, a key element of the research is disregarded. By using a reflexive approach in research, it is enhanced by a continual reflection thus enhancing the researcher’s awareness of their influence on their research. A practitioner-researcher must appreciate the value of their research position and regard themselves as an ‘integral element in the research process’ (Drake

and Heath, 2011, p.107). Decisions on the research question, methodological approach and methods and analysis of the data are influenced by the researcher's knowledge, experience and personal qualities.

The unique approach to this thesis using a practitioner – researcher approach whilst at the same time adopting a Critical Realist philosophical stance allowed for a deeper understanding and application of these two approaches. Whilst historically a practitioner-researcher approach has been seen as a less scientific method of answering a research question, Critical Realism offers a perspective on the value of looking deeper than what is objectively observable and striving to focus on the causal mechanisms which influence a particular phenomenon. Critical Realism aims to move away from a positivist paradigm where objective measures are gold standard and aims to delve deeper into the core reasons and mechanisms at play. This has parallels to the practitioner-researcher who whilst in clinical practice often experience difficulties implementing evidence-based interventions or practices due to the complex nature of the patients they work with. Therefore the practitioner-researcher role offers potential to adopt a Critical Realist approach to be able to research into the deeper complex problems associated with patient outcomes. In long-term conditions management it is important to consider the influence of the 'subjective experience of complex health and illness' (Thorne, 2011, p.443). This is especially relevant to the current research into behaviours and the associated influences of how the individual experiences their own health and the impact on their ability to successfully self-manage their condition.

One of the key values of approaching a research question from a practitioner-researcher background is that knowledge and experience within a particular field can allow the researcher to investigate real-life problems in clinical practice. Thorne (2011) describes that practitioner-researchers 'orient their research logical around the clinical problem, using and applying various theories to test out their relative contribution toward a meaningful and applicable interpretation' (p.448). The basis of this thesis started with identifying a clinical problem and then a range of philosophical and methodological approaches were employed to interpret the findings to be able to relate back to clinical practice. A reflexive approach is key for practitioner researchers to adopt to be able to evaluate their findings in relation to clinical practice.

At the start of this PhD journey as a Healthcare Professional, my views were aligned with a more positivist paradigm. As a clinician, I held pre-existing assumptions that were situated in a biomedical model. There is a tendency as a Healthcare Professional to adopt a paternalistic role and perhaps not intentionally but naturally taking an authoritative role towards support for self-management. This is often due to the structure of NHS organisations and service models. It is also apparent that Healthcare research often favours quantitative methods which focus on objectively measured outcomes. In my clinical role, these external factors influenced both my conscious and unconscious views of Healthcare delivery and clinical practice. The journey through this thesis has allowed me to reflect upon my own assumptions and approach to support for self-management. This includes realising a move away from a positivist approach through adopting the principles of a Realist methodology. Throughout this thesis I have explored the varying perspectives on what constitutes adherence, self-management and behaviour change. Although my assumptions have been challenged and I recognise a change in my clinical practice, I am aware of the difficulties in achieving a whole system change within the NHS, and particularly in clinical practice within Pulmonary Rehabilitation. Much of our clinical practice is governed by policy, organisational structures, targets and financial constraints which influences our ability to embed changes in approaches to Healthcare.

Using reflexivity as social critique is focused around managing the power imbalance between researcher and participant (Finlay, 2002). For example, during the focus groups, I wore my Physiotherapy uniform, by appearing in my clinical role I intended to be seen as an approachable empathetic Physiotherapist with a keen interest in research into findings ways to improve clinical services for them rather than wearing smart plain clothes, I might have come across as distanced from the reality of their situation. I was also a familiar face for many of the Pulmonary Rehabilitation and Breathe Easy patients within my clinical role as the Physiotherapist working in Pulmonary Rehabilitation. This worked in different ways. In the patient and Breathe Easy focus groups, this ensured that I was more approachable and appeared interested in what they had to say and with the Healthcare Professionals focus groups I intended on being seen as a colleague as well as a researcher to allow for a more

natural conversation. Also, by being present for the focus groups for all participant groups I intended to reduce the authoritative stance as a researcher whilst at the same time allowing for some distance to reduce bias I used a moderator to facilitate the discussions. Within Critical Realism, the relationship between the researcher and participant is an important aspect to consider with regards to understanding how the causal mechanisms influence the outcome. The power imbalance in research is associated with tensions from conflicting social positions. Critical Realism allows for the exploration of the influence of the social world. The limitations of this approach will be discussed in more detail in the Discussion and Conclusion Chapter. Reflexivity allows the researcher to adopt a naturalistic enquiry using empathy and being aware of their own personal influences on the research (Darawsheh, 2014).

From a Critical Realist approach investigating within the domains of the Real, the Actual and the Empirical are essential to determining the causal mechanisms at play. Whilst conducting practitioner-research the value of using a reflexive approach should be used positively to be able to reflect and re-design throughout the research process to ensure that the research methods employed are suitable for the research question being investigated. The role of power in practitioner-research is discussed by Fox *et al* (2007) and that practitioner-researchers need to be aware of when and where power is being exercised (p.88) but also being aware of their own power within the research process.

A PhD is a journey of self-discovery and knowledge acquisition which I have embraced with enthusiasm and dedication. My ambition to enhance the quality of care for patients within my clinical field has been the driving force in completing this study. When investigating patients and their behaviours, particularly in relation to a complex phenomenon such as self-management and behaviour change, my clinical knowledge and experience were paramount in being able to situate the research question with clinical relevance. It does however, pose limitations such as finding it harder to maintain a distance between the research and clinical practice, particularly when considering the influence of Healthcare Professionals Behaviours on the success of patient's behaviour change. Practitioner-researchers are often driven by a desire to investigate the complexities of the patients they see in clinical practice. Qualitative

research has become a more popular research method for health researchers in the last 50 years as practitioner-researchers became aware of the value of qualitative research in investigating the complexities of health behaviours and health beliefs particularly in relation to long term conditions management (Thorne, 2011).

Costly and Gibbs (2006) discuss the ethical considerations in relation to practitioner-researchers and academic researchers. The latter are able to distance themselves from the research setting where as practitioner-researchers are unable to due to the existing relationships within the workplace. The research output from practitioner-researchers also inevitably takes place within the political contexts of the workplace. For example, particularly within Pulmonary Rehabilitation, there are often funding, structural and staffing issues which influence the ability to make effective changes within services despite clinical demands to adapt service models. Reflexivity has become a more widely accepted and applied approach within qualitative research. It allows the researcher to situate the research question within their knowledge and experience with the aim of understanding insights into the personal and social experiences individuals under investigation (Finlay, 2003). It is becoming more widely accepted that Allied Health Professionals (AHP's) are actively involved in research and recently a framework for AHP research has been developed with the view to embed research at a clinical level (Harris *et al*, 2020).

Reflexivity links the elements of the current study of Critical Realism, qualitatively-led mixed methods and a practitioner-researcher approach. Finlay (2002) suggests that 'we no longer seek to eradicate the researcher's presence – instead subjectivity in research is transformed from a problem to an opportunity' (p.212). The issue in contemporary research is now more about how to ensure that a reflexive approach is applied within research rather than explaining the limitations of it. A research journey is a path of discovery. But it is inherent to ensure that the researcher is the central figure which within contemporary research is seen to actively construct and influence the selection and interpretation of the data with a critical perspective whilst being able to anchor the data with clinical relevance (Finlay, 2002). The path journeyed throughout this thesis changed course due to the influence of increased knowledge on the influences on self-management and through a deeper view of the literature

surrounding behaviour change, models of analysis were discovered. During a part-time PhD journey, it is inevitable that initial thoughts and directions change due to developments in the literature as well as clinical practice. This will be discussed more within the Discussion and Conclusion Chapter. Reflexivity allows the researcher to negotiate the path of discovery whilst ensuring trustworthiness, transparency and accountability (Finlay, 2002).

Christ (2013) note that the researcher's worldview influences how the research is produced. This not only links with a researcher-practitioner approach but also the value of using a Critical Realist approach as well as a mixed methods approach to the research. Critical Realism also focusses on how individuals' worldviews influence their behaviours. Being more aware of the influence of this was crucial to be able to understand how different perspectives could influence the success of behaviour change in relation to self-management.

Reed and Procter (1995) outlined three research positions: the 'outsider', the 'hybrid' and the 'insider' researchers. The 'outsider' is described as a 'researcher undertaking research into practice with no professional experience', a 'hybrid' researcher is when 'a practitioner undertakes research into the practice of other practitioners' whilst an 'insider' is described as 'a practitioner undertaking research into their own and their colleagues practice' (Reed and Procter, 1995, p.10). This thesis was undertaken with an 'insider' researcher approach. Drake and Heath (2011) also recognise the value of using an insider researcher approach when working as a practitioner-researcher. It is important to recognise the importance and relevance of the research position. As a researcher I had knowledge and experience within the field of Pulmonary Rehabilitation, the value of 'tacit' knowledge is an advantage to using a practitioner-researcher approach. However, the clinical knowledge of expert clinicians is often difficult to quantify as it is embedded within clinical practice. Within this thesis I employed elements of reflexivity such as intersubjective reflection and a social critique. Intersubjective reflection allows the researcher to explore the mutual meanings within the research relationship. It was important to ensure that my clinical role did not impact upon the participant's ability to freely discuss their opinions within the focus groups. The use of a moderator within the focus groups allowed for a distanced approach.

However, my clinical relationships allowed me to recruit a range of Healthcare Professional participants as well as having links with the local Breathe Easy support group.

Although there are many positives from adopting a practitioner-researcher approach it is also important to acknowledge the risks of introducing bias to the results. It was essential to ensure that my personal experiences and assumptions did not influence to interpretation of the results and that participant views were not influenced by me being present during the focus groups. There is the risk that participants would be reluctant to voice their opinions with a Healthcare Professional present. These risks will be discussed in further detail within the Methods Chapter with reference to how they were acknowledged and minimised.

Using reflexivity in mixed methods research allows for transparency in the methods, data collection and data analysis which is usually only applied in qualitative research. Mixed methods allows for the researcher to have a dynamic relationship with the research (Walker, 2011). Self-awareness and an appreciation of the lived experience of the individual are key elements within reflexivity (Rae and Green, 2016). These elements are also essential components of a critical realist approach.

3.10. Chapter Summary

The current study employed a qualitatively-driven mixed methods approach. The principles of Critical Realism have been presented in relation to the philosophical underpinnings of the study with particular reference to the ontological domains including the factors associated with self-management and adherence, influences of behaviours and individual experiences. This thesis provides a unique perspective on behaviour change by using a Critical Realist approach; recognising and identifying that social phenomenon are complex with the influence of causal mechanisms. Critical Realism is used to determine the influence of social and environmental contexts as well as the influences of emotional and behavioural regulation to determine which elements impact effective behaviour change. The value of triangulation in mixed

methods has been discussed alongside the process of retroductive reasoning through confirmation, completeness and abductive inspiration. The role of a practitioner-researcher enhanced by using a reflexive approach has been discussed in relation to the current research question. The methods and data analysis employed in this qualitatively driven mixed methods study will be presented in Chapter 4.

Chapter 4: Methods

4.1. Overview of Chapter

This chapter will outline the methods employed in the current research study. To answer the research question and objectives, the methods employed were threefold. To determine barriers and facilitators as well as behavioural factors two data collection methods were used: focus groups and a survey. Then a further data analysis was completed using both sets of data in conjunction with the Behaviour Change Wheel as the basis for analysis alongside framing the research findings within the context of the Critical Realist ontological domains: the Real, the Actual and the Empirical. The rationale for selecting focus groups, survey and combining the data analysis, in relation to sampling and recruitment will be explained as well as data collection and data analysis. Ethical considerations will also be discussed in relation to each of the methods.

4.2 Rationale for the structure and sequence of methods

Following the comprehensive literature review the research methods were considered in relation to answering the research question. The focus groups explored the complexities surrounding behaviour change and self-management from the individual perspectives and experiences of patients, Breathe Easy support group members and Healthcare Professionals. These focus groups were aimed to explore a gap in the literature which have tended to focus on either patients or Healthcare Professionals separately. These focus groups aimed to provide a unique opportunity to compare and contrast the views and experiences of a range of participant groups in relation to the topic of adherence and self-management in Pulmonary Rehabilitation.

In keeping with using a mixed methods approach in Critical Realism, methodological triangulation was employed by then conducting the survey to Physiotherapists. To achieve completion and confirmation, key findings from the focus groups surrounding behaviours and behaviour change led to the development of the survey. The range of

perspectives from the focus group participant groups provided evidence of a disparity between what Healthcare Professionals and patients views and beliefs are in relation to self-management. The survey sample was chosen to include Physiotherapists only, to be able to explore further the current practice in Pulmonary Rehabilitation and specifically in relation to Physiotherapists knowledge and skills in relation to support for self-management.

Following the two distinct research methods of the focus groups and survey, which used a primarily deductive approach. The data from the focus groups and survey were combined to evaluate both sets of data by testing against behaviour change theory which aligns more with an inductive approach.

4.3. Focus Groups

To identify behavioural factors influencing uptake and adherence to self-management in Pulmonary Rehabilitation at a local level, a series of focus groups were completed with a range of participant groups. Focus groups were formed with a purposive sample of individuals who had recently completed a local Pulmonary Rehabilitation programme (2 groups, total 4 participants), Healthcare Professionals (2 groups, total 8 participants) and Members of the Breathe Easy support group (2 groups, total 8 participants).

The use of focus groups as a research method has become increasingly popular in qualitative research. Focus groups offer an environment where participants have more opportunity to feel comfortable and free to discuss their thoughts and opinions. Traditional interviews often use closed-ended questions which limits the interviewer's ability to develop an in-depth understanding of the topic area (Krueger and Casey, 2009). Focus groups allow for group interaction where often new thoughts and opinions are uncovered (Krueger and Casey, 2009). The researcher aimed to allow for new ideas and thinking to be revealed through focus groups with different types of participants in each group. Focus groups aim to understand the beliefs that influence participant's attitudes and beliefs surrounding a particular topic (Rabiee, 2004).

Acocella (2012) describe two main research aims for focus group discussions: to facilitate interaction and to gain high quality information. Homogeneity is an important factor to consider when planning focus group discussions (Acocella, 2012). Although the focus groups were aimed at being homogenous it is important to recognise that within this patient population there are often wide-ranging descriptions and experiences in symptoms which will in turn influence an individual's experience of the disease. The individual experiences add value and depth to the data obtained. Discussions in a homogenous group around a similar topic are more fluid and structured compared to a discussion amongst a group of heterogeneous individuals where the discussion would be vague and unfocussed. Focus groups offer a relatively safe environment for participants to share their experiences amongst a homogeneous group and allow for the power balance between researcher and participant to be diluted (Barbour, 2005). This allows for a more natural discussion around a specific topic compared to what may be achieved during a one-to-one interview.

4.4. Sampling and Recruitment

Purposive sampling is advocated when using focus groups to be able to ensure adequate representation from a range of participants (Barbour, 2005). Participants are selected 'by virtue of characteristics thought by the researcher to be likely to have some bearing on their perceptions and experiences' (Barbour, 2008 p. 52). A purposive sampling approach was used to define the focus group types. Krueger and Casey (2009) discuss the use of 'multiple-category design' where different participant groups were used to gain a deeper understanding of the research topic by making comparisons. The three group categories were: patients who had recently completed hospital-based Pulmonary Rehabilitation, Breathe Easy support group members who were attending their maintenance exercise class and Healthcare Professionals who were working in Pulmonary Rehabilitation. Focus groups work best when participants have homogeneous characteristics. For example, participants with similar traits. Participants are then able to discuss the topics freely among like-minded people. Participants with similar traits tend to feel more comfortable and are more likely to express their opinions on the topic of discussion (Krueger and Casey, 2009). In the

current study, the common theme was experiences within Pulmonary Rehabilitation. It was decided to separate out the participant groups and hold group specific focus groups. One of the driving reasons for this was to allow the Pulmonary Rehabilitation patients and Breathe Easy support group participants the opportunity to discuss their thoughts in confidence. Homogeneity in the focus groups maximises the potential for the discussion to be conducted in a supportive environment (Plummer – D’Amato, 2008). There is the risk when mixing groups to include both Healthcare Professionals and patients that the hierarchical structure of the biomedical model of healthcare could influence the power dynamics within the group (Barbour, 2005). There is the risk that the Healthcare Professionals dominate the conversation, and the patients might feel less able to give their opinions. Therefore, to maximise the potential for the generation of rich qualitative data, homogeneous focus groups were used in the current study. Following completion of all the focus groups, the data was triangulated in order to achieve an in-depth understanding from different perspectives of the factors influencing behaviour change in self-management.

Once the sample groups were decided, a convenience sampling approach was used to recruit the participants. For example, invitation letters were given to specific cohorts of Pulmonary Rehabilitation patients, Breathe Easy support group members and Healthcare Professionals.

Focus groups were kept separate from the usual Pulmonary Rehabilitation sessions to allow group members to feel more comfortable in the discussion. It also allows for potentially more discussion and more opportunities to give personal opinions on issues related to behaviours associated with self-management. Focus groups ‘encourage research participants to explore issues of importance to them, in their own vocabulary, generating their own questions and pursuing their own priorities’ (Kitzinger, 2006 p. 22). The groups had varying levels of knowledge, experience and clinical roles. Therefore, it was important to segregate the groups into the three distinct groups. To reduce the influence of hierarchy, it was decided to keep participant groups separate and form three distinct groups: Pulmonary Rehabilitation patients, Breathe Easy support group members and Healthcare Professionals. Some patients or Breathe

Easy support group members may have found it intimidating discussing personal aspects in a group with Healthcare Professionals. Conversely, some Healthcare Professionals may have found it hard to express their opinions on behaviour change amongst patients if they were present in the same group.

Despite evidence-based research on the benefits of Pulmonary Rehabilitation, there still remain difficulties with achieving long-term behaviour change. Clinicians in clinical practice are ideally placed to be able to determine key reasons for the barriers and facilitators to behaviour change. Therefore, Healthcare Professionals are a key participant group to include within the focus groups discussions (Thorne, 2010). Focus groups provide an environment where conversation can be more natural than a one-to-one interview and participants are more likely to feel at ease and comfortable to discuss their own thoughts and experiences. By taking part in the current research study, participants in the focus group contributed their own thoughts and opinions which were then used to determine common factors associated with adherence to exercise and behaviour change in relation to self-management. When considering individual's behaviours and factors associated with successful behaviour change it is essential to hear their thoughts and opinions.

There are many different methods which can be used for recruiting for focus groups such as advertising, finding specific groups of people and targeting them and also finding participants at another event (Krueger and Casey, 2009). The current research study participants were selected in different ways for the different participant groups. These will be outlined.

4.4.1. Pulmonary Rehabilitation Patients

Pulmonary rehabilitation patients were selected using a pre-existing record of patients who had attended Pulmonary Rehabilitation through the local NHS hospital. The researcher applied for 'Local NHS Management Permission' for the focus groups. Participants were recruited over a 3-month period. Two community Pulmonary

Rehabilitation groups were invited to participate in the study. Participants were included if they met the following criteria:

- Attended Pulmonary Rehabilitation within the last 6 months
- Medically stable
- Able to travel to community venue for the focus group
- Able to provide written consent

To reduce the risk of coercion, patients attending two Pulmonary Rehabilitation groups (n=20) were invited to participate in the study with an invitation letter (Appendix I) and participant information sheet (Appendix II) with a reply slip and a pre-paid envelope. Six patients responded and expressed their interest in attending a focus group discussion. However, one participant did not attend on each of the days of the focus group discussions. Therefore, the final sample size for Pulmonary Rehabilitation participants was four. Participants were contacted by the researcher to arrange a date and time for the focus groups. Both during the phone call and when they initially arrived at the focus group, participants were reminded that their participation in the study was voluntary, and they could withdraw at any time without giving reason.

4.4.2. Healthcare Professionals

One of the benefits of using a Practitioner-researcher approach for this study was that the researcher was able to invite colleagues from clinical practice to participate in the focus groups. Drake and Heath (2011) discuss the pitfalls of using colleagues as participants in practitioner-research such as the potential to cause conflict, reveal problems or poor practice in the workplace or friends / colleagues saying the right things for the researcher's research. However, in the current study, Healthcare Professionals were used from the researcher's workplace to have local representatives from the Pulmonary Rehabilitation service and to discuss their opinions on behaviours associated with uptake and adherence to self-management in Pulmonary Rehabilitation locally.

Healthcare Professionals were invited to take part in the study directly by the researcher. The researcher contacted them individually via email including the invitation letter (Appendix I) and the participant information sheet (Appendix II). Healthcare Professionals (n=14) comprising Physiotherapists, Occupational Therapist, Respiratory Specialist Nurses and Respiratory Consultants were approached. Eight individuals agreed to attend a focus group discussion.

4.4.3. Breathe Easy Support Group Members

The local Breathe Easy support group were contacted by the researcher due to pre-existing links from clinical practice and they were keen to be involved in the research project. The researcher attended their monthly group meeting twice and informed the group (n=20) about the research project and their potential involvement and they were then provided with the participant information sheet (Appendix II) and invited to take part in the focus group discussions.

4.4.4. Invitation to participate

All participants were provided with an invitation letter (Appendix I) and a participant information sheet (Appendix II) informing them about the research project. The letter included a tear off slip to send back in a stamped addressed envelope if they were willing to take part in the study. There was a minimum of two weeks to return the reply slip of interest in the study.

4.4.5. Group Sizes

Group sizes are an important factor to consider when planning a focus group. There are varying suggestions on ideal group sizes. Krueger and Casey (2009) suggest that groups should be between five and eight people, whereas more commercial research is often carried out with up to twelve people. Smaller groups offer more time and opportunity for individuals to contribute, especially when talking about sensitive topics. Two groups of approximately five were planned per participant category which allowed for potential drop-outs. Research has shown that completing a series of focus groups

provides more opportunity to gain a deeper understanding into the research question whilst at the same time allowing for different viewpoints. There are two distinct methods of group selection. It depends whether the researcher aims for segmentation or saturation of the data (Krueger and Casey, 2000). Agan *et al* (2008) describe that segmentation is achieved by purposively categorising participants into groups. Segmentation allows for formulation of themes and categories of data so therefore more groups are required. In contrast, saturation requires the researcher to continue to complete focus groups with the same category of participants until no more new data is revealed. The segmentation method was used in the current study by using two groups per participant category to compare and contrast the findings from different groups, allowing for common themes to be recognised (Agan *et al*, 2008). Whilst the individual groups were aimed to be homogenous, it has been recognised that the patients within this population can have varying levels of disease severity which in turn had the potential to produce a range of data within the focus groups (Plummer D'Amato, 2008b). By having separate focus groups per participant group it enabled the participants to be able to discuss their thoughts on the issues surrounding attendance in Pulmonary Rehabilitation within a group of similar participants (Krueger and Casey, 2000). The purpose of using segmentation by having three types of focus groups was to explore the issues surrounding behaviour change and self-management from different perspectives to be able to develop common themes. In contrast, using the saturation method would have involved using the same participant groups but repeating the focus groups until no further new data was obtained (Krueger and Casey, 2000). This would have led to an in-depth understanding of the perspectives from one participant group but the aim of this thesis was to explore the concepts of behaviour change and self-management from multiple perspectives. Therefore, segmentation was more appropriate to use a range of focus groups to explore the same issues but to gain data from varied perspectives.

4.5. Data Collection

Group sizes were between 2 and 5 participants. Participants were informed to expect the focus group session to last up to one hour. Kruger and Casey (2009) suggest that focus groups with smaller numbers often allow for greater richness in the data and

there is less chance of having one dominant participant. The smaller group allows for more depth of conversation and the ability for participants to share experiences in a supportive environment. In a larger group there would be less opportunity for each participant to have their voice heard. This is especially important when investigating behaviour change. The participants need to be allowed to have their thoughts and opinions heard.

During a focus group discussion there are two main types of interaction. At the beginning of the discussion there is usually more interaction between the moderator and the participants which is asymmetrical. Then as the discussion develops, the interaction changes. Participants begin to interact and discuss on a more equal footing and the moderator has less input (Acocella, 2012). It is also important to ensure particularly when completing focus groups that all participants have the opportunity to be heard and feel that they can voice their views openly. Sometimes this can be more challenging with groups who already know each other. It can be a risk when grouping together Healthcare Professionals from different clinical backgrounds, particularly when including respiratory consultants. However, it can also be seen as a positive when a clinical professional group, all of whom have a common link such as working within the Pulmonary Rehabilitation service are put together. In this case, the participants were able to feel at ease, were able to voice their opinions and were also able to expand upon each other's ideas.

The focus groups were audiotaped using two separate recorders to ensure that all participants' voices were heard. The researcher tested each recorder at the start of the focus groups to ensure good sound quality. Participants consented to the focus groups being audiotaped and understood that their names and identities would be anonymised in the data analysis.

In keeping with the practitioner-researcher approach, I independently transcribed the audio data. Some researchers chose to have the audio recordings transcribed by a professional independent transcriber. In this study, I chose to transcribe each focus

group myself. Although it is a very time-consuming task, as a practitioner-researcher I felt that it would allow me to understand the content and aid in my own data analysis if I was more familiar with the content of each focus group. By transcribing the focus groups myself it also enhanced my ability to ensure reflexivity within the data analysis. I was able to reflect upon each focus group in turn and gradually build a picture of the content across all six focus groups before embarking on the specific data analysis process. I read the focus group transcripts initially to familiarise myself with the conversations and then coded the data by highlighting common key words to be able to define common themes. An analytic framework using key concepts was used to code and analyse the data. The note taker notes from each focus group were used to depict key information / statements with timings to cross reference with the audio transcript.

4.5.1. Consent

Consent was gained on the day of the focus group discussion using a consent form (Appendix III). Participants were informed about their role in the study and what to expect and were allowed time to read the participant information letter again. Written informed consent was then taken prior to starting the focus group discussion.

Some researchers use financial incentives for focus group discussions. It is more common in marketing research. However, in non-profit and public organisations such as the NHS it is less common (Krueger and Casey, 2009). Participants were offered 'out of pocket' expenses to participate in the focus group discussions. These were directed at travel expenses, but no-one asked to claim.

4.5.2. Location

It is important to consider the location for focus group discussions, particularly when using participants from different groups. The researcher aimed to use convenient locations for each participant group to reduce the travel time and cost burden. Healthcare professionals were asked to attend a meeting room on the hospital site.

Pulmonary Rehabilitation patients were asked to attend the community setting location where they attended their Pulmonary Rehabilitation course and Breathe Easy support group members were asked to stay after their monthly meeting at their usual meeting location. It is not only important to reduce costs incurred during the study, but it is also beneficial to hold the focus groups in a convenient location to increase the likelihood of participants' attendance.

4.5.3. Moderator

Although it is important to allow participants the opportunity for open discussion, the role of the moderator is invaluable and facilitates the extraction of the most valuable data out of the discussion. A potential pitfall in focus groups is that some members can become more dominant. There is a risk of others not having the chance to give their views or opinions and more dominant individual's views being accepted by others even if they might have their own viewpoint (Kruger and Casey, 2009). To reduce the risk of this possibility, a moderator has a key role to play to ensure that all members of the group have the opportunity to speak. A successful moderator allows for thorough discussion but at the same time is able to prompt further discussion if required. A moderator should be skilled in active listening (Krueger and Casey, 2009) as well as demonstrate the ability to show respect for the participants varying viewpoints. Some researchers prefer to moderate their own focus groups. However, it is often beneficial to have some distance between the researcher and the participants.

By having an independent moderator, it was possible to moderate the discussion without the influence of clinical knowledge or their own views / thoughts influencing the discussion. From a practitioner-researcher point of view, there could have been a strong influence of the clinical knowledge and personal thoughts and opinions which would inadvertently cause bias to the direction of the conversation if the researcher moderated the focus groups. Hence, an independent moderator was planned for the current research project. An independent or neutral moderator helps to facilitate the flow of the conversation, ranging from prompting further discussion in quieter focus groups as well as being able to move the conversation along in more complex

discussions. A neutral moderator should be able to improve the objective data within the focus group whilst not influencing the clinical content of the discussion (Plummer – D'Amanto, 2008b). The moderator was a doctoral student and Physiotherapist in an unrelated clinical role with training in focus group delivery. The researcher spent time with the moderator ahead of the focus group to ensure they were familiar with the content and to provide them with a topic guide document (Appendix IV) which explained and referred to common discussions so that they would know what to expect. It also included a list of useful key phrases which could help to move the conversation along as well as prompt quieter members of the group with phrases such as 'Would you like to add anything.....?' 'So, what do you think about.....?' and 'Does anyone else want to add anything?'

It is also valuable to have a second observer within a focus group discussion to be able to note down non-verbal aspects that are present within the discussion but that may not be captured on the audio recording. The researcher was present as a second observer during the focus group discussion to document key themes, note down any non-verbal communication and support the moderator in the setting up of the focus groups. However, the moderator led the discussion. The researcher did spend time with the moderator before commencing the focus groups to inform them of the research, in particular the topic area and research question so that they had some background knowledge. At the same time, it was emphasised that it was essential for the researcher to remain impartial at this point for the moderator to go into the focus group discussion with an open mind and unbiased viewpoint. Time was spent with the moderator on methods of communication styles and ways in which to facilitate discussions or encourage expansion of conversations. The topic guide (Appendix IV) provided for the moderator for the focus group questions proved invaluable. Moderating focus groups is a difficult skill, they should be able to gain respect from the group, so they feel comfortable discussing sensitive information, whilst at the same time being able to lead and direct the discussion if required (Krueger and Casey, 2009).

An independent moderator was used during 5 out of 6 focus groups. It was not possible to have the external moderator present for all six focus groups for several reasons including Pulmonary Rehabilitation patient availability, moderator availability and limitations with venue availability particularly around the availability of the researcher due to clinical work commitments. Therefore, one of the Pulmonary Rehabilitation patient focus groups was moderated by the researcher. It is preferable to have a moderator who isn't the research themselves to reduce the risk of bias and maintain a degree of neutrality (Krueger and Casey, 2009). The risks with moderating your own focus groups are that there is potential to steer the discussion in a certain direction with your own thoughts and opinions on the subject being discussed which could impact upon the participants ability to ensure their own thoughts and opinions are put forwards (Plummer – D'Amanto, 2008b). Whilst there are limitations to the researcher moderating the focus groups, some researchers choose to moderate their own focus groups, particularly when researching in a researcher-practitioner role. The challenge with this approach is being able to generate interest and discussion in the topic whilst at the same time maintaining a distance to not lead the direction of the discussions. Although not intended, the differences in focus group moderation contributed to reflexivity which acknowledges the multiple ways in which the researcher can contribute to the data being generated (Barbour, 2007). The limitations and influence of having a mixture of an independent moderator and moderating one group myself will be discussed further within the Discussion and Conclusion Chapter.

The process of qualitative data analysis can be described as one that involves producing findings rather than results. Focus groups are particularly useful for examining how knowledge and ideas develop, operate and are expressed in a given cultural setting and it is important to acknowledge that the social context of the relationship between researcher and participants will influence the data obtained (Yardley, 2000). As far as possible, the moderator should attempt to ensure that dialogue occurs amongst focus group members rather than between participant and moderator. The difference in moderator consistency may have influenced the style of questioning and moderating which could have inadvertently influenced the data obtained. The moderator should take a backseat initially, allowing for 'structured eavesdropping' (Kitzinger, 2006 p.26). A more interventionist style, may then be

applied to encourage debate to encourage participants to discuss any inconsistencies, both between participants and within their own thinking.

4.5.4. Data recording

The focus group discussions were audio taped. Visual / video recording can be a distraction to the participants, and they may feel like they can be less 'open' in the discussions. A Dictaphone was placed in the centre of the table to pick up everyone's voices. This was tested before the focus group to ensure it was of adequate quality and it was also tested at the start of each session to ensure all voices were picked up. The focus groups were set up in a circular position to allow eye contact with each other as well as to improve the chances of everyone hearing each other. The researcher was sat on the focus group discussions but away from the group to be able to avoid being part of the discussion and took written notes on non-verbal communication and observable aspects. The researcher remained silent during the focus groups.

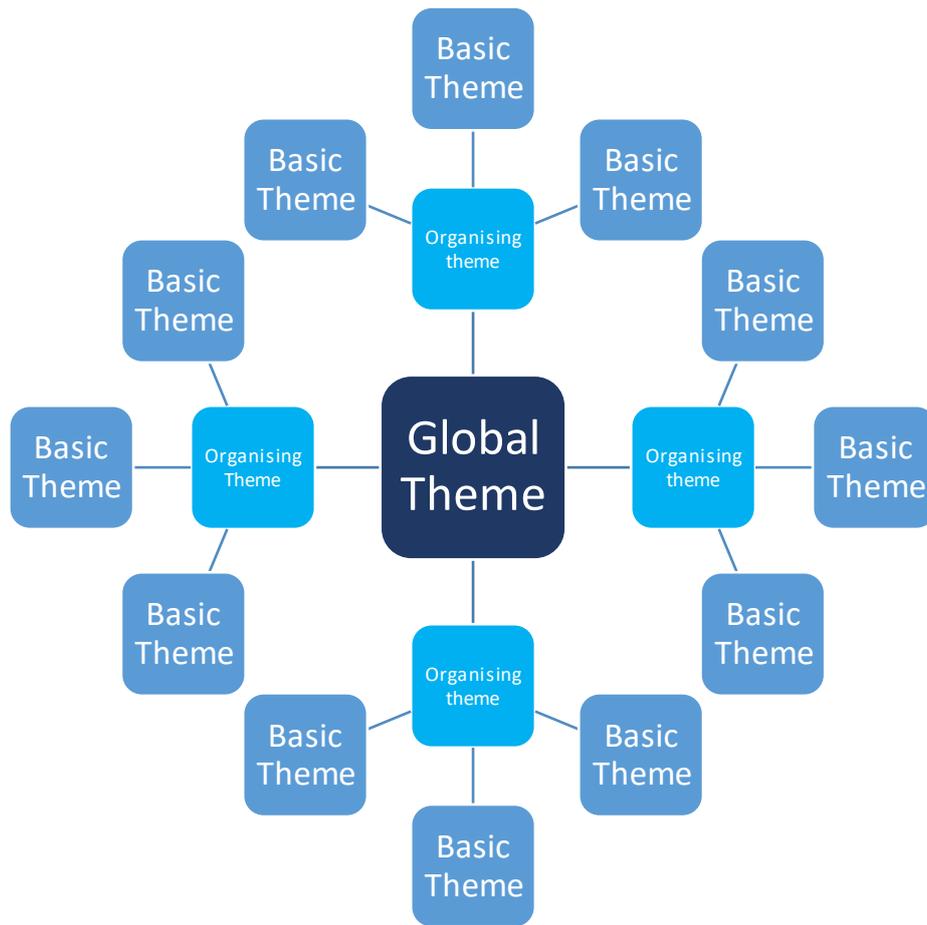
4.6. Data Analysis

Focus groups generate high volumes of qualitative data. To be able to analyse the data thoroughly, a systematic approach must be undertaken. Thematic Analysis is a common method to use to analyse qualitative data, however, although widely used, there is no clear definition of the method (Braun and Clarke, 2006). Essentially Thematic Analysis is 'a method for identifying, analysing and reporting patterns (themes) within data' (Braun and Clarke, 2006, p.6). The researcher employed Thematic Analysis as the method for data analysis with a focus on applying the Attride Stirling (2001) Thematic Networks tool as a way to present the themes as web-like structures. It is common to hear that themes 'emerged' from the data. Nevertheless, this does not acknowledge the active role the researcher has in identifying patterns and themes within the data. Particularly regarding a practitioner-researcher approach, the role of the researcher is central to the interpretation of the patterns and themes in relation to the research question and participants involved. It is also important to acknowledge our own theoretical position within the context of the research and value the influence of this.

Although qualitative research methods have grown in popularity in recent years and indeed in relation to the relevance with practitioner-researchers there are few robust methods available for the data analysis of qualitative data. The thematic networks tool uses the basis of thematic analysis to identify themes but the advantage of using the thematic network tool is that the researcher creates web-like structures to visually represent the relationships between the themes. Initial thematic analysis aims to determine the underlying themes whilst the thematic networks facilitate the understanding and relevance of the themes (Attride-Stirling, 2001). Thematic Networks allows the researcher to organise themes into basic, organising and global themes. Basic themes are described as the lowest order themes. Organising themes aim to group basic themes into relevant categories to describe certain principles, whilst global themes are super-ordinate themes which describe the underlying principles (Attride-Stirling, 2001). The Thematic Networks provide an opportunity to visually present the complexities surrounding behaviour change in relation to self-management.

The Attride Stirling Thematic Networks Tool represents the themes as web-like structures which allows for the themes to be diagrammatically presented. Figure 4.1 shows an example of how the network looks.

Figure 4.1: Thematic Networks (adapted from Attride-Stirling, 2001)



For clarity, the stages of thematic analysis and how the thematic network tools were employed will be outlined:

4.6.1. Phase 1: Familiarising yourself with the data and transcribing the data

Each focus group discussion was listened to in full after each focus group to ensure the recording was accurate and saved appropriately. It was also a useful opportunity for familiarisation with the content of the discussion as well as an initial stage in data analysis. The researcher chose to transcribe all the focus groups independently to be able to become more familiar with the content. This was a more time-consuming task but it enhanced the opportunity to become more familiar with the content.

4.6.2. Phase 2: Generating initial codes

Once the focus groups were transcribed key words / codes and themes were highlighted and noted in the margins of a printed copy of the transcription. The key words / codes and themes were listed in a table organising them into initial codes, issues discussed and basic themes. At this stage it is important to cast a wide net for possibilities of key words / codes. The list can be refined at a later stage once further analysis is completed (Braun and Clarke, 2006). Generally, key words / codes are used initially and then the next stage of analysis will include grouping key words / codes into themes.

4.6.3. Phase 3: Searching for themes

This stage includes a re-focus of the key words / themes to consider how they could be grouped into broader themes. The key words and themes table was reviewed to be able to determine if there were similarities or differences between the focus groups. Attride-Stirling (2001) uses the terms: Basic, Organising and Global themes to differentiate between the different types of themes in relation to their importance and value within the data. The Attride-Stirling (2001) method for using thematic networks was employed as a way of visually presenting the different levels of themes. This method of presenting the data allows the key words / codes to be considered into

overarching themes and the relationships between the themes to be able to determine the different levels of themes, e.g. Basic, Organising and Global themes.

4.6.4. Phase 4: Reviewing themes

Once the themes were defined, the next stage was to review the themes to ensure that they are a true representation of the content within the focus group discussion. The transcribed data was re-read with the list of themes and coded sections of the transcript were reviewed to ensure that each theme was a true representation of the context of the content. At this stage the coded sections were reviewed in relation to the themes to be able to determine whether the themes were appropriate. Once the initial coded sections were reviewed, the themes were then reviewed in relation to the whole focus group transcripts.

4.6.5. Phase 5: Defining and naming themes

This stage involved further refining of the themes in terms of wording and meaning in relation to the content of the transcript data. The key role of this stage is always to be able to ensure the wording of the theme captures 'the essence' (Braun and Clarke, 2006, p. 22) of the true meaning of the theme. The wording of the themes was refined after reviewing the themes alongside the transcripts to ensure that the themes were an accurate representation of the data. A detailed analysis was written for each theme to be able to tell the story for each theme in the context of the data.

4.6.6. Phase 6: Producing the report

Once the themes have been fully refined and confirmed the final stage is producing a report of the full data analysis. For the purpose of the current research, the report was a visual representation of how the themes interacted with each other alongside the full detail outlined in the Focus Group Findings Chapter. Within the data analysis chapter the themes will be described in relation to specific quotes and examples from the transcribed text from the focus groups.

The value of using a practitioner-researcher approach to this thesis was key in using thematic analysis, particularly when deciding what constitutes a theme. For example, a theme does not have to constitute a theme if it is prevalent in the data for more than 50%, and yet a theme can be classed as a theme if the researcher deems it appropriate in relation to the research question (Braun and Clarke, 2006).

From a Critical Realist perspective, the focus groups allowed for a deeper understanding of 'the Real' which relates to the factors influencing self-management in Pulmonary Rehabilitation. From a mixed methods data triangulation perspective, the focus groups served as 'confirmation' of many of the aspects already present in the literature associated with self-management and behaviour change. To be able to lead to retroductive reasoning, the findings from the focus groups led to the development of the survey. The theoretical understanding of self-management and behaviour change from a Critical Realist perspective requires a deeper understanding of 'the Actual' domain. This led to the survey to determine how Pulmonary Rehabilitation is implemented in practice and to be able to observe events that influence behaviour change in self-management. It was key to be able to narrow down the participant group to respiratory Physiotherapists working within Pulmonary Rehabilitation to gain a deeper understanding on their perspectives on self-management as well as determining current practice with regards to behaviour change.

Critical Realism recognises the existence of different types of objects of knowledge, physical, social and conceptual which exhibit different ontological and epistemological characteristics. Therefore, to be able to investigate them, different research methods and methodologies are required to be utilised (Mingers *et al*, 2013). Hence, this thesis employed different research methods for the different elements of investigation; focus groups, survey and finally a combined data analysis focussing on the characteristics of behaviour change.

4.7. Survey

Upon completion of the focus groups, a survey was conducted with Respiratory Physiotherapists. The purpose of this survey was to investigate how behaviour change in relation to self-management was understood and implemented in clinical practice from the perspective of Respiratory Physiotherapists. Using the principles of mixed methods triangulation, the survey contributed to the 'completeness' of the data collection by expanding on the findings from the focus groups.

From a Critical Realist perspective it is important to investigate how mechanisms function within a certain phenomenon to be able to understand the causal influences. To further understand behaviour change in self-management in Pulmonary Rehabilitation, a survey method was chosen as a second research method. A survey method was chosen rather than interviews as it was anticipated that a broader sample population could be targeted using a survey method. A mixed methods approach was employed at this stage to complement the qualitative data from the focus groups. From a Critical Realist perspective, understanding the world in which we live is the driving force (Bryman, 2007). From a practitioner-researcher approach, understanding the world from both the patient and physiotherapists perspective allows for greater understanding of the implementation of support for self-management within Pulmonary Rehabilitation.

The focus groups revealed some detailed themes surrounding the topic of self-management but the next step to determine the barriers and facilitators to self-management in a clinical setting was required. The survey to a larger population of specialist Physiotherapists aimed to find out more specific detail with regards to the global theme of behaviour. The survey aimed to investigate how Healthcare Professionals, in particular, Respiratory Physiotherapists, understand, appreciate and use behaviour change methods in their interactions with patients relating to self-management in Pulmonary Rehabilitation. Pulmonary Rehabilitation is often led by a multidisciplinary team, but often a Respiratory Physiotherapist leads the delivery of the programme. Respiratory Physiotherapists were targeted for the 'completion' stage of this mixed methods study.

4.8. Recruitment

The Association of Chartered Physiotherapists in Respiratory Care (ACPRC) in the United Kingdom is a national specialist interest group of Physiotherapists interested in all aspects of respiratory care.

The ACPRC Chair and Vice-Chair gave written permission (Appendix V) to send the survey to their members via email and advertise within their monthly electronic newsletter. All members were sent the monthly newsletter via email as usual but there was a short piece about the research. The participant information sheet was attached as a link to the newsletter alongside a link to the survey. Members who wished to complete the survey could access and complete the survey by following the link.

Surveys were completed on an opt-in basis therefore consent was assumed from completing the survey. However, the first few questions included confirming that they had read the participant information sheet (Appendix IX), that they understood that their participation was voluntary and that they agreed to be part of the study. Participants were required to complete the questionnaire once only and they were informed that an estimated time to complete the survey was 15-20 minutes.

The ACPRC is a national body of specialist Respiratory Physiotherapists. This body were targeted to be able to gain a deeper understanding of how participants use behaviour change models/approaches and their understanding of self-management across the country. It is especially important when implementing national policy and working towards national agendas for self-management strategies within Pulmonary Rehabilitation to be able to work towards developing clinical practice that is relevant to both patients and clinicians.

4.9. Sample Size

At the time of recruitment, there were approximately 1,000 members in the Association of Chartered Physiotherapists in Respiratory Care (ACPRC). All members received

the monthly newsletter via email as per usual practice. The ACPRC is dedicated to supporting members as well as students, both undergraduate and postgraduate students in their research and advertise research projects such as surveys among their members free of charge. It was estimated that approximately 30-40% of members would respond. It is common for a 75% response rate for surveys (Bowling A, 2002). However, although the sample population was specific to respiratory Physiotherapists, it was unknown how many of the members work or have worked within Pulmonary Rehabilitation and / or would be willing to complete the questionnaire. Thirty-two participants completed the survey. A covering letter has been shown to increase response rate. Therefore, there was a short covering letter included in the email to explain the purpose of the research as well as the participant information sheet. Edwards *et al* (2009) recommend that response bias is influenced by the response rate and several factors can influence the success of the response rate. For example, a shorter questionnaire, financial incentives, pre-paid return envelopes, an assurance of confidentiality and sufficient warning about the survey deadline date.

There is a risk when sending a survey to a relatively small sample group that the response rate will be small and those who respond may be more interested in the subject area, so there is a possibility of responder bias. This is an important factor to consider during the data analysis.

4.10. Pilot Survey

A pilot survey was carried out on a small sample of convenience which included respiratory Physiotherapist colleagues (n=5) within the researcher's workplace. The main aim of the pilot was to check the length of time required to complete the survey as well as ensuring that the questions were clear and understandable. After the pilot study, the researcher had a short conversation with each participant to ask relevant questions such as time to complete, ease of understanding and relevance. Most participants reported that the survey took no longer than 20 minutes to complete and that the language was appropriate for their level of understanding. There were no

changes made from the pilot study to the main survey. Therefore data discussed includes both the pilot survey responses as well as the main survey responses.

4.10.1 Survey Design

The survey was designed through the Bristol Online Survey package for which Northumbria University held a subscription for. All responses were recorded automatically on the Bristol Online Survey as a saved project. Each participant response was saved individually as well as each response being recorded on a summary document which allowed data to be summarised as well as compared to other responses.

The aim of the survey was to enable the researcher to gain a deeper understanding of how Respiratory physiotherapists' behaviour towards self-management influences patient outcomes and to determine whether specific behaviour change techniques were used in clinical practice within Pulmonary Rehabilitation. Using an interpretivist approach, the aim was to gain a deeper understanding from a range of perspectives. In this way, the survey to a broad sample of Respiratory Physiotherapists allowed for a range of responses to build upon the findings from the focus groups. The survey comprised a mixture of open and closed questions to allow for variety in the information received as well as offering different methods of asking a question. Open-ended questions allowed for more freedom of answers. Closed questions may not have allowed for sufficient scope for answers within this complex subject area.

The survey started with simple demographic questions and closed response questions but then moved on towards more open-ended questions which participants could elaborate more or less on, depending on their experiences and clinical background. Survey questions can be found in Appendix XI. It should have taken approximately 15-20 minutes to complete the survey. The researcher recognised that participants may be busy and would be reluctant to complete a survey that would take longer than 30 minutes to complete. The researcher ensured that the anticipated time to complete was made clear to the participant.

4.10.2 Development of the survey questions

The findings from the focus groups surrounding behaviour change led to further consideration of behaviour change models and theories. The literature was reviewed periodically throughout the conduct of this thesis and behaviour change theory literature became more widely cited from 2017 onwards. When the survey questions were developed in 2017 there were fewer papers relating to behaviour change theory. The Behaviour Change Techniques Taxonomy (Abraham and Michie, 2013) influenced the development of the questions but at the time of developing the survey questions it was used as a guide in conjunction with some of the key discussions within the focus groups. The global theme of behaviour change from the focus groups provided a platform to develop understanding of behaviour change in relation to self-management. Key aspects from the focus group discussions included goal setting, support mechanisms, knowledge and skills and the influence of fear and anxiety and access to Pulmonary Rehabilitation, these were areas consistent in the existing literature surrounding self-management in Pulmonary Rehabilitation. Some of the key aspects relating to behaviours were consistent with behaviour change techniques listed in The Behaviour Change Techniques Taxonomy (Abraham and Michie, 2013) but it was not intended to list the behaviour change techniques within the survey questions. The survey was developed at a time when behaviour change literature was developing and since the questions were written and the survey conducted there have been several papers published with particular focus on the Theoretical Domains Framework and the COM-B system (Richardson *et al*, 2018, Cheng *et al*, 2022, Whittaker *et al*, 2022, and McGowan *et al*, 2020). These papers have been introduced in Chapter 2: Literature Review, and will be discussed further in Chapter 7: Conceptualising behaviour change in self-management.

4.11. Data Analysis

Demographic details were recorded to analyse whether certain responses were from a particular group of participants. Closed response data were transferred into an Excel spreadsheet and presented as a series of graphs to indicate frequencies. Open-ended

/ free-text questions will be analysed using the framework method. Themes were generated from the analysis of the open-ended questions.

It is important when handling qualitative data to ensure that it is analysed in an appropriate way using relevant methods. The Framework Method has been used in qualitative data analysis since the 1980's and allows the researcher to categorise and summarise data to be able to make sense of it as well as being able to draw conclusions (Gale, 2013). The Framework Method is a flexible method to use among a variety of philosophical and theoretical approaches. It allows the researcher to identify similarities and differences among the data as well as allowing the researcher to explore relationships between the data to come to conclusions based on themes. This thesis used an inductive reasoning approach, meaning that the research question was approached by aiming to develop theory rather than by testing an existing theory (deductive reasoning). An inductive approach to this thesis allowed for an in-depth review of the aspects associated with behaviour and self-management.

Critical Realism is an important theoretical framework to apply to the context of behaviour change. Critical Realists retain an ontological realism, that there is a real world which exists independently of our perceptions of it, while accepting epistemological construction and relativism, that our understanding of the world is a construction of our own perspectives of it (Maxwell, 2012). From a Healthcare Professionals point of view it is important to consider that the patient is an individual who may be experiencing 'real' physical limitation and psychological emotions which have an influence on their ability to engage with behaviour change. This is especially important when delivering elements of behaviour change such as education on self-management. Therefore, to be able to deliver complex interventions such as Pulmonary Rehabilitation, in particular self-management and adherence to exercise, it is essential to firstly understand the 'mind' of the patient in the first instance. This is why it is important for Healthcare Professionals to have skills in behaviour change techniques. This survey aimed to investigate whether Physiotherapists used behaviour change techniques during Pulmonary Rehabilitation.

Behaviour change is a key component in effective self-management in Pulmonary Rehabilitation. It is especially important to ensure that the content and delivery of this intervention is individually tailored to the patient. It is, therefore, necessary to identify the specific components or 'active ingredients' to optimise patient outcomes. Behaviour Change Techniques have been proposed and suggested as being 'active ingredients' to change behaviour. A Behaviour Change Technique is defined as 'an observable, replicable, and irreducible component of an intervention designed to alter or redirect causal processes that regulate behaviour' (Presseau, 2015). The Behaviour Change Techniques Taxonomy version 1 includes 93 Behaviour Change Techniques which are sub-grouped into 16 categories (Abraham and Mitchie, 2013). The Behaviour Change Taxonomy informed the planning of this survey question. The themes from the focus groups also influenced and contributed to planning to investigate behaviour change strategies. It must be noted that "The Behaviour Change Techniques Taxonomy" only informed the question. It was not intended to include all the Behaviour Change Techniques within the survey questions. One survey question included a list of Behaviour Change strategies which were a combination from aspects from the focus groups and relevant literature which were selected by the author due to the relevance to Physiotherapists working within Pulmonary Rehabilitation. Participants were asked to indicate if they used them in practice. Participants could select more than one answer.

For the three main free-text questions; 13, 21 and 2, the Framework Method (Gale *et al*, 2013) was used for data analysis. The Framework Method allows the researcher to analyse qualitative data by developing an analytical framework to create a new structure to the data which allows the researcher to summarise the data. The Framework Method is commonly used for the analysis of qualitative methods such as interviews. However, it can also be used for other methods such as focus groups. In addition, it can also be used for homogeneous textual data such as that from the survey. The Framework Method is a highly systematic model which comprises seven stages for analysis which will be outlined:

4.11.1. Stage 1: Transcription

Usually this stage involves the transcription of the audio from interviews or focus group. However, for the purpose of this thesis, this stage was slightly different to the model, as the framework was being applied to survey responses rather than interview transcription. Survey responses were recorded in individual PDF documents for each participant as well as on a summary document produced by the Bristol Online Survey. The researcher spent time reading and reviewing the participant responses as each response was submitted.

4.11.2. Stage 2: Familiarisation with the data

Familiarisation with the data is essential for the researcher to be able to have a deeper understanding of the data. It is an important step in data analysis. The researcher read each participant response as they were submitted during the data collection period to become familiar with the responses from the very start of the data analysis. Each response was saved as an individual document. The researcher re-read the responses at regular intervals during the data collection period to become immersed in the data. A summary document was produced for the whole survey responses as well as a separate document for the pilot survey responses.

4.11.3. Stage 3: Coding

Survey responses were read thoroughly, and then key words / themes were highlighted within the text of each document; primarily for the free-text questions. Initial coding included an 'open coding' approach in which the researcher coded any key words that may have been relevant. 'Open coding' is an inductive approach to data analysis which enabled the researcher to allow for themes to be recognised from the data, rather than having 'pre-defined' codes which is more of a deductive approach to data analysis. Coding allows the researcher to categorise the data for the data to be compared systematically (Gale *et al*, 2013). Once the coding was complete for the free-text questions, the researcher documented these in a table format to allow for structure.

4.11.4. Stage 4: Developing a working analytical framework

Framework analysis should involve a team of researchers. When working on the analytical framework, it is important for the research team to discuss the codes which have been attached to the data. From this stage it is then possible for the research team to discuss an analytical framework. The research team met and discussed the initial codes applied to the survey responses. The team agreed on the initial codes selected from the free-text questions.

The Theoretical Domains Framework was used as a lens to view the data from the survey responses to be able to identify the barriers and facilitators to self-management and behavioural mechanisms influencing behaviour change in clinical practice. The qualitative free-text responses from the survey were mapped to the Theoretical Domains Framework.

To date the Theoretical Domains Framework hasn't been applied to focus group or survey data. It has been used in implementation research and systematic and structured literature reviews, although the guidance by Atkins *et al* (2017) relate to implementation research focussing on qualitative approaches such as interviews and focus groups. The Theoretical Domains Framework was used as a theoretical lens to view the cognitive, affective, social, and environmental influences of behaviour change in self-management.

4.11.5. Stage 5: Applying the analytical framework

Data analysis using the Theoretical Domains Framework can be done either deductively or inductively (Atkins *et al*, 2017). If a deductive approach is used, then the Theoretical Domains Framework is used to generate the framework for content analysis. Compared to using an inductive approach, in which themes are generated and then considered in relation to the domains. This study used a more inductively orientated approach by exploring the data initially to develop themes and then these were mapped to the 14 Domains of the Theoretical Domains Framework. The

Theoretical Domains Framework has been more widely applied since the conduct of this survey. Atkins *et al* (2017) suggest the use of an inductive approach to data analysis using the Theoretical Domains Framework. Exploration of the themes was an essential part of the analysis which is in keeping with a mixed methods approach to this study which also aligned with the principles of confirmation and completeness. This level of analysis contributed to abductive inspiration in understanding the components of the complex phenomenon of behaviour change in self-management.

The responses to the survey questions focussing on the meaning of self-management and behaviour change were mapped to the 14 domains of the Theoretical Domains Framework.

4.11.6. Stage 6: Charting data into the framework matrix

A structured method for charting the data to the framework is to use a spreadsheet format. Within this stage, the behaviour change techniques were listed and the survey responses were mapped to these. It is important at this stage to not lose the original meaning of the data by reducing the data to key words (Gale *et al*, 2013). However, it is an important step in analysing the data to map the content of the response to a framework to be able to determine themes.

4.11.7. Stage 7: Interpreting the data

From a practitioner-research point of view, interpreting the data involves using a reflexive approach which means reviewing the data and relating to clinical practice and the clinical problem as well as using the qualitative and quantitative findings. It should be a continual process of reading and refining the data. Once the data was mapped to the Theoretical Domains Framework, the research team met to review the data and discussed the content before a final consensus was agreed. Within this stage it is an opportunity to explore relationships within the data as well as determining causality. If the data is rich enough, it can lead to determining reasons for phenomena.

Although there was a small response rate to the survey, the data was rich and specific to the topic area of behaviours and behaviour change techniques.

4.12. Wider Ethical Considerations

This section will provide an examination of the ethical issues associated with the design and conduct of the focus groups and survey. Some aspects relate specifically to the focus groups, and some relate to the survey, whilst some may be applicable to both.

4.12.1. Independent Review

Prior to conducting the focus groups and survey, ethical approval was sought via an independent review through the Integrated Research Application System (IRAS). A full ethics application was submitted with a request for proportionate review. This application was successful after some minor amendments to some of the documentation. After making the minor amendments and re-submitting, ethical approval was granted on 10th September 2015 with REC reference number 15/SW/0240 and IRAS project ID 167849 (Appendix VI). Following ethical approval from the Integrated Research Application System (IRAS), both the local NHS trust, dated 15th October 2015 (Appendix VII) as well as Northumbria University ethics submission, dated 3rd April 2018 (Appendix VIII) were completed and approved.

4.12.2. Consent

As previously indicated, all participants were asked to provide consent prior to conducting the focus groups and completing the survey. Written informed consent was gained prior to the focus groups (Appendix III) and consent was given during the initial questions on the survey (Appendix X). Participant information sheets were provided for both the focus groups and survey. Focus group participant information sheets (Appendix II) were given to read prior to expression of interest for the focus groups and also were provided on the day of the focus groups to review if required.

Participant information sheets (Appendix IX) were provided alongside the survey to read prior to giving consent.

A potential concern from a practitioner-researcher perspective is always going to be focussed on the risk of coercion when conducting research with colleagues or patient groups with whom the researcher has existing relationships with. For this reason and to reduce the risk of potential coercion, the participant information sheets, and expression of interest forms were given to the participants and they were asked to reply using a pre-paid envelope if they wished to be part of the study. Participants were reminded that their participation was voluntary at the start of the focus groups and were reminded that they were able to withdraw from the discussion at any point and their clinical care would not be affected.

4.12.3. Anonymity and Confidentiality

ACPRC members are required to select that they are happy to be contacted via email for information and to contribute to research when they sign up as a new member. The researcher did not have access to personal data such as name, address or email address. Participant names were not provided so their answers were anonymous. Data such as area of work were requested but this was not identifiable to the participant. The researcher provided personal contact details via the information provided within the newsletter email which also facilitated contact, as well as it being clear on the participant information sheet. Participants could easily get in contact if required. Participants were not obliged to complete the survey as it was an opt-in basis. Data was stored on a personal password protected USB stick as well as having a back-up version which was also password-protected. Documents created were password-protected.

Focus group participants were informed that they would remain anonymous and coded labels would be used rather than names when transcribing the focus group discussions. Participants were assured that information discussed within the focus groups would remain confidential. This was particularly important during the

Healthcare Professionals focus group sessions during which they were reassured that matters discussed around service provision would not impact their clinical role. Therapy team managers were informed about the project and permission was gained before recruitment took place.

4.13. Conceptualising Behaviour Change in self-management

In keeping with a Critical Realist approach using data triangulation, the data from the focus groups and survey were analysed together to be able to identify causal mechanisms associated with behaviour change in self-management. This level of conceptual thinking aligns with the concept of abductive inspiration. To be able to conceptualise the causal mechanisms associated with behaviour change in self-management, abductive inspiration encourages using one method to generate ideas which are then tested by another method. This method was used within this thesis. The focus groups aimed to confirm aspects from the literature and the survey expanded thinking on clinical practice surrounding behaviour change in self-management by means of completion.

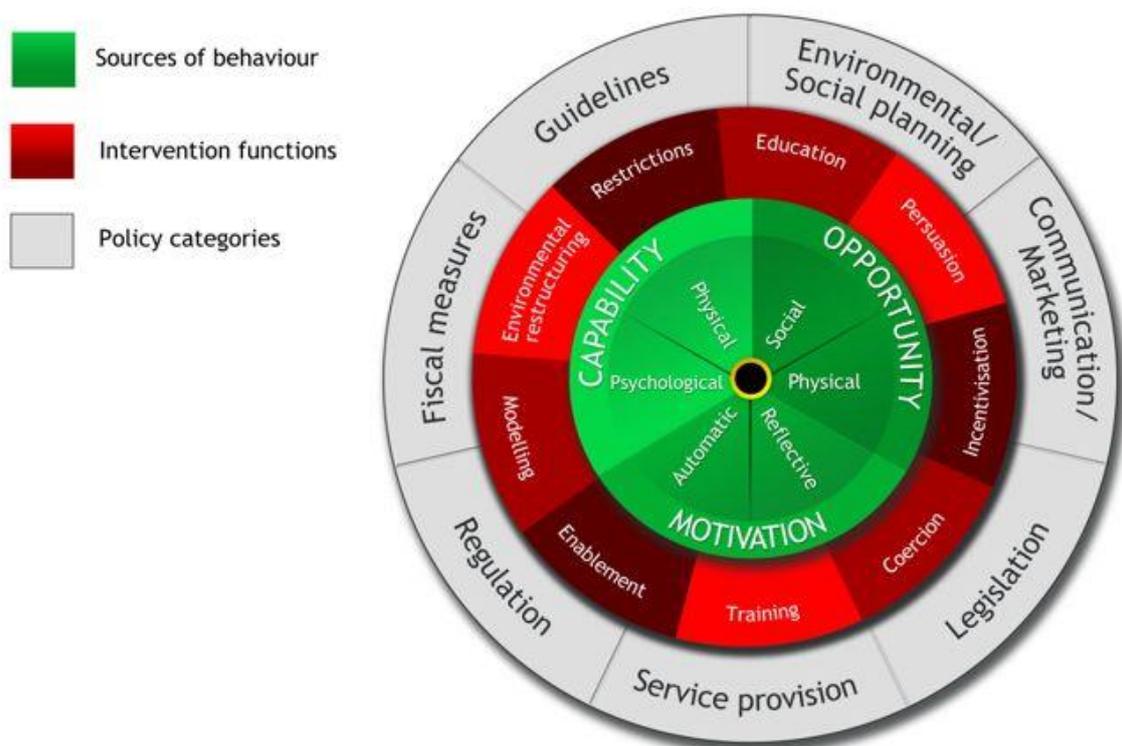
The focus groups centralised around the ontological domain of 'the Real', focussing on determining the factors influencing self-management and behaviour change in Pulmonary Rehabilitation. The survey primarily focussed on the domain of 'the Actual', focussing on the implementation of self-management in Pulmonary Rehabilitation and the consequent events. This third level of data analysis allows for the development in thinking surrounding the domain of 'the Empirical' to conceptualise the causal mechanisms associated with behaviour change in self-management.

During the course of this thesis the concept of behaviour change became more widely appreciated and investigated within the literature. Therefore, critical thinking surrounding the emerging literature influenced the direction of this third level of data analysis. The Behaviour Change Wheel with particular reference to the COM-B model at its centre formed the basis of this third level of data analysis. This data analysis was completed mapping both the focus group and survey data using the Behaviour

Change Wheel as a framework and by conducting a COM-B diagnosis to determine the factors associated with the Capability, Opportunity and Motivation for successful self-management. The Behaviour Change Wheel framework will be presented as a method to determine how behaviour change in relation to self-management has influences from different aspects by conducting a COM-B diagnosis as well as considering the intervention types within self-management in Pulmonary Rehabilitation and the influence of policy on behaviour change in this context.

The Behaviour Change Wheel and COM-B models were described within the Introduction Chapter but are outlined again to describe the methods used.

Figure 4.2: The Behaviour Change Wheel (Michie *et al*, 2011)



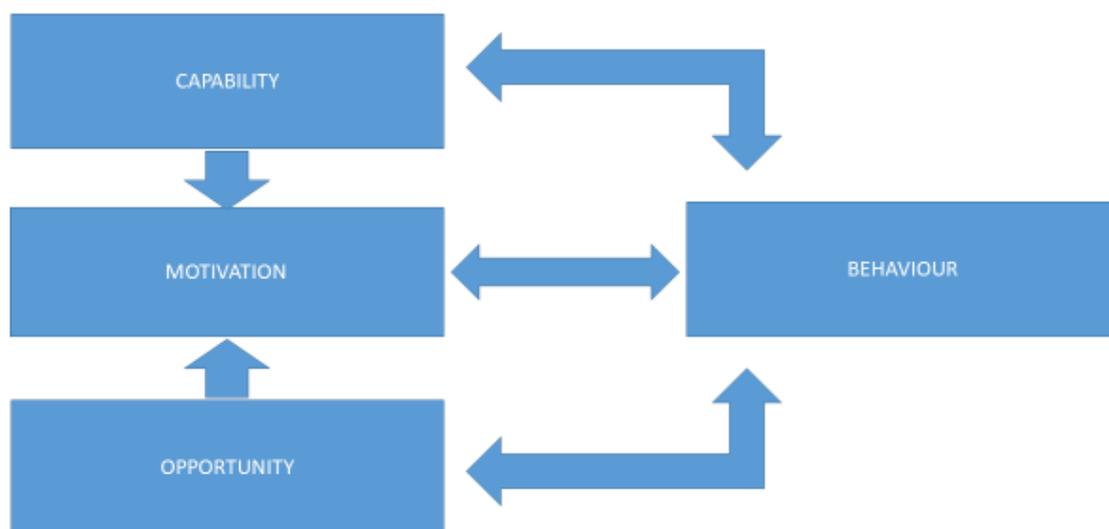
At the centre of the wheel are the sources of behaviour categorised by the Capability, Opportunity and Motivations (COM) associated with the Behaviour (B). From a Critical Realist perspective, it is within these elements that the causal mechanisms were explored. Firstly, a COM-B diagnosis using both the focus group and survey data allowed for the data to be categorised into the physical and psychological capability, the physical and social opportunity and the reflective and automatic motivation.

Michie *et al* (2011) proposed the COM-B model which reflects the elements required to perform a behaviour. Within the COM-B model, also termed a 'behaviour' system by Michie *et al* (2011), Capability, Opportunity and Motivation interact to generate Behaviour that at the same time can influence each of the components. The COM-B model represents the causal links between the elements which can in turn influence each other. Using a Critical Realist approach, this thesis also investigated the causal links between the different elements at play within the behaviour of self-management. Michie *et al* (2011) defines Capability as 'the individual's psychological and physical capacity to engage in the activity concerned which includes having the necessary knowledge and skills' (p.4). Motivation is defined as 'all those brain processes that energise and direct behaviour, not just goals and conscious decision-making and includes habitual processes, emotional responding as well as analytical decision-making' (p.4). Opportunity is defined as 'all the factors that lie outside the individual that make the behaviour possible or prompt it' (p.4). Michie *et al* (2011) also subdivided each category. Capability is divided into physical and psychological, with the 'psychological capability being the capacity to engage in the necessary thought processes' (p.4). Opportunity is divided into physical opportunity which refers to the environmental aspects, whilst the social aspect refers to the cultural influences such as 'the way that we think about things' (p.4). Motivation is divided into 'reflective processes including evaluations and plans and automatic processes involving emotions and impulses that arise from associative learning and / or innate dispositions' (p.4).

Secondly, the data from the focus groups and survey analysis were mapped onto the intervention functions associated with self-management as a behaviour. The COM-B

model is presented as a model of behaviour which will be used to determine the factors associated with each element; Capability, Motivation and Opportunity, using the data from the focus groups and survey responses.

Figure 4.3: The COM-B model (Michie *et al*, 2011)



Critical realism will form the basis of this analysis. Triangulation of the data from the focus groups allows for a deeper understanding of the causal mechanisms involved in successful self-management. Triangulation of data in critical realism and mixed methods is particularly valuable due to the potential for multiple interpretations of reality from the participants in the focus groups and survey. By triangulating the data from the focus groups and survey and analysing using the COM-B diagnosis and determining the intervention functions the causal mechanisms were investigated. Further analysis was completed relating the COM-B diagnosis to the ontological domains. The data will be discussed and discussed in relation to the Critical Realist ontological domains of The Real, The Actual and The Empirical.

4.14. Chapter Summary

This chapter has outlined the research methods employed in the current study and presented an account of planned data analysis as well as ethical considerations. Chapter 5 will provide a detailed account of the focus group findings, followed by a detailed account of the survey findings in Chapter 6. These will be considered together in relation to conceptualising behaviour change in self-management in Chapter 7.

Chapter 5: Focus Group Findings

5.1. Overview of Chapter

This chapter will present an overview of the findings from the six focus groups conducted with individuals who had recently completed Pulmonary Rehabilitation, Healthcare Professionals and members of the local Breathe Easy support group. The focus group findings will be discussed in relation to the Thematic Analysis using the Attride Stirling Thematic Networks tool.

5.2. Background to analysis and presentation of focus group findings

Focus groups were conducted over a six-month period between December 2015 and May 2016 at irregular intervals which were due to participant, researcher and room availability. Focus groups were carried out with a purposive sample of individuals who had recently completed Pulmonary Rehabilitation (2 groups, total 4 participants), Healthcare Professionals (2 groups, total 8 participants) and Members of the Breathe Easy support group (2 groups, total 8 participants).

5.3. Response Rate

There were only two participants in each of the Pulmonary Rehabilitation patient focus groups. Participants were invited from two Pulmonary Rehabilitation group cohorts, which included approximately 15-20 people. Only five patients responded and agreed to attend. One participant was unable to attend due to being unwell on the day of the focus group but there was generally poor uptake from the groups. This is indicative of some of the difficulties encountered when attempting to engage this patient group. As the focus group research was not part of the Pulmonary Rehabilitation programme, this may have influenced the patient's decision to agree to attend. With such a small response rate, the data obtained is only a snapshot of a potentially much larger patient population group. The patients who did respond are likely to be more motivated, which could lead to bias in the data obtained. It may not be a true representation of the

sample population. The focus groups varied in length due to a varied number of participants in each group and so the conversation flow was different. Duration of the focus groups varied from 32 to 60 minutes.

Table 5.1: Summary of the Pulmonary Rehabilitation and Breathe Easy group participants' demographic details:

Focus Group	Coded Name	Age / Gender	Condition
Pulmonary Rehabilitation (Group 1)	PR 1	58 Male	COPD
Pulmonary Rehabilitation (Group 1)	PR 2	73 Male	Bronchiectasis / COPD
Pulmonary Rehabilitation (Group 2)	PR 3	73 Female	COPD
Pulmonary Rehabilitation (Group 2)	PR 4	70 Male	COPD
Breathe Easy Support Group (Group 1)	BE 1	72 Male	Bronchiolitis
Breathe Easy Support Group (Group 1)	BE 2	75 Male	COPD
Breathe Easy Support Group (Group 1)	BE 3	67 Female	Bronchiectasis / COPD
Breathe Easy Support Group (Group 1)	BE 4	74 Male	Asthma / Bronchiectasis
Breathe Easy Support Group (Group 1)	BE 5	84 Female	COPD
Breathe Easy Support Group (Group 2)	BE 6	74 Female	COPD
Breathe Easy Support Group (Group 2)	BE 7	70 Female	COPD
Breathe Easy Support Group (Group 2)	BE 8	74 Female	COPD

Average age of non-medical participants: 72

% Female: 70%

% Male: 30%

Table 5.2: Summary of the Healthcare Professional group participants' demographic details:

Focus Group	Coded Name	Age / Gender	Profession
Healthcare Professionals (Group 1)	HCP 1	Female	Occupational Therapist
Healthcare Professionals (Group 1)	HCP 2	Female	Physiotherapist
Healthcare Professionals (Group 1)	HCP 3	Female	Respiratory Nurse
Healthcare Professionals (Group 1)	HCP 4	Female	Physiotherapist
Healthcare Professionals (Group 2)	HCP 5	Female	Consultant
Healthcare Professionals (Group 2)	HCP 6	Female	Consultant
Healthcare Professionals (Group 2)	HCP 7	Female	Physiotherapist
Healthcare Professionals (Group 2)	HCP 8	Female	Physiotherapist

*Participant names have been replaced by coded letters and numbers to ensure anonymity and confidentiality.

5.4. Thematic Networks Analysis

Verbatim transcripts formed the basis for thematic network analysis. The Attride Stirling (2001) thematic networks method of data analysis was used to define themes from all 6 focus groups.

Phase one included reviewing the transcripts to become more familiar with the data from all six focus groups. During this stage, it was an opportunity to listen to and read all the transcripts together to be able to recognise similarities and differences. Phase two comprised identifying codes or key words within the text. These were then related to the issues discussed within the focus groups. These issues were then grouped into the basic themes. Table 5.3 outlines the codes, issues discussed and basic themes, which are steps 1 and 2 from the Attride Stirling Method (2001). Data from all six focus groups was reviewed and the key words were noted and highlighted in the text, and so these formed the initial codes as listed in Table 5.3. Following this, the issues discussed were noted to be able to formulate the basic themes. The Thematic Networks tool allows for the organisation and representation of Thematic Analysis. Thematic Analysis forms the basis for Thematic Networks, but the Thematic Networks tool is a way of presenting the Thematic Analysis.

Table 5.3: Steps 1 and 2 of Attride Stirling Method analysis of focus group data

Focus Group	Codes (Step 1)	Issues Discussed	Basic Themes identified (Step 2)
Rehabilitation Pulmonary	<ul style="list-style-type: none"> • Support • Social • Depression • Anxiety • Embarrassment • Confidence 	<ul style="list-style-type: none"> • Group support / peer support • Fear and anxiety of attending a group and exercising • Physical limitations • Psychological impact of symptoms • Friendship and support mechanisms 	<ul style="list-style-type: none"> • Psychological impact plays a large part in motivation and attendance • Group/peer support helps with symptoms of anxiety and depression
Support Groups Breathe Easy	<ul style="list-style-type: none"> • Medication • Exacerbations • Infection • Learning • Health Status 	<ul style="list-style-type: none"> • Medicalisation of condition • Unpredictable nature of the disease • Fear of exacerbations • Hospitalisation • Importance of Education 	<ul style="list-style-type: none"> • Fears of frequent exacerbations, spreading infection in group environment • Comparing medications with each other • Education on self-management during an exacerbation • Decrease in physical ability when unwell
Healthcare Professionals	<ul style="list-style-type: none"> • Medical support • Education • Goal Setting • Confidence 	<ul style="list-style-type: none"> • Follow-up • Motivation • Exacerbation management • Self – management • Improved physical outcomes 	<ul style="list-style-type: none"> • MDT support to guide physical activity and self-management • Education on self-management, pacing and goal setting • Positive feeling when improving physical outcomes

Phase three comprised of a review of the codes and Basic themes and these were considered within the context of the whole content of the focus groups. Many of the issues discussed within all focus groups centralised around aspects of behaviours related to self-management. For example, motivation, confidence, knowledge and anxiety and depression. Aspects of behaviours towards self-management were frequently identified throughout all 6 focus groups across the three participant groups. It was therefore appropriate that the influence of behaviour on self-management was defined as the Global theme.

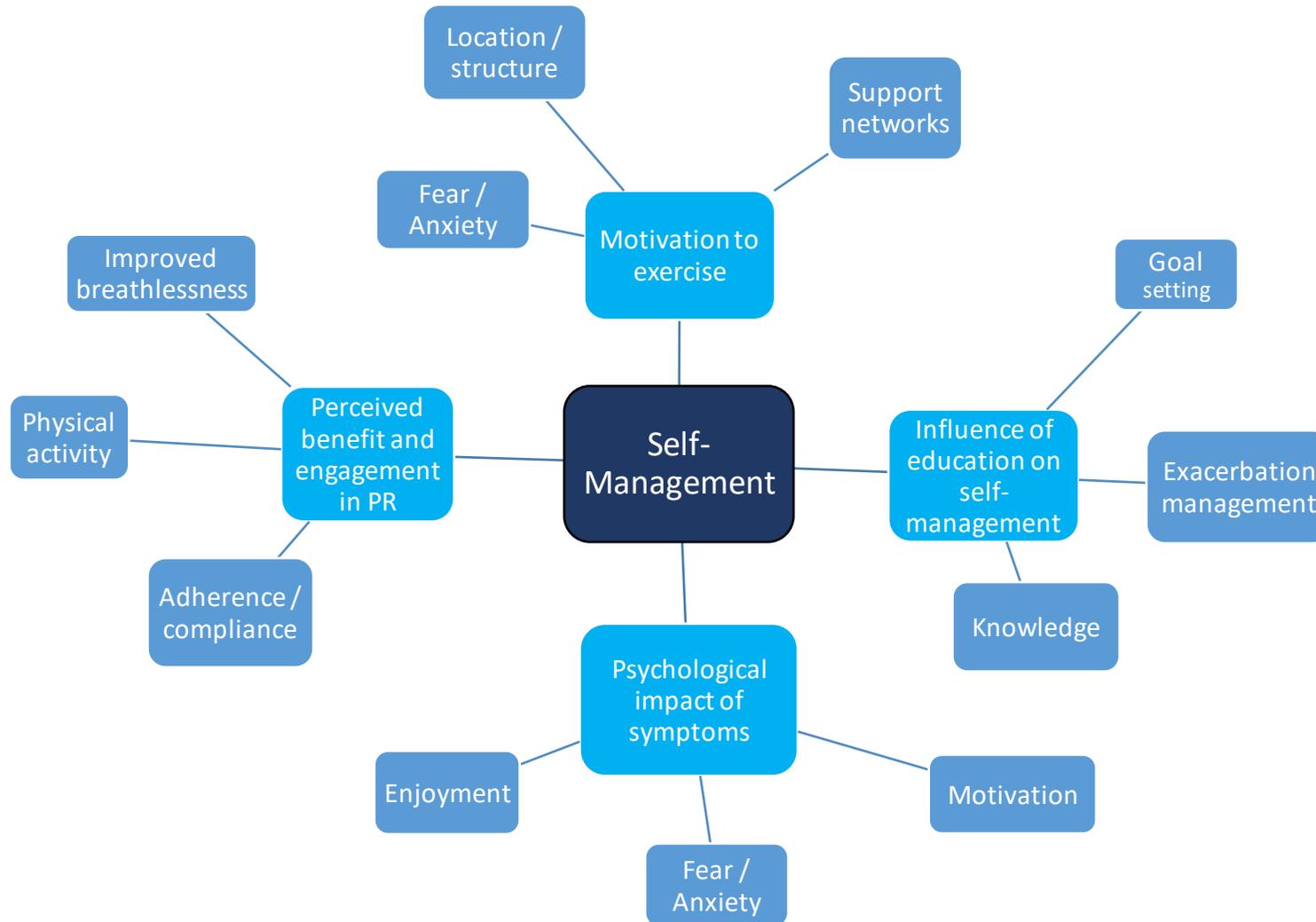
The next level of analysis in Thematic Networks is to categorise the Organising themes. The Basic themes were reviewed and common themes were grouped together in relation to behaviours associated with self-management. These groups then formed the Organising themes. The Organising themes included Motivation to Exercise, Influence of Education on Self-Management, Psychological Impact of Symptoms and Perceived Benefit of and Engagement in Pulmonary Rehabilitation. The Basic themes encompassed a variety of topics, and some spanned more than one Organising theme. Table 5.4 demonstrates the Global, Organising and Basic themes. The Global theme regarding the influence of behaviour on self-management is underpinned by the Organising themes which were discussed in terms of their influence on self-management behaviours. There were multiple Basic themes discussed which were related to more than one Organising theme but within the table the Basic themes are listed in relation to the Organising theme associated with it. The Basic themes tended to be associated with barriers to adherence in Pulmonary Rehabilitation.

Table 5.4: Attride Stirling data analysis presenting themes

Global Theme	Influence of Behaviour on Self-Management in Chronic Lung Disease			
Organising Themes	Motivation to Exercise	Influence of Education on Self-Management	Psychological Impact of Symptoms	Perceived Benefit of and Engagement in Pulmonary Rehabilitation
Basic Themes	Location	Exacerbations Management	Blame	Maintenance
	Time	MDT input	Support Mechanisms	Adherence / Compliance
	Transport	Expertise	Confidence	Physical activity
	Support Network	Medications	Fear	Improved Breathlessness
	Structure	Goal Setting / Pacing	Trust	Walking
	Confidence	Knowledge	Group Dynamics	Education
	Fear/Anxiety	Exercise / Physical Activity	Anxiety / Depressions	Walking ability
	Adherence	Advice / Support	Motivation	Daily activities
	Outcome Measures	Hospital Admissions	Enjoyment	Fear
	Friends / Social Support	Education		
	Programme Structure			
	Education			

Figure 5.1 shows how the themes were mapped onto the Thematic Networks Tool. The spider-type diagram shows how the themes are linked. It starts with the Global theme as the higher order theme followed by the Organising theme and then the Basic themes as the lowest order theme. This thesis demonstrates a unique representation of the links between the thematic networks using the Attride Stirling tool (2001) which shows the connections between the elements associated with self-management. The three levels of themes show the underlying mechanisms discussed in the focus groups and present the associated links with key factors relating to barriers and facilitators to achieving self-management in Pulmonary Rehabilitation from the varied participant perspectives. There are some aspects which cross over between themes as some have influence on more than one aspect of self-management, this highlights the complexity of the interconnecting elements. For example, fear and anxiety can have an impact on the motivation to exercise as well as the psychological impact of symptoms.

Figure 5.1: Thematic Networks of Global, Organising and Basic themes from focus groups



The themes are presented as a diagram (Figure 5.2) to demonstrate how the themes interact with each other:

Figure 5.2: Interaction of the Global, Organising and Basic themes as represented from the focus group analysis



Figure 5.2 shows the cogs as different sizes, Self-management behaviour is the largest central cog-wheel as the global theme which was prominent throughout all focus groups. The five organising themes have influence and inter-connections with the global theme of behaviour. Each Organising theme interacts with the Global theme. Therefore, the diagram shows how the Organising themes and Global theme inter-connect as cog-wheels and could connect with the behaviour cog-wheel at any point as the Organising themes rotate around.

The Basic themes are represented by the smallest cog-wheel, and they show how they have influence on both the Organising and Global themes. During the focus group discussions it was apparent that similar Basic themes were related to several Organising themes. For example, fear and anxiety had links to both the 'Psychological

Impact of symptoms in chronic lung disease' as well as 'Motivation to exercise'. These accounts were different in nature. However, the Basic themes of fear and anxiety were linked to more than one Organising theme. This was apparent for other Basic themes as well. For example, education links to 'Influence of education on self-management' as well as 'Motivation of exercise' and 'Perceived benefit and engagement in Pulmonary Rehabilitation'. The Basic themes cog-wheel is dynamic and can rotate to allow the Basic themes to be applicable to all of the four Organising themes as well as the Global theme of behaviour.

The cog-wheel representation of the themes from the focus group findings is an effective way to demonstrate how the findings were complex with varying levels of influence but also interconnected and fluid in how they fit together to outline the complexity of the discussion with all three participant groups. Although the findings were complex, the diagram describes how the themes were similar across all three groups.

Whilst it is a necessary part of qualitative analysis to analyse using thematic analysis to determine key themes within the data, it is also important to listen to individual participant's thoughts and opinions. Therefore, the next stage of this data analysis will use key quotes from the focus group participants in relation to the key themes.

5.5. Global Theme: Influence of Behaviour on Self-Management

In the first instance and for the purpose of this focus group analysis, it is important to outline the definition of 'behaviour'. Within this chapter, the researcher will refer to the definition as 'Health Behaviours'. Health Behaviours have been defined as 'overt behavioural patterns, actions and habits that relate to health maintenance, to health restoration and to health improvement' (Gochman, 1997, p.3). During the focus groups, the Healthcare Professionals referred to patients' Health Behaviours as 'Compliance', 'Adherence', 'Self-Management and 'Maintenance'.

“I think it is to do with adherence and I think there’s quite a big responsibility to trying to sort of work out people’s personality types and what they’re going to respond to best.” [HCP, 2]

“It is unfortunately quite regular that we do see patients coming back into hospital and wanting to come back to the programme. And it just depends on the personality type and what experiences in life they’ve had up to that point as to if they’re going to continue on or not.” [HCP, 2]

“The compliance with that (annual reviews) is atrocious as well and that’s from the patients because, one patient said to me yesterday that they didn’t like going to see their GP because it’s full of sick people and every time they go there they get a chest infection, so they don’t go to the GP.” [HCP, 3]

“So I think the referral process is kind of paramount really to getting patients on board with the programme in the first place and you know that information that’s provided to them makes a big difference to their compliance, to their involvement, whether they are on side and whether they think it’s going to work for them or not really.” [HCP, 8]

The Healthcare Professionals’ Health Behaviours were associated with education and encouragement as well as support to change habits and behaviours in relation to self-management.

“Some patients are absolutely not ready to accept that this is a condition that they are stuck with. We still get, we had a chap who finished Pulmonary Rehab yesterday that we sort of, was still ‘So, there’s no cure then?’ Almost as if we were withholding something from him. You know, a magic wand that would make him better until the end of the course, you know ‘Oh, you’ve completed it now, here is the cure’.” [HCP, 7]

This Healthcare Professional then related this to compliance.

“You know, it’s almost sad that you know they are getting to that point, and they still feel like we are withholding something from them and that actually there is a magic cure that’s just going to make them better. And I think that probably that’s why compliance is a big issue because they have to do it themselves, there isn’t something that we can give them that’s easy to do.” [HCP, 7]

Many of the Basic and Organising themes centralised around the Global theme of the ‘Influence of Behaviours on Self-Management’. The Healthcare Professionals, Pulmonary Rehabilitation patients and members of the Breathe Easy Support group all discussed varying elements of behaviour including behaviour change and how attending or not attending Pulmonary Rehabilitation impacted upon their ability to self-manage.

Behaviour in the context of the focus group findings relates to key attributes and behaviours which impact upon their ability to ‘self-manage’. Behaviour is a global term which encompasses traits such as non-adherence, poor attendance, motivation, fear, confidence, compliance, embarrassment, drop-out and blame which were all aspects which were expressed within the focus groups. There is a wealth of evidence (Goodwin *et al*, 2010) into behaviours associated with long-term conditions management. The focus group findings further exemplify the role of Healthcare Professionals in understanding and facilitating behaviour change particularly with patients with chronic respiratory disease.

Within the focus groups it was apparent that there were common themes, but the different participant groups expressed elements of behaviour change in relation to Self-management differently. It was apparent that the Healthcare Professionals expressed their intention to support behaviour change so that patients could self-manage their condition, but, in reality, the accounts from the patients and Breathe Easy Support group members suggested that they sought on-going support and supervision from Healthcare Professionals. Morgan *et al* (2016) describe two types of approaches to self-management; a narrower approach is defined as ‘supporting people to manage their conditions’ whilst a broader approach is defined as ‘supporting people to manage well with their condition’. They found that there were often

difficulties for practitioners working in busy healthcare settings such as acute Trusts where there are time, resource and financial pressures as well as often the need to work with colleagues who are generally more 'narrower' approach orientated. They also describe that when Healthcare Professionals adopt a more 'disease control' narrower approach they assume positions of power and the relationship between Healthcare Professional and patient is of a hierarchical nature. From their superior authoritative position, Healthcare Professionals often monitor biomedical indicators to monitor and judge patients on their progress.

Within the Healthcare Professionals focus groups, it was apparent that they were striving to promote Self-management, but their methods were often didactic in nature. One of the Respiratory Nurses discussed their role in educating patients on their 'self-management' plan when they are admitted to hospital.

"A massive part of our role on the wards is self-management education so we do spend quite an exhaustive amount of time with the patients, and we focus on that area. But they could come in every other week and we go through the same thing with them. So it's about information retention....and it's also important about the relationship they have in the community with the COPD nurses...." [HCP, 3]

This is focussed around prescriptive elements on a graded scale which has varying levels of information for each scale. It highlights that when patients are reviewed in hospital and referred to Pulmonary Rehabilitation, it may not be the right time for them to take on board advice and recommendations. Therefore, referral and information about Pulmonary Rehabilitation should be given at the right time for the patient.

There was a tone of 'blame' among the Healthcare Professionals focus groups in which their views on self-management seemed to be focussed around the patient having 'ownership' of their condition and if they did not then they were more likely to be re-admitted to hospital. They did, however, discuss that they needed to consider

how they could help the patients to remain out of hospital and able to 'self-manage' their condition.

"I think a lot of them fall back on relying on us to exercise them when they come twice a week. So it is that sort of thinking about encouraging them to continue that home exercise programme under their own steam and for a lot of people, they don't have that motivation." [HCP, 7]

"Do you think Pulmonary Rehabilitation repeated, sort of a year or two later is helpful to sort of motivate to keep it up?" [HCP, 5]

"Yeah, absolutely, but it always makes me a little bit sad that they are having to come back cos you think, oh you did so well last time. And if you'd carry it on, you know, it would be better..... It's the battle for us and we're always thinking about how we can improve patients, kind of carrying that forward." [HCP, 7]

"Yeah, all the intention is there but not the action." [HCP, 7]

Within the Breathe Easy Support group focus group there was quite a lot of focus on the 'biomedical' management of their condition(s). In both focus group discussions there was an emphasis on what medications they were each on and which Doctor they saw for their condition. These individuals expressed themselves as 'expert patients' and seemed to focus highly on their medical management even when being asked about their physical condition. Within both these focus groups, the Moderator found it hard to steer the conversation towards exercise and Self-management as they were quite focussed on what medication each other were taking:

"I meant to bring that up, I take antibiotics all the time." [BE 3]

"So do I." [BE 1]

“Yes, but the only thing with that is if you have to have antibiotics cos you’ve got a chest infection, you’ve got to stop taking them.” [BE 3]

“I haven’t had them, have you?” [BE 2]

“I wonder if that preventative drug has helped.” [BE 6]

“I’ve just started that drug today.” [BE 7]

Medical management does play an important role in the management of their lung condition. As this patient group tend to need to have several different medications regularly as well as intermittent courses of antibiotics and steroids it is important for Healthcare Professionals to consider the impact of this upon the individual when encouraging self-management. The medical management of COPD impacts upon an individual’s motivation as well as highlighting the importance of the role of education on medical management. Individuals in both the Breathe Easy and Pulmonary Rehabilitation patient focus groups focussed their discussions around what medications they took and comparing with each other in their group. Whereas the Healthcare Professionals noted that the location of the classes could impact upon adherence. For example,

“I think having it not at the hospital really helps with that because a lot of patients have lots of co-morbidities and are coming to millions of appointments anyway and they just get completely turned off at the suggestion of coming to something else at the hospital.” [HCP, 5]

“Yeah, absolutely. And I guess it’s that medicalisation as well, when you attend something at the hospital it feels very medicalised.” [HCP, 7]

It was apparent in all three groups that the impact of a chest infection was ranked as a high indicator of reduced exercise ability and motivation. For example;

“...you don't really feel too motivated because you know you'd get there and you'd be struggling a little and performance would be well down” [BE 4]

Exacerbation management is a key part of the self-management education within the Pulmonary Rehabilitation course. Although the Healthcare Professionals recognise that exacerbations and infections negatively influence an individual's ability to attend the course, they are unable to provide a more flexible service approach to suit the fluctuating needs of this patient group:

“I think that there's the other big thing that keeps people back is obviously that their disease can be rocky and people get you know exacerbations and setbacks.” [HPC 6]

“...the thing that often stops them completing the course or knocks them back is getting an infection or something like that or having an exacerbation.” [HCP 7]

A common variable regarding self-management during the focus groups was that the Healthcare Professionals advocated the importance of the patient taking ownership with self-management whilst also taking an authoritative role and often blame and judgement if self-management is not successful. In contrast, although the patients and Breathe Easy Support group members adopted self-management behaviours, they still sought on-going support and guidance from Healthcare Professionals. These competing views of ownership and responsibility is a challenge in support for self-management. Healthcare Professionals often exert authority on decision-making but also expect patients to be in charge of their own health. This conflict in power relations is challenging to decipher in relation to self-management. The 'Healthcare Professional knows best' approach aligns with a paternalistic model of healthcare delivery in which Healthcare Professionals cling to professional dominance and can be detrimental to the relationship with the patient.

The Healthcare Professionals talked about trying to encourage patients to take ownership of their condition:

'We're trying really hard to get them to take kind of charge of their own rehab and their own exercise programmes' [HCP, 7]

'I think it's very much that it has to be patient related and they need to own it' (HCP, 1)

'A lot of it is about ownership as well because what we know is that if they don't own it they're not going to sustain it.' [HCP, 1]

During one of the Pulmonary Rehabilitation patient focus groups both participants spoke about the value in having 'expert-patient' type roles which is a prime example of how positive health behaviours can be used to guide and support others:

'I suppose it's a matter of giving them more information.....and maybe, it might be difficult but putting them in touch with those who have actually benefitted from the course before.' [PR, 2]

Strategies such as engaging with the patients and explaining the importance of exercise were discussed as key strategies to enable patients with self-management:

'Positive re-enforcement just all the time..... because these people tend to be quite negative about kind of their self-image and their confidence so as much you can give positive feedback then I think that can only benefit them really.' [HCP, 2]

Whilst a Consultant noted that:

'When I do see people sort of come back and completed rehab I will say "Oh, are you still doing the exercises?" because it's kind of re-enforcing that message that it's not just about getting a course of treatment and that's it, it's about maintaining the changes' [HCP, 6].

The Healthcare Professionals recognised that the patient's rely on them for motivation and support and as patients are likely to value their knowledge and skills and therefore seek advice from them:

'I think a lot of them fall back on relying on us to exercise them when they come twice a week' [HCP, 7]

'Having an actual person there can often be the catalyst to make them work a bit harder' [HCP, 7]

'Sometimes people's perceptions of exercise is that, like you say, that we are asking them to do quite high-level exercises that they are not going to be able to do so I try and do a lot of reassurance of how we can adapt the programme to meet their needs..... It's all going to be directed by the, with kind of encouragement from us rather than us telling them what to do' [HCP 2]

Healthcare Professionals have an influence on the success or failure of self-management amongst patients with long-term conditions such as chronic lung disease. Patients respect and value their knowledge and skills and it is also important to recognise that the Healthcare Professionals seek to provide a patient-centred approach to self-management:

'Some patients.....if they have a set programme that they have to follow, some people see that as a negative that they are almost being told that this is what they have to do as opposed to looking at what they do in their daily lives..... so it's about how that person will interpret whether you are being helpful or telling them what they need to be doing' [HPC, 3]

The Healthcare Professionals reference the importance of behaviour change and that there are often barriers to this such as confidence and ability to maintain the benefits once the Pulmonary Rehabilitation course has finished:

'I think a lot of the time with patients you can tell and tell them but they don't always know and have the confidence to know what to do about it and who to ask.' [HCP, 4]

'You have to make it, it's like anything, you want people to change their behaviours, you have to make it easier for them to do the right thing and easy for them to join in.....' [HCP, 6]

'I think it's one of the challenges with a lot of long-term conditions is getting people to stick to good behaviour because we all kind of slip back into bad habits' [HCP, 6]

However, these examples show more of a didactic approach to support for self-management with more of an authoritative stance.

Ultimately, it is about facilitation - helping the patient to enjoy a patient-centred intervention which will enable them to improve their future health:

'If it improves their quality of life and their enjoyment and happiness then they are much more likely to continue on with it.' [HCP, 2]

'It's taking their word and you get really good feedback at the end and the majority of patients have completed it saying that they've had an enjoyable experience and they're keen to continue...' [HCP, 8]

One example discussed in both the Healthcare Professionals' focus groups was about the value and importance of follow-up after completing Pulmonary Rehabilitation:

'There isn't anything set up that allows us to be able to follow the patients up after the programme. It's the directions towards self-management, offering them what services we have available and it's up to them if they want to take those opportunities or not.' [HCP, 2]

It was apparent that there is a lack of services for follow-up from both the Physiotherapy and Nursing teams:

'We don't follow-up as a nursing team, we don't follow up COPD patients in the community but every patient we see as a direct result of an exacerbation we provide them with a self-management plan.' [HCP, 3]

A Respiratory Nurse discussed that they used to be able to offer Cognitive Behavioural Therapy (CBT) to patients but due to a low referral rate it was stopped. She also emphasised the importance of assessing for anxiety and depression.

The current service provision does not allow for additional support after a Pulmonary Rehabilitation programme for follow-up. However, several of the participants found that they wanted the course to last for longer and relied upon the Healthcare Professional taking the course to provide the motivation:

'....maybe a 2 week break and it started again but like you say it's funding and everything.' [PR, 1]

"Yeah, I feel the hardest part is that when you finish it you don't have that person like you and you miss that side of it. You really miss the motivation side without a doubt, plus the other people around you." [PR, 1]

"I couldn't wait until the next time. And people asked me how did you get on, 'oh, I really enjoyed it', you know. And then the course just stopped." [PR, 3]

Health Behaviour is a Global theme which the Organising and Basic themes all have an influence upon. Health Behaviour in this context enables the individual to achieve Self-management but there are multiple factors which influence their ability to achieve it.

5.6. Organising Theme 1: Perceived Benefit of and Engagement in Pulmonary Rehabilitation

5.6.1. Basic themes

5.6.1.1. Physical ability

There were a range of responses regarding what constitutes exercise and physical activity and whether they are similar or different. There was discussion on whether exercise was functional tasks such as housework and gardening or whether it was just structured exercises. The Pulmonary Rehabilitation group participants responded in varying ways:

'Well walking is the main thing, without a doubt. Then sort of exercising your muscles and your legs.' [PR, 4]

'Well, all that he says but I mean I don't do it. I mean, to me, it's hanging my washing out and fetching my washing back in.....then cleaning, housework.' [PR, 3]

'Well anything apart from sitting on a chair.' [PR 2]

On the other hand, there was a different attitude regarding what exercise is and this appeared to cause some conflict between how the different groups described exercise.

'A lot of patients I think, don't quite understand what constitutes as exercise, so they might see just their activities during the day as exercise. A lot of patients will say to us "Oh, yeah, well I do, I hang my washing out, and I do this and that and it's very difficult," that's not going to be the benefit that Pulmonary Rehabilitation give patients.' [HCP, 7]

"So, for me, it's something that would increase their heart rate and make them out of breath." [HCP, 7]

“I think you’re right but I suppose I come from a different angle where I’m as much as anything else encouraging people to be active because I may just be imagining it but I have this idea in my head that a lot of them just sit and don’t move at all for long periods of time. And if so, I think just from the point of view of being on your feet, pottering around and doing stuff, moving about is also of benefit, although perhaps not in the same way as what you define as exercise, so yeah, I guess it depends on how you use the language isn’t it?” [HCP, 6]

There were similar responses from the Breathe Easy support group participants:

‘I suppose walking.’ [BE, 2]

‘Walking is a good exercise isn’t it? Swimming is supposed to be very good.’ [BE, 5]

‘My idea of exercise is that it gives your muscles a workout and increases your breathing and heart rate you know, sustained for a while and I think that’s the important thing.’ [BE, 4]

It was apparent that the members of the Pulmonary Rehabilitation group who were more active and able described exercise more as a specific activity such as walking and strengthening exercises. In contrast, the participants who were less able due to breathlessness classed exercises as day-to-day activities such as household chores. This is an important element to consider when determining exercise ability and adherence to exercises. If an individual is unable to complete specific structured exercises due to breathlessness, then they are more likely to find day-to-day tasks strenuous. There was consensus that doing something was better than sitting for long periods but mostly the Healthcare Professionals deemed exercise to be structured and specific whilst most of the Breathe Easy support group members and Pulmonary Rehabilitation participants attributed day-to-day household physical tasks as exercise.

Both the Pulmonary Rehabilitation and Breathe Easy focus groups were in the ‘maintenance’ phase of their exercise journey. They had all been through the hospital Pulmonary Rehabilitation group sessions with structured exercise and were all trying

to continue to exercise within their own limitations of time, ability and resources. The participants varied quite considerably in their exercise ability. One participant was still working and was quite active compared to one participant who was extremely breathless and unable to walk any distance outside of the house. This is an important factor to consider when encouraging self-management support for continued exercise. It needs to be an individual approach as to what works best for the patient. This is expressed nicely by a Physiotherapist:

'I think it's quite variable depending on the patient's functional ability as to what they might class as exercise so it might be something that it incorporated into their activities of daily living.' [HCP, 2]

Conversely, another Physiotherapist noted that:

'I think we tend to focus more on the functional day-to-day activities rather than specifically prescribe exercise, and I think that's something we could definitely be better at.' [HCP, 4]

An Occupational Therapist related to the public perception of exercise:

'I think that what the public and patients view as exercise is very different. I think there has to be a change, isn't there in how exercise is traditionally used to be seen as a structured thing of going to the gym or some sport type of activity that would increase your heart rate whereas I think we view it very differently now.' [HCP, 1]

It was apparent that the Healthcare Professionals perceptions on how to describe exercise from a patient perspective varied. Therefore, it is important to ensure key messages are given to patients. There was also varied response from both the Pulmonary Rehabilitation patients and Breathe Easy support group members as to what constitutes exercise. This was often related to physical ability as well as the influence of daily life on their ability to commit to long term exercise.

5.6.1.2. Adherence / compliance

There was reference to the barriers of attending Pulmonary Rehabilitation courses in the first instance. But in addition, it was recognised that there was another limitation to on-going commitment to self-management strategies such as continuing exercise. This was seen to be due to the lack of structured support following on from completion of a Pulmonary Rehabilitation programme:

“It’s the transition from doing Pulmonary Rehabilitation to them maintaining it in the community so then they are actually doing it themselves. I think they quite like the structure of coming to something and somebody doing it for them.”

[HCP, 4]

In contrast to this, the Breathe Easy support group members talked with pride about how their exercise group was set up by individuals who had previously attended Pulmonary Rehabilitation. This demonstrates that the Breathe Easy Support group members were motivated to continue their exercises.

“Basically, we all were waiting for the hospital, after you’ve done the group there to do a follow-up, but no, it doesn’t seem to come about. The British Lung Foundation was training people to do these and we thought they would be coming around to groups. Well, the one for this area in effect ended up joining Roko but their sort of exercises are for people walking around the street and that for us is a No, No. So basically we set up our own little group and what we do is the Pulmonary Rehab course basically on the same basis.” [BE8]

During one of the Healthcare Professionals focus groups, they suggested that patients may often be less inclined to attend Pulmonary Rehabilitation and exercise as they find day-to-day tasks such as personal cares and housework challenging. It was suggested that this was a barrier to attending Pulmonary Rehabilitation. This demonstrates a potential area for conflict between the Healthcare Professional and patient, as the Healthcare Professional often encourages participation in Pulmonary Rehabilitation and promotes exercise and the patient can often be overwhelmed by the idea of exercise when they find day-to-day tasks difficult.

“For some people if they have a set programme that they have to follow, some people see that as a negative that they are almost being told what to do...”
[HCP, 3]

5.6.1.3. Improved breathlessness

Healthcare Professionals focussed on the benefits of completing Pulmonary Rehabilitation including improving breathlessness on exertion. Both the patients and Breathe Easy support group members attribute value to completing Pulmonary Rehabilitation and continuing to exercise and also in addition acknowledge that not keeping physically active has a negative impact upon symptoms.

All participant groups recognised the impact of breathlessness on overall functional ability. Healthcare Professionals showed empathy towards patients who suffer badly with shortness of breath:

“I’ve found that they really don’t like the feeling of being short of breath.....they feel like they are never going to recover from it.....and then you’re asking them to go and do stuff that’s going to make them short of breath....it’s one of the barriers. I think it’s about education.....and increasing their confidence...”
[HCP, 4]

Whilst from a patient perspective, the fear is very real and a personal experience:

“Well, if I knew that I wasn’t going to get out of breath I could do all sorts.....you feel like they’re all looking at you breathing because you’re making a noise as you’re breathing you know.” [PR, 3]

“I thought I was dying. I didn’t know what was happening. I’d just got off the coach and I started walking forward and that was it, I just came over all, you just can’t describe it. I couldn’t breathe or anything and I remember my eyes were shut. But nobody came to see if I was alright, nobody at all.” [PR, 3]

This is an example of how themes spanned across participant groups, but were expressed in different ways. This has implications on the success of behaviour change in relation to self-management.

5.7. Organising Theme 2: Motivation to Exercise

5.7.1. Basic themes

5.7.1.1 Support networks

Motivation as a concept, was described and discussed differently in each group. The Pulmonary Rehabilitation group participants valued motivation from Healthcare Professional support. The Healthcare Professionals argued that they provided the tools for the patients to self-manage and they needed to continue themselves once the course had finished. They did note that family members and spouses could provide the support for motivation as well as the value of group dynamics. Whereas the Breathe Easy support group members relied upon the social support within the group with social interactions and friendships to motivate each other.

The Pulmonary Rehabilitation patients had developed trust in the Healthcare Professional as well as learning to have the motivation to do it. The Pulmonary Rehabilitation patients tended to need the support and guidance to be able to continue their exercises, despite having being taught 'self-management' during the course. This emphasises that the 6-week course may not be long enough to make successful behaviour change with their motivation to continue to exercise.

One of the Respiratory Nurses linked motivation with a social support network at home as well as having support from spouses attending the course with them. Both the Physiotherapist and a Consultant echoed this view that having a spouse at the class can help to motivate them. In particular, the Consultant noted that patients may:

"...feel safer doing it because their partner is kind of regulating it a bit" [HCP 5].

The positive influence of spouses and friends is also discussed within the Breathe Easy support group focus group. They discuss how they enjoy the social side of the group as they are all friends which encourages them to attend. They do social activities such as charity events and meals out. As the exercise group is continuously running, the members are able to form friendships and they support each other. For example, by offering lifts to and from the class were offered. The difference between

this group and the Pulmonary Rehabilitation group is that there is more time to form friendships and support networks within the support group compared to the 6 week Pulmonary Rehabilitation course.

Although the participants found it difficult to be specific about motivation. It was apparent throughout both focus groups that they enjoyed and relied upon the social support network. In particular, one participant said that:

“We are like a special group really, I look forward to coming even if I don’t do any exercises” [BE 2]

The Breathe Easy support group members spoke about supporting their members by offering transport to those who could not access the venue for exercise or social events.

The other focus groups did discuss the role and importance of the social support, but perhaps they did not attach as much importance to it as the Breathe Easy support group participants did.

5.7.1.2. Fear / Anxiety

Fear and anxiety was mapped to the Organising theme of ‘Motivation to exercise’ as well as ‘Psychological Impact of symptoms in chronic lung disease’. It was discussed as a barrier to motivation to exercise and in turn successful self-management.

“It’s the psychological side that makes you actually get up out of the armchair and go and do the exercise isn’t it? I mean, it’s so easy to just sit there and read a book or watch television or just do nothing. I mean it’s got to be a mental thing to make you actually want to get up to go and do something and I think that’s, I mean, that’s one of the problems. With exercising and coming to the class I suppose it’s much easier if you don’t feel brilliant to give up and not come whereas you force yourself to come and then you realise you weren’t as bad as you thought you were and you manage to do the exercises and everything.”
[PR, 2]

A Pulmonary Rehabilitation patient attributes avoidance of exercise or going out due to fear of what other people would think of her when she is coughing and breathless:

“Like this morning in the doctor’s surgery, you feel like they’re all looking at you breathing cos you’re making a noise as you’re breathing you know.” [PR, 3]

“And does what other people think around you influence what you do?”
[Moderator]

“Well, I think, I mean the last time I did get on a bus on my own and I started coughing because I’ve got a horrible cough as well, and with this wheezing and the driver turned around and he played pop with me. He didn’t want all the germs and all this, that and the other.....so that was one of the reasons why I don’t go on a bus on my own now.” [PR, 3]

Several of the Pulmonary Rehabilitation and Breathe Easy support group participants admitted that fear of breathlessness contributed to their motivation to exercise and avoidance of physical activities, including staying at home more which ultimately leads to further deconditioning and worsening breathlessness.

“I’m always frightened that I’ll go too far, you know, I get out of breath and then I can’t breathe.” [PR, 3]

“I was doing it every week and doing bits of everything else until I couldn’t breathe and it’s the fact that I can’t breathe that I just don’t do it because it’s not very nice.” [BE, 7]

“Yeah, I mean we don’t even, we used to go out a lot with our friends for meals and things like that. I’d rather be at home.” [PR, 3]

“....you tend to give up cos you hate, you’re forever feeling that you’re taking your last breath so in other words you get fed up of trying to do things because you just lose it all the time.” [BE, 7]

“I have no motivation at all, none. I had to argue with myself to get ready to come here. And I’ll admit, it’s not that I don’t like it, I love it. Everything I do is an effort. Absolute effort. So it’s my head really that’s not in a good place rather than, or rather than the body.” [BE, 3]

These accounts reflect that fear and anxiety have an influence on an individuals’ motivation to exercise.

5.7.1.3. Location / structure

The Healthcare Professionals recognised that the current service provision was not suited to the needs of the patients. The cohort groups of 6 weeks Pulmonary Rehabilitation did not allow for patients to make up sessions if they missed sessions due to infection or exacerbation. They discussed how a different model of programme such as a rolling programme structure would allow for patients to continue the course when they were well enough.

“It is a condition by definition that exacerbates and if there were the resources to have regular or routine post-exacerbation rehab it (rolling programme) would just integrate those exacerbations into the rehab.” [HPC 5]

Pulmonary Rehabilitation and Breathe Easy support group members frequently cited the location of the Pulmonary Rehabilitation programme, parking and car park at the hospital as a barrier to their attendance:

“...you’ve got that car park, you come in the afternoon and your appointment is something like 2 o’clock, jammed with people visiting, you couldn’t get in, eventually I ended up an hour late. So I thought I can’t do this.” [BE, 1]

“I think one of the things that needs taking into consideration is for us, is that it wasn’t at the hospital.” [PR, 2]

In contrast, another Pulmonary Rehabilitation patient who was still working, actually based at the hospital, found that it was more difficult to get to a community venue due to work commitments and would have found it easier if it was a hospital-based programme. The Healthcare Professionals also recognised the limitations from the programme structure for those who are still working.

“We’ve had a couple of people who work full-time that have had to take time off work, you know arrange their work schedules to allow them to attend.” [HCP, 3]

The Breathe Easy support group classes were also influenced by the location and accessibility:

“Yes, it’s easy for me to get here. If there was only the other side of York, well, I couldn’t go because I don’t drive. So, it’s easy for me to get here.” [BE, 3]

“Yes, it’s easily accessible, well it’s really within about biking distance so, well I do come in the car, mainly to save time rather than anything else but I could cycle here really.” [BE, 4]

“See, we don’t have a car or anything so I have to rely on lifts from everybody.

We’re very lucky, a lot of them have cars and they will pick us up.” [BE, 6]

The Healthcare Professionals recognised that location and transport were often significant barriers to attendance. Transport and location were linked to social isolation and inequalities of service provision.

“Some people, because of where they are situated, the programmes, they are getting two buses sometimes to get there and it doesn’t always add up and they don’t have anyone else, so they come for a couple of sessions but then it’s just too much for them to do it so they end up dropping out.” [HCP, 3]

“So the social isolation is quite a big thing and I think that’s the group that we really miss out at rehab cos if they can’t get there unfortunately we can’t arrange transport to get there and actually they would probably be a key group that would benefit from it.” [HCP, 2]

5.8. Organising Theme 3: Influence of Education on Self-Management

5.8.1. Basic themes

5.8.1.1. Knowledge

Education was discussed primarily within the Pulmonary Rehabilitation and Healthcare Professionals groups. There were less references to education within the Breathe Easy support group focus groups. This could be because they are an independent group who run their own exercise classes and social events. They have often attended the Pulmonary Rehabilitation course but in the past. Whereas the Pulmonary Rehabilitation and Healthcare Professionals are more actively involved in the receiving and delivering of education within the programme.

“...they’re given a lot of information during the education sessions as well to take away and digest and then they can come back to us and speak to us about that afterwards....” [HCP, 7]

The Pulmonary Rehabilitation programme patients reflected upon their experiences of education during the course:

“I think the advantage of coming on one of the courses is that you get to know the sort of exercises that are most beneficial for your particular complaint.” [PR 2]

“I didn’t realise how technical it was to think that you know..... you seem to know every single drug we were taking and I didn’t know there was that side of it.” [PR 1]

“I didn’t really realise that Physiotherapists sort of really specialised in different fields.” [PR 2]

One Pulmonary Rehabilitation participant reflected upon how they benefitted from the education which they received during the course:

“I mean, I’ll go in the shower and I’ll come out and I’ll sit, stand at the basin or what-have-you and do this exercise, what they taught me in the session and it helps you know. Everything helps.” [PR 4]

On discussion around ways in which to encourage more people to attend and complete the course one participant noted that:

“I suppose it’s a matter of giving them more information.” [PR 2]

“It’s knowledge as well, knowledge of how you can maybe aim better or improve your circumstances.” [PR 2]

They also reflected on their own experiences of being referred and attending the course and found that they did not have sufficient information about the course and its benefits prior to starting the course. They noted that more information and promotion of the positive benefits would encourage more people to attend the course. They thought of methods to promote the benefit of the course:

“It’s a matter of giving them more information. Giving them information about their condition, their complaint, whatever’s wrong with them and how they can

improve it. And maybe, it might be difficult, but putting them in touch with those who have actually benefitted from the course before.” [PR 2]

This was echoed within the Healthcare Professionals group:

“...just raising the profile of Pulmonary Rehab so that actually, you were saying about getting the same messages from the GP’s and from the respiratory nurses out in the community but also from the hospital staff and physios and that same message can re-enforce ‘Ah, this Pulmonary Rehab thing is worth doing and there are good outcomes and it is possible for me to benefit from it’.” [HCP 7]

Education is important at all levels to ensure that Pulmonary Rehabilitation is successful. As previously discussed, the behaviour of Healthcare Professional’s influences how a patient ‘behaves’ in Pulmonary Rehabilitation so it is essential to ensure that the correct messages are being given from the start when the referral is made. Healthcare Professionals in Pulmonary Rehabilitation need to invest time in educating the referrers to have more successful outcomes for the patients.

Within the Healthcare Professionals focus groups it was clear that they intended and strived to promote Pulmonary Rehabilitation at different stages such as at referral, during an inpatient stay or at assessment in triage clinic, as well as during the course. However, as noted by the Ex-Pulmonary Rehabilitation participants, it was felt that they did not have sufficient information and attributed this to the reason why others did not attend.

One Physiotherapist noted that the patient’s perception of exercise and what is involved in Pulmonary Rehabilitation needs addressing. They need educating on what they can do within their exercise limitations:

“I think they find the concept hard to understand actually what it is that you are going to make them do.” [HCP 4]

Perhaps the way in which Healthcare Professionals promote Pulmonary Rehabilitation has an impact upon whether the individual attends and completes the course. It was apparent from one Healthcare Professional that a somewhat negative approach was used. For example,

“Educating them that the longer you stay as you are the more breathless you’re going to be, the least amount of effort and the longer that it’s going to take. So it’s about conditioning and deconditioning and their understanding so it’s all education from that point as well.” [HPC 3]

However, it was also clear that others appreciated that they needed to get individuals on-board by considering how to approach them. One consultant talked about using different terminology:

“....some people don’t like the word ‘rehab’ and some people you know if you say this exercise programme and they all think you’re joking. So, I tend to emphasise more about the benefit or potential benefits and the improvements in outcome that people get and the evidence for that” [HCP 6]

Whilst others emphasised the importance of educating and giving the correct information at the point of referral to encourage patients to consider attending.

“We get referrals through from not just consultant Doctors but GP’s as well, who often have very little time to talk through those things with patients so they often refer them for Pulmonary Rehabilitation and patients don’t even know they’ve been referred.” [HCP 7]

“I think the referral process is kind of paramount really to getting patients on board with the programme in the first place and you know, that if information is provided to them, it makes a big difference to their compliance, to their involvement, whether they are on side, whether that think it’s going to work for them...” [HCP 7]

Education has a key role to play within Pulmonary Rehabilitation starting at the point of referral going right through to the education elements within the programme and continuing beyond finishing the course. Patients who have been on the course recommend that more information should be available to promote the benefit of Pulmonary Rehabilitation and Healthcare Professionals want better quality of referrals. Both these aspects call for more time and ultimately more funding to be able to deliver these elements. In the current NHS climate, funding is finite and therefore, perhaps other methods of improving referring information and educating patients' needs should be considered.

5.8.1.2. Exacerbation management

The role of the medical management of COPD plays an important part in self-management but can also be a barrier. It was apparent in primarily the Breathe Easy and Healthcare Professionals focus groups that infections and exacerbations played a huge part in motivation levels and completion of the Pulmonary Rehabilitation course.

"I'm not very good today, I was in hospital in November and December with pneumonia then I came home. Then I went back in with pneumonia again. I've had pneumonia twice in 2 or 3 months." [BE 7]

"Well unfortunately this year hasn't been very good. For one reason or another. I've had 3 lots of antibiotics and steroids with the last chest infection I had then I got the shingles..." [BE 3]

It was apparent that infections and exacerbations affected a patient's motivation and psychological state:

"You're in and out of hospital sometimes and I just haven't had that this year at all, I'm so thrilled." [BE 6]

"Exacerbations, I think when they have an exacerbation they feel worse and if people are having them regularly as well psychologically they're back in

hospital, they're not feeling well, they've done everything you've told them to do and they're still back in hospital.” [HPC 4]

“I think often patients who have an exacerbation while they're doing rehab feel as though they have completely failed and that's obviously not their fault.” [HPC 5]

Exacerbations and infections often have a negative impact upon mood and an individual's psychological state. Patients often struggle to complete the course due to infections but there are some patients who actually feel benefit from coming to the class when they are feeling unwell:

“With exercising and coming to the classes I suppose it's much easier if you don't feel brilliant to give up and not come whereas to force yourself to come and then you realise you weren't as bad as you thought you were and you manage to do the exercises.” [PR 2]

5.8.1.3. Goal setting

There was more emphasis on goal setting from the Healthcare Professionals focus groups compared to the Pulmonary Rehabilitation and Breathe Easy support group focus groups. One Physiotherapist discusses about goal setting during Pulmonary Rehabilitation:

“as part of the programme we look at goals before they start and personally, I try and get them focussed on things they enjoy like hobbies and sort of things that they are going to want to improve on with and improve with because it improves their quality of life.” [HCP, 2]

This indicates that often goal setting is initiated from the Healthcare Professional and may start with a patient-centred goal setting conversation. Goals are more likely to be achievable if they are patient-centred and mutually agreed.

5.9. Organising Theme 4: Psychological Impact of Symptoms

5.9.1. Basic themes

5.9.1.1. Fear/anxiety

It was apparent throughout all the focus group discussions that the psychological impact on adherence to exercise and self-management plays a huge role. Similar themes were concurrent throughout, such as fear, anxiety, depression and confidence. Although similar themes were apparent throughout the groups, the accounts of fear and anxiety and depression were described in a more personal manner within the Breathe Easy and Pulmonary Rehabilitation groups. The Healthcare Professionals recognised the impact of psychological aspects but did not have clear strategies to support their psychological needs. It is clear that these individuals' experiences of breathlessness can severely affect their ability to live their lives on a daily basis, before even considering taking part in an exercise group or home exercise programme.

"You've got to have will power. I'm an anxious person and just lately I did think I'd gone back into agoraphobia a bit. When we go anywhere I panic like mad. I can't breathe then I get out and as soon as I get in the car and we set off, I'm not so bad then.... You're forever feeling that you're taking your last breath so in other words you get fed up of trying things because you just lose it all the time." [BE 7]

"I've cancelled my holidays this year cos I had a real big panic attack when we were on holiday last year and it frightened me to death." [PR 3]

"I mean we don't even, we used to go out a lot with us friends for meals and things like that. I'd rather be at home." [PR 3]

The Healthcare Professionals recognise the impact of the psychological side of the condition:

“A lot of it is also looking at psychological needs as well isn’t it, not just the physical needs cos sometimes the psychological needs are actually a barrier to getting them to sort of doing the actual exercise programme.” [HCP 1]

“I think you’ve touched on it as well. It’s about the psychological issues that, a lot of these patients have anxiety issues, depression and that unfortunately that’s going to hinder even their ability to come to the sessions or even agree to be assessed for the session.” [HCP 3]

However, it was evident that the Healthcare Professionals’ views were, at times, from a different perspective:

“Some patients are absolutely not ready to accept that this is a condition that they are stuck with.” [HCP 7]

Patients with long-term conditions cannot be cured but this alone needs to be considered when engaging with patients to improve their adherence and self-management to exercise. Perhaps this is because the Healthcare Professionals have not had the personal experience of breathlessness and fear and therefore find it hard to direct their empathy and support for self-management on an individual basis. It is clear that the Healthcare Professionals are aware of the impact of the psychological aspects. However, within their service there are limited resources available to address these issues:

“One of the things is about the MDT that we’ve all talked about, is that we don’t have psychology and I think that one of the big key things is that what we’ve all mentioned about the psychological need and I think it’s about accepting, the patient having to accept the condition and what they’ve got and what it means for them because if they accept the condition then they actually will then self-manage a lot better.” [HCP 1]

“We did a brief period where we could offer patients CBT that was being run by one of the respiratory nurses in the community but the uptake for that was very

small..... people were too far gone, and do you know what I mean that the CBT wouldn't have been enough for them.” [HCP 3]

The Healthcare Professionals had insight into the impact of the psychological element of chronic disease but lacked the skills to tackle this themselves and were perhaps more dismissive regarding their transferrable skills that they could use to help these patients. As Healthcare Professionals, they have the skills of empathy, listening and coaching which could all be used to help patients with psychological problems. It is apparent that the main limiting factor is having the time to consider using these skills. In turn, the Healthcare Professionals' dismissive behaviours could negatively influence the patient's experience and therefore their ability to self-manage their condition. This, in turn, could lead to poor attendance at Pulmonary Rehabilitation and lack of independence with self-management strategies.

It was clear during one of the Breathe Easy focus groups that the person's psychological state played a huge role in their motivation levels. One participant said that:

“My motivation is absolute zilch for anything right now. It is, I can't seem to get myself out of it either, I've never felt like this in my life but I can't get out of it”
[BE 3]

The Healthcare Professionals talked about the terminology used when discussing and referring patients for Pulmonary Rehabilitation. For example:

“So, the nature of COPD, the fact that you do get breathless just doing minimal activity, depending on how severe your COPD is but I think that some patients, like the word 'exercise' just fills them with fear so immediately they just think 'Oh well I'm not going to be able to manage that'.” [HPC 8]

This is apparent from different Healthcare Professional's roles. For example, the Respiratory Consultant found it hard to promote Pulmonary Rehabilitation in particular, when discussing the importance of exercise:

“I think that’s one of the reactions that I’ve had with patients when I’ve talked about referring them. When you talk about the exercise side of things it is that they seem very worried about going into a room full of really breathless people and seeing people that are either a lot better than them or a lot worse than them.” [HPC 5]

“Well one of the main things I’ve found is that they really don’t like the feeling of being short of breath. So then you’re going up to them and saying let’s go do some exercise that’s going to make them more short of breath and they just don’t like, they don’t like the feeling of it.” [HCP 4]

The Healthcare Professionals recognised that the psychological aspects were associated with difficulties with self-management and adherence, but it was also apparent that they lacked the resources and skills to be able to effectively influence change. The Pulmonary Rehabilitation and Breathe Easy group participants expressed genuine fears and anxieties associated with their condition but lacked the appropriate support and management from Healthcare Professionals. It is apparent when comparing the focus groups that the psychological needs of the individual have an impact upon many other aspects of self-management, but there is a lack of resources available to tackle these needs in long-term conditions management.

5.9.1.2. Motivation:

Motivation was discussed within all the focus groups but with slightly different approaches. The Healthcare Professionals linked motivation to self-management and cited family and spouses as key to assisting patients with their motivation.

The Pulmonary Rehabilitation patients associated the Healthcare Professionals as their source of motivation, perhaps as a role model. Whilst the Breathe Easy support group seemed to have lost hope of having support from Healthcare Professionals and used their group as a source of social support and motivation amongst each other. It is apparent that all three models of motivation discussed are not sufficient to enable

successful independence with self-management. Therefore, different models of Pulmonary Rehabilitation and support for self-management need to be considered.

It was evident that although some participants were motivated to continue to exercise, once they had finished the course, their internal motivation was not enough for them to succeed. They lacked the professional support mechanism which they had become reliant upon during their 6-week course. This suggests that perhaps six weeks is not long enough for individuals to be able to self-motivate to continue exercise without professional support.

One of the Breathe Easy support group members said that:

“I didn’t like the idea, you went because people thought you should go. But I went, I didn’t particularly enjoy it but I realised the value of it. It wasn’t until sometime after that I really started to take it to heart” [BE 1]

This implies that he was advised to attend but perhaps he did not really know or understand the value of attending until after he had finished. Healthcare Professionals who refer to Pulmonary Rehabilitation should have a thorough understanding of the purpose and potential benefits of the programme to encourage people to attend. It also implies that if the programme were longer, then he may have realised the benefit whilst completing the course.

Within one of the Pulmonary Rehabilitation patient focus groups, one participant reported that she struggled with motivation due to being busy and forgetting to exercise, but felt that she was still exercising whilst doing day-to-day tasks such as walking around the shops. She then discussed that her motivation is linked to having a set routine in which she tries to do some exercise at the same time each day. In contrast, another participant said he had no routine. Motivation is linked to individual personality types where some respond well to routine and structure, whilst others did not. This links with the education element of Pulmonary Rehabilitation. Motivation as part of self-management should be included in the education sessions with particular

emphasis on individualised strategies to tackle motivation with different personality types.

One participant reported that they valued the support from the Healthcare Professionals in keeping them motivated:

“the hardest part is that when you finish it you don’t have that person like you or Becky, you miss that side of it. You really do miss the motivation side without a doubt, plus other people around you” [PR 1].

While another participant reported that his motivation was driven by fear of a loss of mobility and independence:

“I’m driven by losing my mobility, very driven by losing mobility.... So anything to do with lack of mobility for me really drives me. I’m almost pathologically terrified of it. That’s one of the reasons that motivates me to do it” [BE 1]

A Physiotherapist in one of the Healthcare Professionals group revealed that she often tried to gauge people’s personality types when she met them in clinic and during Pulmonary Rehabilitation to be able to tailor her approach to motivate them to attend the course. She would decide whether the group Pulmonary Rehabilitation programme was the best method to get them to exercise or whether she needed to take a different approach to:

“get the most out of it” [HCP 2].

An Occupational Therapist reported a key issue which can affect motivation was that many patients have to wait a long time from being referred to then commencing the Pulmonary Rehabilitation programme. She also noted that they can be motivated to join the group when they are seen in clinic, but then they can often have to wait for 5-6 months to commence the programme and many lose motivation in this time. One Physiotherapist echoes what the Pulmonary Rehabilitation patient was saying in that

once the programme finishes, the patients find it hard to continue the exercises at home without the Healthcare Professional to guide them. Another Physiotherapist reported that she tries to get patients to:

“...take kind of charge of their own rehab.... And I think that they like that aspect of having somebody push them and somebody to come and see and check in with” [HCP 7].

She also adds that:

“I think a lot of them fall back on relying on us to exercise them when they come twice a week” and “What’s probably lacking with the home exercise programme is that they haven’t got somebody that can say to them ‘You’re ready to move up or work a bit harder’” [HCP 7].

One Physiotherapist describes three tiers of motivation:

“....there’s the motivation of the patients that won’t attend the class and aren’t ready to attend, there are patients that are ready to attend but that’s kind of as much as they are willing to do then there are patients that will get in touch with us afterwards and go ‘Oh, what was that thing you said about during the class and I’m following that up’” [HCP 7].

She describes that the latter patient group ‘type’ are in the:

“...cycle of change and they are going to make a big difference” [HCP 7].

It is important to decipher which level of motivation or where in the cycle of change an individual is in, to be able to successfully approach their motivation to exercise. This links with the Transtheoretical Model of behaviour change which refers to the stages of change that individuals go through to successfully change their behaviour.

The importance of personality types and how to influence change were also considered:

“I think there’s quite a big responsibility to trying to sort of work out people’s personality types and what they’re going to respond to best.” [HCP 2]

They noted that they aim to gauge the patient's personality type at the triage clinic appointment to be able to direct their approach and encourage them to attend Pulmonary Rehabilitation. It is not clear that they use any particular model or method to determine personality types or in relation to their approach for different personality types, or whether they adapted their approach, once they had defined their personality type.

During the Breathe Easy support group focus group, the Moderator found it hard to get the participants to focus on specific aspects of motivation. They probed by asking the question in different ways, but each time to conversation seemed to revert back to a negative tone, such as discussing the limitations due to exacerbation and infection, fatigue and lack of time as well as anxiety and depression. It was apparent from these two focus groups that the patients tended to be more focussed on the negative aspects of their disease and although they were motivated to attend the class, it was hard for the moderator to get them to consider why they attended, other than that they had formed social support networks with other members. One participant said that the group helped him to do the exercises:

"...you get together and it makes you do the exercises and because we know that at home we don't. So, it's the fact that you are actually coming somewhere to do it, it makes you want to do it if everyone else is doing it as well" [BE 8].

5.9.1.3. Enjoyment

The Breathe Easy support group and Pulmonary Rehabilitation participants report that they found the group exercises enjoyable which enabled them to complete the course and encouraged them to continue exercise.

"I think it's very enjoyable. In addition to the Breathe Easy I do lung exercises in the morning and evening anyway." [BE, 4]

"We have a laugh.....we've known each other for a long long time." [BE, 7]

“It’s friendly because we’ve known each other for I don’t know how many years.”
[BE, 8]

“I can say now cos when, you know everybody used to walk you know on the cones, but I don’t know if it was you or Becky forced me to run it and yeah, now I love that I can do it.” [PR, 1]

“It was a really friendly group like, and I think that helps a lot.” [PR, 1]

“I felt great. I used to come home and I used to say to him, I’ve thoroughly enjoyed it and I couldn’t wait for the next one. And people asked me know did you get on, ‘Oh, I right enjoyed it’, you know. And then the course just stopped.”
[PR, 3]

“I thought it was brilliant. Absolutely, I used to look forward to going. For the confidence of doing it and the company. Everybody was in the same position. Very good, I think it’s really practical. It helps and we should have more courses.” [PR, 4]

These personal accounts of how some of the participants enjoyed Pulmonary Rehabilitation and continued exercise are examples of positive experiences. They show how enjoyment can contribute to improved confidence, better engagement and increased likelihood of behaviour change and continued participation in exercise.

5.10. Chapter Summary

This chapter has summarised the key findings from the six focus group discussions in relation to the Thematic Networks Analysis. The themes discussed are consistent with findings within the literature on the barriers associated with adherence to exercise and self-management. To expand further on these findings the researcher will focus in

more detail on how the Global theme of behaviour is influenced by both Healthcare Professionals and patients. Chapter 6 will discuss this in relation to the findings from the survey to Healthcare Professionals.

Chapter 6: Survey findings

6.1. Overview of Chapter

This chapter will present an overview of qualitative and quantitative findings from the survey data. Demographic data will be presented in Table format and results from free text questions will be discussed in detail in relation to their relevance regarding whether Healthcare Professionals use Behaviour Change Techniques to influence behaviour change. The purpose of this survey was to build upon the findings from the focus groups which suggested that behaviour and behaviour change has an influence on the success of self-management. The survey aimed to identify causal mechanisms associated with behaviour change in Pulmonary Rehabilitation from the perspective of Respiratory Physiotherapists, so that recommendations for future intervention development could be considered.

6.2. Background to analysis and presentation of the survey

The survey offered to Respiratory Physiotherapists was designed to investigate the behaviours of both patients and Physiotherapists, but from the perspective of the Physiotherapist. The purpose of the survey was to determine how Physiotherapists approach self-management and whether this has an influence on patients' behaviour and attitude towards self-management. Secondly, the survey aimed to determine whether any key strategies or techniques were used by the Physiotherapists to influence behaviour change.

The focus group data analysis highlighted the complexities of the interactions between Healthcare Professionals and patients, particularly in relation to support for self-management. There were some common Basic level themes across the focus group themes, but the most prominent theme centralised around how behaviours influenced successful self-management from both a Healthcare Professional and a patient perspective. Although there were similarities across many of the themes, they were

expressed differently among the participant groups. A particularly important example focussed on behaviours in relation to support for self-management. There was a disparity between what Healthcare Professionals perceptions of self-management were compared to what the patients and Breathe Easy Support group members believed they needed to self-manage their condition. Patients and Breathe Easy Support group members sought on-going support from Healthcare Professionals whilst the Healthcare Professionals advocated that patients should be independent regarding their self-management after completing a Pulmonary Rehabilitation course. This survey was designed to investigate further into the complexities of self-management support from the perspective of Physiotherapists, in particular those working within a Pulmonary Rehabilitation setting.

6.3. Sample characteristics

Thirty-two participants responded from an estimated 1,000 ACPRC members. It was unknown how many members worked within the relevant field for the survey. Therefore, prior to sampling, the estimated response rate was unclear. There may have been a relatively small proportion of members who work within the field of Pulmonary Rehabilitation and self-management with patients with chronic respiratory disease. Those who responded to the survey may have been those who were generally more likely to be motivated themselves to facilitate behaviour change which can impact upon the validity of the results due to responder bias (Mazor *et al*, 2002). The survey was sent to a target group but it wasn't possible to know who would respond. Therefore, the sample may not be completely representative of the opinions of all Physiotherapists working in Pulmonary Rehabilitation or Chronic Respiratory Disease. Participants who responded are likely to be engaged in the clinical area which may have impacted the way in which they answered the question. This allows for a potentially biased representation. Yardley (2000) advises caution with larger sample sizes as it can be difficult to conduct analysis in sufficient detail. Rigour is related to the ability of the data to tell the full story and is not always dependent upon the sample size (Yardley, 2000). This primarily qualitatively-led thesis required individual accounts from the survey responses to understand current practice amongst specialists within the field. This will be discussed more in the Discussion and

Conclusion Chapter 8. It does however, provide an insight into a discrete participant group who are key members of the Pulmonary Rehabilitation team. Investigating Physiotherapists is also enhanced by the Reflexive and Researcher-practitioner approach to this thesis.

Demographic data is outlined in Table 6.1. Participants were primarily working in clinical roles with adults, but in varied clinical settings, across both inpatient and outpatient areas and 21 participants worked within Pulmonary Rehabilitation. Eighty four percent of participants used self-management within the context of Pulmonary Rehabilitation. Sixty two percent of participants worked in both individual and group settings. It was clear that participants worked with a wide range of members of the multidisciplinary team. The characteristics of the participants provided a range of perspectives, varying from level of experience to clinical or research setting, as well as perspectives from those working in varied clinical settings.

Table 6.1: Demographic details of survey participants

Number of Years Qualified	Working Role	Type of Patients you work with	Age of Patients you work with	Which MDT do you work with?	Do you educate patients on Self-Management?	Do you see patients in a group or individual setting?
0-5 years N = 4	Clinical N = 30	Acute N = 18	Adult N = 26	Respiratory Nurse N = 26	Yes N = 27	Individual N = 11
5-10 years N = 4	Research N = 3	Inpatient N = 18	Paeds N = 1	Respiratory Consultant N = 27	No N = 5	Group N = 2
10-15 years N = 9	Academic N = 2	Outpatient N = 18	Both N = 6	Occupational Therapist N = 16		Both N = 20
15-20 years N = 7	Other N = 3 • Career break	Pulmonary Rehabilitation N = 21		Psychologist N = 9		

	<ul style="list-style-type: none"> • Managerial Role • Clinical and managerial role 					
20-25 years N = 2		Respiratory N = 29		Dietician N = 12		
25-30 years N = 6		Community N = 2		Community Respiratory Nurse N = 8		
		Other N = 2 <ul style="list-style-type: none"> • Cardiac Rehab • General Medical, Surgical and Critical Care 		GP N = 8		
				Other		

				<p>N = 8</p> <ul style="list-style-type: none"> • Neuro Clinical Nurse Specialists • Physiotherapy Assistants • MDT Members across geographical area • CBT therapists • Smoking Cessation Specialist x2 • Trainee Assistant Practitioner, Community Matron, Health and Fitness Instructor • Pharmacist, Speech and Language Therapists, Surgical Consultant, Intensivists 		
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The Theoretical Domains Framework was used as the analytical framework. The data from the three free text questions and the enablers and barriers questions will be discussed in relation to the individual domains within the Theoretical Domains Framework. Behaviour change strategies will be presented using the Behaviour Change Techniques Taxonomy as a framework to identify key behaviours expressed by the participants.

Critical Realism underpins this thesis and by undertaking the survey data analysis with a Critical Realist approach it aimed to identify the causal mechanisms surrounding behaviour change within clinical practice from a Healthcare Professional perspective. For the purpose of this data analysis, the causal mechanisms will be presented as themes related to the Theoretical Domains Framework domains and also the behaviour change qualities highlighted by participants. To investigate the causal mechanisms the survey method was used as confirmation of existing literature regarding barriers and enablers to self-management as well as completeness by using both quantitative and qualitative methods.

6.4. Presentation of Survey Findings

Quantitative data analysis will be presented in the first instance, including the closed response questions focussed around the barriers and facilitators to self-management and the behaviour change strategies used. Following this, qualitative data will be presented from the open response questions.

6.5. Quantitative data analysis: The Barriers and Enablers to Self-Management

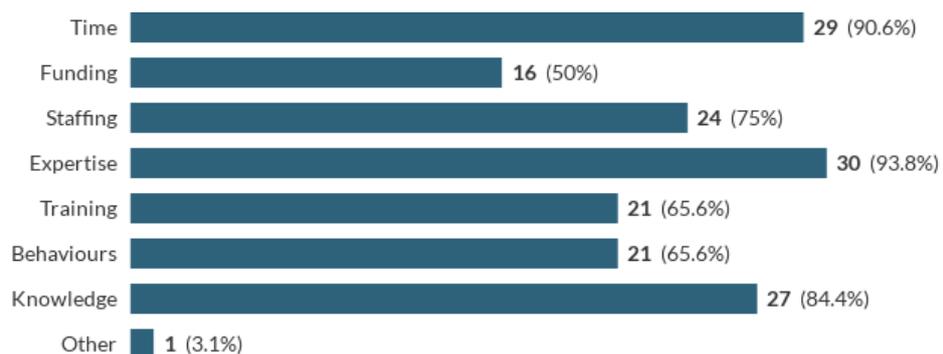
Participants were asked what the barriers and enablers are to self-management to confirm aspects within relevant literature, to expand upon aspects already highlighted from the focus groups and to see if there were any new concepts. Questions were split into considering the enablers and barriers to self-management from three different viewpoints to determine whether there were any similarities or differences between

responses. The questions were split into the barriers and enablers to self-management from a Patient, Service and Physiotherapist's viewpoint. It is important to be able to differentiate between aspects that are influenced by service delivery and those that are influenced by individual Physiotherapist or Patient behaviour, so that causal mechanisms can be explored. The purpose of the survey was to determine whether Physiotherapists' behaviours had an influence on patient behaviour. However, it is also important to recognise that the service delivery constraints may also have an impact. Although patient and service perspectives were discussed, it is key to note that these three elements of responses were all from the participant perspective and they were all Respiratory Physiotherapists. Therefore the responses on views on patient, Physiotherapist and Service enablers and barriers were all from the perspective of the Physiotherapist.

6.5.1. Service Delivery View

Respondents reported that, from a Service viewpoint, some aspects were seen as both enablers and barriers. Time, expertise and knowledge as well as staffing were the most commonly cited enablers to successful self-management. Patients are more likely to be well-supported with their self-management if the Physiotherapist has the time to spend with them and if they are experienced and have the relevant level of knowledge for behaviour change. Participants also recognised the importance of training and behaviours as enablers. One participant commented that the environment should be comfortable and easy to access.

Figure 6.1: Physiotherapists saying what the enablers are from a Service perspective:

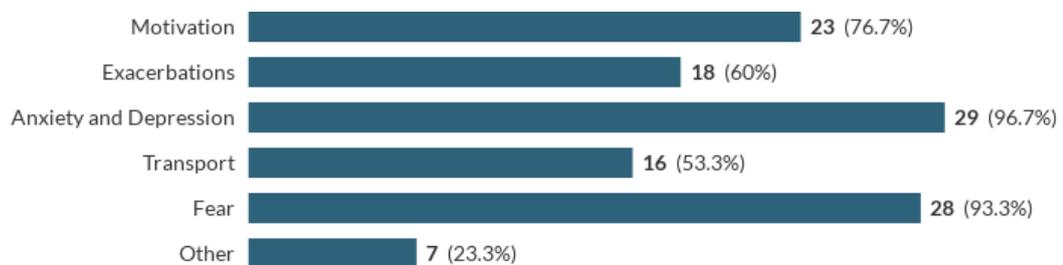


Comparatively, time, staffing, funding and expertise were commonly cited as barriers from a Service viewpoint. This seems logical as a lack of time, reduced staffing and less expertise may be linked to less funding and therefore would influence the Physiotherapist's ability to successfully support patients with self-management. One participant also commented that:

'Lack of flexibility for those patients who are unable to get to rehab because of transport' [Participant 19]

Transport is a common barrier to patients being able to attend Pulmonary Rehabilitation sessions and it links into the funding problems. The most frequently cited barriers were motivation, anxiety and depression and fear.

Figure 6.2: Physiotherapists saying that the barriers are from a service perspective:



6.5.2. Enablers from a Physiotherapist and Patient Viewpoint

There were some similarities between the enablers from a Physiotherapist and Patient viewpoint.

Figure 6.3: Physiotherapist saying what patients' enablers are:

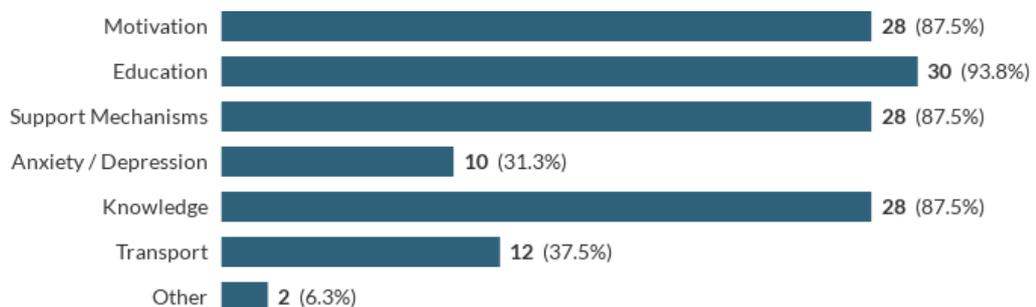


Figure 6.4: Physiotherapist saying what the enablers are from their own perspective:



For example, participants recognised that ‘Motivation’ was both an enabler and barrier to self-management from both a Patient and Physiotherapist’s viewpoint. Education was also recognised as an enabler from both the Patient and Physiotherapist viewpoint. Thirty participants selected ‘Education’ as an enabler from a patient perspective and 23 as an enabler from a Physiotherapist view. Knowledge and support mechanisms were also cited as an enabler from both the Physiotherapist and Patient viewpoint.

‘Behaviours’ were cited as an enabler from a Physiotherapist viewpoint indicating that a Physiotherapist’s behaviours could have a positive impact on the patient’s ability to self-manage. Whilst at the same time, ‘behaviours’ were also cited as a barrier which highlights the importance of how Physiotherapists’ behaviours can influence a patient’s behaviours.

6.5.3. Barriers from a Physiotherapist and Patient View

There were also some similarities in responses to barriers: motivation, anxiety and depression primarily but also exacerbations and transport were also common barriers. There were, however, some different responses. These were primarily due to different answer options within the question but fear was cited as a common patient barriers and support mechanisms, knowledge and behaviours were cited as common Physiotherapist barriers.

Figure 6.5: Physiotherapist saying what patients' barriers are:

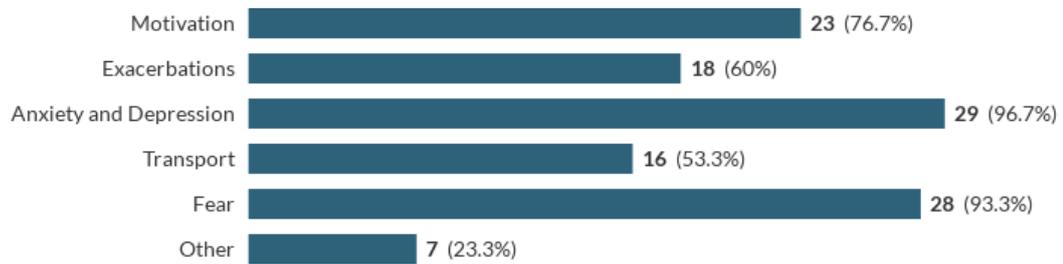
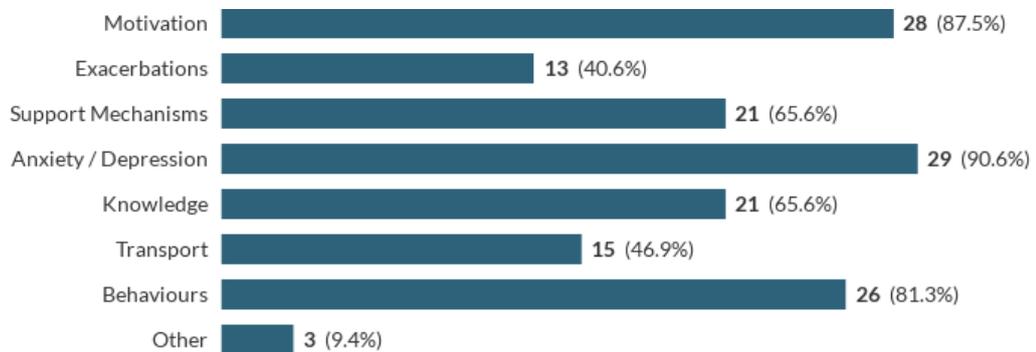


Figure 6.6: Physiotherapist saying what the barriers are from their own perspective:



Knowledge goes alongside Education as both an enabler and barrier from both the patient and Physiotherapist's viewpoint. 'Lack of Knowledge' was cited as a barrier by some participants. Both patients and Physiotherapists need to have the knowledge of the condition they are either experiencing from a patient perspective or in the provision of education from a Physiotherapist perspective.

Anxiety and Depression were also frequently cited by participants as barriers from both patient and Physiotherapist's viewpoint. Twenty nine participants responded that Anxiety and Depression were barriers to self-management from both a patient and Physiotherapist perspective.

Twenty-one participants felt that support mechanisms were enablers to successful self-management. However, it is also important to note that support mechanisms were also recognised as a barrier as without appropriate support mechanisms, patients will find it hard to be able to self-manage.

Several of the barriers and enablers recognised by the participants confirm aspects of issues related to self-management. For example, barriers from a patient perspective include anxiety and depression, exacerbations, fear and transport. It was important to include these questions in the survey as a means to confirm aspects already recognised in the literature. There was also confirmation in the participants response from a Physiotherapist's perspective, that they thought the barriers were often exacerbations, anxiety and depression, knowledge, transport and support mechanisms.

Many of these aspects are interlinked and it is important to appreciate the links between the different aspects in relation to the enablers and barriers to successful self-management. There is not just one aspect or quick-fix answer which would enable a patient to successfully self-manage but each element has an important role to play in the complex web of interactions between both physical, psychological and practicalities of self-management within this patient group.

6.5.4. Behaviour Change Strategies

Behaviour change is a key component in effective self-management in Pulmonary Rehabilitation.

Figure 6.7: Response to behaviour change strategies used by participants:

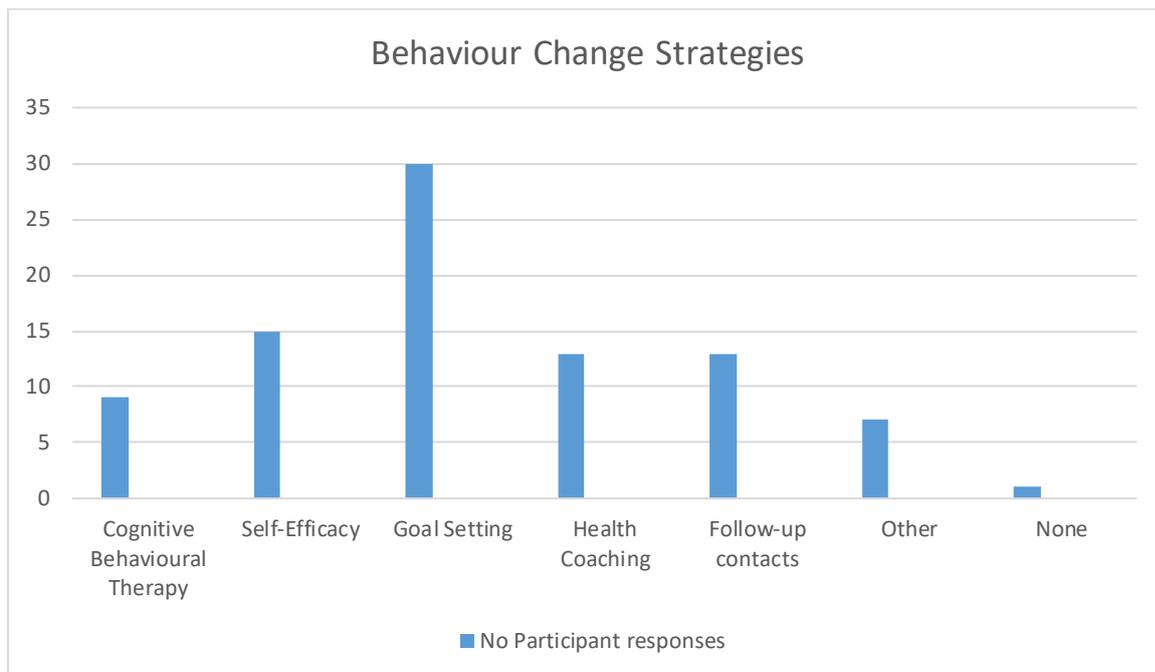


Figure 6.7 shows that Physiotherapists use Behaviour Change Techniques such as Goal-Setting, Health Coaching, Self-Efficacy and Motivational Interviewing as well as an important strategy of following up patients. Thirty participants used Goal-Setting as part of their Behaviour Change strategies and 15 used Self-Efficacy. Thirteen participants used Health Coaching and 13 used follow-up contacts. Nine participants reported using Cognitive Behavioural Therapy (CBT) and when prompted with an option for 'other', five participants responded that they used Motivational Interviewing as a Behavioural Change Technique. Only 1 participant reported no use of any Behaviour Change Techniques. It is clear that Respiratory Physiotherapists working with patients on self-management within the context of Pulmonary Rehabilitation use some Behavioural Change Techniques and the survey data opens up the scope for further analysis to identify which Behaviour Change Techniques are part of the 'active ingredients' of self-management in Pulmonary Rehabilitation.

Participants were also asked to identify key behaviours in self-management from different perspectives. They were asked to state three key behaviours of a successful self-managing patient, as well as three key behaviours of a Physiotherapist who

successfully supports self-management. The responses from participants on Physiotherapists' key behaviours were not specific Behaviour Change Techniques. Participant responses on both the patient and Physiotherapist behaviours were more focussed around attributes and behaviours rather than Behaviour Change Techniques. For example, the most commonly cited responses for patient behaviours were 'knowledge', 'willingness', 'motivation', 'supported', 'understanding' and 'engagement'. There are some similarities between what the patient and Healthcare Professionals think key behaviours are of a physiotherapist who supports self-management. For example, key words such as 'knowledgeable', 'supportive', 'motivation' and 'understanding'.

This highlights that from both a patient and Physiotherapist perspective. Behaviour Change Techniques are not commonly used in relation to self-management. Key words such as 'Motivation' and 'Self-Efficacy' are associated more commonly with Behaviour Change Theories such as the Self-Determination and the Social Cognitive Theory. Physiotherapists perhaps more easily relate to and focus on Behaviour Change Theory rather than specific techniques. The results from the survey are, however, just a snapshot of a small sample of participants.

6.6. Qualitative data analysis

All survey responses for the free text questions were coded by highlighting key words within the responses. Following this coding, the Theoretical Domains Framework was used as an analytical framework to determine how the key words and statements mapped to each of the domains. Atkins *et al* (2017) suggest that the Theoretical Domains Framework is ideally placed to identify barriers and facilitators to change, particularly in relation to behaviour change. Therefore, it was appropriate to apply this framework to analyse the data.

A copy of the survey questions are in Appendix VI. But, as a reminder, the free-text questions were:

- What do you think self-management means?
- In your experience / opinion, please state no more than 3 key behaviours of the successful self-managing patient.
- In your experience / opinion, please state no more than 3 key behaviours of Physiotherapists who successfully support self-management.

These three questions will now be presented together and mapped onto the Theoretical Domains Framework. Descriptions of the domains are adapted from Cane *et al* (2012). Responses to these questions were coded for key words and then mapped to the Theoretical Domains Framework. The key words associated with the different domains are presented in Table 6.2.

Table 6.2: The coded responses and association with individual theoretical domains

	Key words / codes from responses		
TDF Domain	<i>'What do you think self-management means?'</i>	<i>'3 key behaviours of the successful self-managing patient'</i>	<i>'3 key behaviours of Physiotherapists who successfully support self-management'</i>
Knowledge <i>An awareness of the existence of something</i>	Understanding, information, education, knowledge, awareness of condition, knowing baseline symptoms, guidance, manage independently, teaching	Knowledge of their "normal", knowledge / understanding of condition / disease pathology / diagnosis, knowledgeable, understands disease process, good understanding, take on board management strategies	Knowledgeable, knowledge and understanding, providing key information
Skills <i>An ability or proficiency acquired through practice</i>	Skill sets, tools and advice, necessary tools, management strategies, learned skills		Active / good listening, motivational, CBT skills, trained in psychological approaches, effective communicator, expertise, experience, training and education, good educator

<p>Social / professional role and identity <i>A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting</i></p>	<p>Seek assistance from community respiratory support, GP or family, empowering patients</p>	<p>Confidence in their decision with no anxiety traits, accepts their condition with its limiting factors, higher educational ability (ability to understand, interpret and utilise the information)</p>	<p>Clinical experience, inspiring, practice what they preach</p>
<p>Beliefs about capabilities <i>Acceptance of the truth, reality or validity about an ability, talent or facility that a person can put into constructive use</i></p>	<p>Empowering, motivating, manage their condition independently, recognising a change in their symptoms, understand how and when to step up/down treatment, undertake their treatments independently</p>	<p>Willingness to learn and adapt to condition, motivation / motivated, positive outlook, acceptance of current state, openness to change</p>	<p>Encouraging, instilling confidence in patient, understanding, motivational,</p>
<p>Optimism <i>The confidence that things will happen for the best, or that desired goals will be attained</i></p>	<p>Give confidence</p>	<p>Confidence in their decisions, positive outlook</p>	<p>Positive, confidence</p>

<p>Beliefs about consequences <i>Acceptance of the truth, reality or validity about outcomes of a behaviour in a given situation</i></p>	<p>Maintain their own personal well-being, being proactive and recognising deterioration, knowing when to seek assistance and when to present to hospital, optimise their quality of life, know how to get help if struggling, seek appropriate medical advice</p>	<p>Realistic, accepts their condition with its limiting factors, know when to seek help, realistic expectations, desire to improve / limit disease progression</p>	<p>To understand patterns of behaviours</p>
<p>Reinforcement <i>Increasing the probability of a response by arranging a dependent relationship or contingency, between the response and a given stimulus</i></p>	<p>Being compliant with advice, continuous compliance</p>	<p>Access to HCP to instil confidence in decision making, feeling well supported / that there is a 'back-up' person for advice, engagement with services, seeking education and knowledge, listen to HCP's,</p>	<p>Encouraging, supportive, experience to make explanations relevant to the individual</p>
<p>Intentions <i>A conscious decision to perform a behaviour or a</i></p>	<p>Locus of control, taking onus of the situation</p>	<p>Commitment, willingness, willing to learn / try, engagement with services</p>	<p>Proactive, openness to engage with the patient</p>

<i>resolve to act in a certain way</i>			
Goals <i>Mental representation of outcomes or end states that an individual wants to achieve</i>		Clear goals	
Memory, attention and decision processes <i>The ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives</i>		Informed, confidence in their decision, habit formation, acceptance, listens to advice and take on board management strategies	Providing key information that the person can understand
Environmental context and resources <i>Any circumstance of a person's situation or</i>		Transport / means of getting to the venue, considers using all modes of treatment including PR and psychology	

<p><i>environment that discourages or encourages the development of skills and abilities, independence, social competence and adaptive behaviour</i></p>			
<p>Social Influences <i>Those interpersonal processes that can cause an individual to change their thoughts, feelings or behaviours</i></p>		<p>Support mechanisms, supportive home circumstances</p>	<p>Supported / supportive</p>
<p>Emotion <i>A complex reaction pattern, involving experiential, behavioural and physiological elements, by which the individual attempts</i></p>		<p>Anxiety</p>	

<i>to deal with a personally significant matter or event</i>			
Behavioural regulation <i>Anything aimed at managing or changing objectively observed or measured actions</i>	Modify lifestyle, self-efficacy	Self-efficacy, confidence, acceptance, motivation, engagement,	Empathy, Coaching style, empower

6.6.1. Knowledge

Within the Theoretical Domains Framework, knowledge refers to ‘an awareness of something’. This was one of the most frequently cited domains. Participants responded that self-management meant having knowledge of their condition, knowing their symptoms and knowing what to do when they become unwell. There was a link between knowledge and the importance of education and it was suggested that patients could self-manage their condition if they were given knowledge. Some example responses include:

“Educating patients to make them aware of condition” [Participant 22]

“Providing patients with the knowledge of their condition” [Participant 23]

“Teaching the patient to manage their condition independently” [Participant 27]

The survey findings reflect that Healthcare Professionals value the importance of education during Pulmonary Rehabilitation, particularly in relation to knowledge on self-management. For example, Survey participants said that self-management means:

“Giving patients the tools and advice to help themselves” [Participant 8]

“Providing those with a chronic condition with the appropriate information / education and necessary tools to be able to manage their condition independently” [Participant 4]

“Educating patient to make them aware of condition, medications, when exacerbation likely to occur, methods to minimise exacerbations and duration of them. Pro-active.” [Participant 22]

In these examples, participants suggest that providing patients with knowledge and educating the patient on their condition and how to manage it leads to self-management. There was less emphasis upon collaborative working with patients to reach patient-centred goals.

In terms of behaviours, participants suggested that a patient should be knowledgeable and understand their condition, whereas Physiotherapists should also be knowledgeable and understand the patient's condition to be able to support self-management. Whilst this is important, it is not clear how this influences the success of self-management.

6.6.2. Skills

Physiotherapists who completed the survey responded that skills were a key behaviour in self-management from both the patient and the Physiotherapist. Survey participants responded that skills were both a barrier and an enabler to self-management from a Service perspective and an enabler from a Physiotherapist's perspective. There is a lack of clarity on what specific skills are required to enable successful self-management. However, many of the Survey responses suggested that self-management meant being provided with 'skill-sets', giving patients 'tools and advice', 'knowing best management strategies' and 'the ability to undertake required treatments as prescribed'. Many of these statements are focussed around Physiotherapists giving patients tools, advice and guidance on treatments rather than supporting them with individual behaviour change. The Theoretical Domains Framework description of a skill is 'an ability or proficiency acquired through practice'. It is unclear from the Survey responses with regards to the skills, tools and advice and strategies, whether there is any specific practice of these skills.

Participants responded that self-management means having the tools and advice but there was minimal reference to which specific tools were most relevant. It is important to determine which tools and advice are relevant to supporting self-management, particularly in relation to behaviour change. There were no suggestions of behaviours related to skills for patients but for Physiotherapists some suggested skills such as active listening, which is a Health Coaching technique, Cognitive Behavioural Therapy

(CBT) as well as being trained in psychological approaches. Other skills listed were being a good communicator and having relevant expertise, experience and training.

6.6.3. Social / professional role and identity

This domain was recognised as both an enabler and barrier to self-management from the patient, Service and Physiotherapist perspective.

The survey responses suggested that the Physiotherapist's role was to 'empower', 'provide patients with' tools and advice and guidance and 'educate' patients on how to manage their own condition.

There was reference to the influence of educational ability on the success of self-management:

"Higher educational ability – (ability to understand, interpret and utilise the information provided, knowledge transference)." [Participant 31]

It was suggested that Physiotherapists should have:

"Clinical experience." [Participant 2]

As well as being:

"Trained in psychological approaches." [Participant 10]

The influence of the social environment and wider support network was suggested with regards to self-management. It was suggested that patients should accept their condition and limitations but to have confidence in their abilities. From a Physiotherapist point of view, they suggested key behaviours were:

"clinical experience" [Participant 2]

And:

"being an inspiring role model" [Participant 5]

6.6.4. Beliefs about capabilities

Several of the survey participants responded that self-management means 'empowering patients' to manage their own condition and 'recognise their symptoms' to 'take control' of their condition. For this to be effective, the patient needs to understand their abilities as well as limitations.

Many participants described self-management as empowering patients to maintain themselves:

"Empowering the patients to help them maintain their own personal wellbeing"
[Participant 1]

As well as:

"Empowering the patient with the skills to maintain and treat their health condition" [Participant 11]

Whilst others described empowering in relation to behaviours such as confidence and knowledge:

"Empowering patients to take control of the management of their condition in an individualised manner. Education forms a significant part of this and ensures the patients understand they are not defined by their condition" [Participant 16]

"Empowering patients to feel confident in making positive decisions in managing their condition" [Participant 18]

Physiotherapists felt that their role in self-management was to instil confidence in patients so that they could make decisions about their own health.

Some participants described self-management in terms of “control” which links into behaviour as well as the psychological aspects of self-management. Participants describe patients having control of their condition:

“Patient taking control of his condition in a way that empowers them to make changes to improve their quality of life” [Participant 19]

“Expert patients create real belief through mentorship” [Participant 29]

This both reflects the importance of control, as well as how this influences their empowerment to manage their own condition.

Some participants focussed around supporting patients to improve their quality of life and well-being, whilst still providing them with the necessary advice and tools, but in a more empowering way. For example:

“Empowering the patients to help them to maintain their own personal wellbeing” [Participant 1]

“Patient taking control of his condition in a way that empowers them to make changes to improve their quality of life” [Participant 19]

“Empowering patients to understand and then better manage their own symptoms” [Participant 15]

“Awareness of condition and its symptoms and management of these whether well or not, in order to live a healthy purposeful life” [Participant 12]

“Changing people’s locus of control i.e. they should manage themselves rather than someone or something else sorting or managing them. Also medication is only a small part of the self-management jigsaw” [Participant 29]

Motivation was also a frequently cited answer as a key behaviour of both the successful managing patient as well as the Physiotherapist who successfully supports self-management. Motivational Interviewing was also cited as a strategy for behaviour change.

6.6.5. Optimism

Optimism is described within the Theoretical Domains Framework as ‘the confidence that things will happen for the best’. Motivation links with optimism as if an individual feels optimistic then they are more likely to be motivated to attend Pulmonary Rehabilitation and succeed at their goals to change their behaviours. Motivation was cited frequently within the survey responses as both a barrier and enabler to successful self-management from a patient and Physiotherapist’s perspective. Motivation was also cited frequently as a key behaviour of a successful self-managing patient.

“Motivation to want to change / improve” [Participant 4]

“Motivation” [Participants 3, 5, 11, 14, 19, 26, 27, 28, 31]

“Motivation to help themselves, motivation to change” [Participant 15]

Several participants referred to ‘giving confidence’ to patients so they could help themselves, which suggests patients have optimism. Similarly, patients and Physiotherapists having confidence in their abilities was also seen as a key behaviour.

“Instilling confidence in patient” [Participant 23]

“Positive outlook2 [Participant 9]

6.6.7. Beliefs about consequences

Described as ‘the acceptance of truth’, this domain was represented as the acceptance of their condition, being realistic about their limitations and recognising deterioration and when to seek help. From a Physiotherapist view, it is essential to recognise patterns of behaviours to be able to detect deterioration as well as behaviour change. Most of the quotes relevant to this domain refer to key patient behaviours. The importance of being knowledgeable and informed, regarding their condition is reflected upon as a key behaviours, essential to be able to understand the disease process.

“Knowledge of their ‘normal’ health indicators e.g. sputum colour, volume etc.”
[Participant 2]

“Accepts their condition with its limiting factors, understands the disease process” [Participant 13]

“Acknowledgement of condition” [Participant 15]

Alongside having knowledge and acceptance a patient has to be realistic about their condition and abilities:

“Realistic expectations” [Participant 19]

“Acceptance of current state” [Participant 29]

6.6.8. Reinforcement

Reinforcement is described as ‘increasing the probability of a response by arranging a dependent relationship or contingency, between the response and a given stimuli. Behaviour Change Techniques can help facilitate a positive change in health behaviours. For example, survey participants responded that support mechanisms were both a barrier and enabler from a Physiotherapist perspective. This suggests

that a lack of support mechanisms for continued reinforcement would lead to poorer outcomes, whereas availability of support mechanisms would support successful self-management and behaviour change. One participant described it as:

“Being compliant with advice and medication and having continuous compliance” [Participant 5]

The value of having support mechanisms and in particular the support from Healthcare Professionals was noted:

“Those who have access to HCP to instil confident decision making” [Participant 6]

“Feels well supported / that there is a ‘back-up’ person for advice” [Participant 14]

There was some reference, in relation to key behaviours, to the importance of ‘empowering’ patients, but this was mainly through means of ‘education’ and ‘providing tools and advice’ and ‘knowledge’ to manage their own condition, rather than guiding them through the process. Pulmonary Rehabilitation sessions are in a group format, so it is often difficult to give patients one to one support for their individual needs and behaviour change.

“empathy” [Participant 13]

“Empower the patient within the individual situation / circumstances they are in – not assuming that as the professional they know better than the patient, working alongside the patient and not dictating to them” [Participant 14]

There were several responses which described self-management involved empowerment, suggesting that the Healthcare Professionals role was to empower patients to self-manage their condition:

“Empowering the patients to help them maintain their own personal well-being”
[Participant 1]

“Empowering the patient with the skills to maintain and treat their health condition” [Participant 11]

“That the patients are given guidance and are empowered about how they can be proactive in managing their condition themselves” [Participant 14]

“Empowering patient to understand and then better manage their own symptoms” [Participant 15]

“Empowering patients to take control of the management of their condition in an individualised manner” [Participant 16]

“Empowering people to feel confident in making positive decisions in managing their condition” [Participant 18]

Although there are several references to the importance of empowering patients to make changes, the mechanisms of empowering are not clear, other than suggestions of providing patients with information, guidance, skills and knowledge.

6.6.9. Intentions

Intentions are described as ‘a conscious decision to perform a behaviour or a resolve to act in a certain way’. The survey participants made few references to intentions to perform a behaviour or to act in a certain way. There were some suggestions of the commitment to change and willingness to try new things. It was also suggested that engagement in Services showed positive intentions to change.

“being proactive in optimising one’s own medical status including seeking professional help” [Participant 5]

“Engagement with services” [Participant 17]

“Engaged with healthcare staff” [Participant 18]

“Engagement” [Participant 26, 28]

“Engagement in treatment” [Participant 27]

Several responses were around patients being ‘willing’ to learn:

“willingness to learn and adapt to condition” [Participant 2]

“willingness” [Participant 9]

“willing to learn” [Participant 11]

This suggests that patients will have greater success if they are willing to learn and change their behaviours for successful self-management.

6.6.10. Goals

Goal setting as described within the Theoretical Domains Framework emphasises that there are ‘outcomes or end states that the individual wants to achieve’. It is especially important that the goal is set by the patient around something they want to achieve, as they are more likely to successfully change their behaviours to be able to achieve something they want to, rather than something set by a Healthcare Professional. Thirty participants said they used goal setting as a Behaviour Change strategy, but none mentioned it within their definition of self-management. In response to key behaviours from a patient perspective; the only reference to goal setting was:

“have clear goals” [Participant 31]

There was a lack of detailed consideration of goal setting throughout the survey responses. Therefore, it is difficult to understand perspectives and current practice on goal setting from these survey responses.

6.6.11. Memory, attention and decision processes

This is described as 'the ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives'. Some participants responded that key behaviours of a Physiotherapist who successfully supports self-management included:

“providing key information that the patient can understand” [Participant 23]

“empowering the patient within the individual situation they are in, so that the patient can make their own decisions about their self-management” [Participant 14]

“Patient taking control of their condition in a way that empowers them to make changes and improve their quality of life” [Participant 19]

In addition, it was suggested that patient key behaviours were:

“habit formation towards treatments” [Participant 25]

“Acceptance of current state” [Participant 29]

“confidence in their decision with no anxiety traits” [Participant 6]

As well as being well-informed to make decisions.

6.6.12. Environmental context and resources

The environment and resources available for Pulmonary Rehabilitation have an influence on the successful attendance and completion of the course. From a Service delivery perspective, participants cited transport, access and availability and lack of support and social isolation as barriers to successful self-management. Key behaviours of a successful self-managing patient were suggested as:

“transport / means of getting to a venue” [Participant 3]

Other resources cited, include aspects of information, tools and skills, knowledge and support from Healthcare Professionals:

“Seeking education and knowledge” [Participant 25]

“Medicines and pharmacy” [Participant 22]

In relation to the definition of self-management, some participants suggested that resources such as tools and knowledge / skills influenced its success:

“It is the ability of an individual to utilise the tools given to them (education etc.) to improve their self-efficacy (achieve desired outcomes)” [Participant 31]

“Giving patients the tools and advice to help themselves. Motivating them to help themselves and give confidence” [Participant 3]

“Providing those with a chronic condition with the appropriate information / education and necessary tools to be able to manage their condition independently” [Participant 4]

“Using learned skills to address these changes including non-pharmacological strategies, when to seek assistance from community respiratory support, GP, family and when it is the right time to present to hospital if required.” [Participant 13]

There were several responses which included suggestions that giving patients tools and advice, as well as education and knowledge would lead to improved self-management. However, there remains a lack of clarity on how to support behaviour change in relation to self-management through giving tools and advice and education.

6.6.13. Social Influences

Social influences are described as ‘interpersonal processes that can cause an individual to change their thoughts, feelings or behaviours’. Often when people are breathless they stop doing hobbies or activities they enjoy due to embarrassment or worrying about not being able to keep up. Survey participants responded that a lack of support and social isolation and having other responsibilities such as being a main carer for a family member, were all barriers to successful self-management from a patient perspective. Supportive home circumstances were attributed to being a key behaviour for successful self-management.

“Supportive home circumstances” [Participant 18]

“Feels well supported / that there is a ‘back-up’ person for advice” [Participant 14]

The interactions with patients and their family members as well as engagement in Healthcare services are important to appreciate.

6.6.14. Emotion

Emotion is described as “a complex reaction pattern, involving experiential, behavioural and physiological elements, by which the individual attempts to deal with a personally significant matter or event”. This was a frequently cited domain within the survey responses. Emotion can be linked to anxiety and depression, which was commonly cited as a barrier to successful self-management in the survey responses. The psychological impact of Chronic Respiratory disease was cited frequently from the Healthcare Professionals, Pulmonary Rehabilitation patients and Breathe Easy support group members within the focus groups. From a Healthcare Professional perspective it was recognised as a barrier and issue for further support. Whilst from a patient and Breathe Easy support group perspective personal experiences were discussed, which highlighted the impact it had upon their success of self-management.

Emotion was not expressed simply as pure emotions within the survey responses to defining self-management and suggesting key self-management behaviours. However, participants responded with aspects that could be associated with emotions such as empathy:

“Empathy and kindy” [Participant 15]

“Empathy, understanding of condition and not all patients will respond the same way to advice, treatment and adherence” [Participant 13]

As described within the Theoretical Domains Framework, emotion is a complex reaction pattern. Therefore, there are different physical and psychological mechanisms which interact to produce emotions. The themes from the survey

responses suggest that supporting patients by empowering their decision making, giving confidence and providing education and knowledge allows the patient to better manage their condition. The specific emotions associated with these mechanisms need further investigation.

6.6.15. Behavioural Regulation

This was a frequently cited domain within the survey responses. Behavioural regulation is described as ‘anything aimed at managing or changing observed or measured actions’. Strategies cited by survey participants included: goal setting, providing tools and advice, empowering patients with independent decision making, providing patients with knowledge and helping patients with an agreed plan for how to manage their condition.

From the survey, only two out of thirty-one responses to the question ‘What do you think self-management means?’ responded in relation to Behaviour Change mechanisms. For example, one participant responded that it was about:

“Changing people’s locus of control i.e. they should manage themselves rather than someone or something else sorting or managing them”
[Participant 29]

And another responded that it was:

“the ability of an individual to utilise the tools given to them to improve their self-efficacy” (Participant 31).

Self-efficacy was cited as a key behaviour for successful behaviour change, this is also a key Behaviour Change Technique. The role of self-efficacy warrants further investigation. Empathy and empowerment were also seen as key aspects of behaviour change.

6.7. Chapter Summary

The survey data has affirmed that behaviours in self-management are complex. Although the sample size was small, the responses are valuable to contribute to findings from the focus groups, as well as enhance knowledge on specific practices among Physiotherapists. The mixed methods approach to the survey allowed for deeper understanding of the complexity of behaviours in self-management by using both quantitative and qualitative data. Qualitative data from the survey provides a deeper understanding into a personal narrative from each participant, which allows the researcher to understand their approach to self-management. In addition, the quantitative data from the responses allows for the researcher to contextualise the qualitative data in numerical terms. For example, the number of participants who responded that anxiety and depression was an enabler to self-management. This is an example of triangulation. Themes were determined from both the qualitative and quantitative data which provides a more structured analysis.

There were common elements from both patient and Physiotherapist behaviours. The qualitative data regarding the definitions of self-management showed a richness of individual perspectives on what self-management means to them. A personal account of how their view on what self-management means is valuable to determine how Physiotherapists' behaviours can influence patient behaviours. There were some short-term approaches to self-management such as the provision of education, knowledge, tools, and advice. Comparatively, more long-term changes such as empowering, self-efficacy, goal-setting and health coaching were frequently suggested. These were more aligned with Behaviour Change Techniques, but further detail is required on the specifics of how these interventions are used. It is necessary to identify the specific components or 'active ingredients' of self-management to be able to optimise patient outcomes. Behaviour Change Techniques have been proposed to be 'active ingredients' to change behaviour. It was apparent that Physiotherapists had less knowledge and practice of using specific Behaviour Change Techniques although some participants referenced Behaviour Change Theory. The most commonly used Behaviour Change Technique was goal setting which is often a key component of therapy interventions amongst Physiotherapists, so this is not

surprising. However, the survey does not have sufficient detail in the qualitative responses to evaluate the quality of the goal setting. This is an important aspect to consider when determining the approaches to self-management.

Mapping using the Theoretical Domains Framework has highlighted elements presented within survey responses in relation to self-management. However, for behaviour change to be successful, it is essential to understand the Behaviour Change Strategies currently used in clinical practice. This is an essential step in being able to explore the mechanisms associated with behaviour change.

This survey has started to identify the definitions and approaches to self-management and begins to identify the 'active ingredients' of self-management and Behaviour Change Techniques. Chapter 7 will analyse the combined data from the analysis of both the focus groups and survey responses by mapping to the Capability, Opportunity and Motivation to Behaviour (COM-B) model and the Behaviour Change Wheel.

Chapter 7:

Conceptualising Behaviour Change in Self-Management:

7.1. Overview of Chapter

To conceptualise behaviour change in self-management it is necessary to investigate beyond the well-documented issues surrounding adherence and to delve deeper into identifying the causal mechanisms associated with self-management behaviours. Critical Realism underpins this thesis. Therefore, an essential component of this final data analysis chapter is to employ Methodological Triangulation with the data obtained through the focus groups and survey responses. The principles of triangulation in Critical Realism will be presented in relation to achieving retroductive reasoning by moving through the stages of confirmation and completeness. To be able to situate the data within the field of behaviour change, the Behaviour Change Wheel (BCW) was used as a framework to analyse the combined data to be able to determine key behaviours associated with successful behaviour change in self-management. The Capabilities, Opportunities and Motivation to Behaviours (COM-B) model will be presented to determine the behavioural factors associated with the Capability, Opportunity and Motivation to successful self-management. Intervention types will also be discussed in relation to the COM-B model. Within the Behaviour Change Wheel there are nine intervention functions. These will be discussed in relation to self-management. By using data from the focus groups and survey responses and identifying the causal mechanisms, this will all facilitate a deeper understanding of the complex interplay between adherence, self-management, and behaviour change.

7.2. Critical Realism

In keeping with the philosophical approach to this thesis, this chapter will focus on conceptualising behaviour change in self-management to be able to determine the causal mechanisms involved. From a Critical Realist perspective, a key element in understanding behaviour change is to identify the causal mechanisms which influence the behaviour. This data analysis contributed to the development of retroduction or

abductive inspiration to develop a more complete understanding of the phenomenon of behaviour change and self-management by mapping its different components rather than merely confirming the accuracy of a set of data (Risjord *et al*, 2002).

In relation to behaviour change in self-management, the causal mechanisms can be described as the barriers and facilitators influencing the elements of adherence, compliance and ultimately behaviour change. One of the key questions in Critical Realism is to understand how the causal mechanisms operate within a particular situation and how they influence certain changes. This chapter will begin to unravel the complex web of interactions associated with causal mechanisms in relation to behaviour change in self-management. Previous research has identified barriers and facilitators to adherence, but this thesis begins to identify the causal mechanisms associated with these barriers and facilitators to better understand how they are activated in relation to behaviour change in self-management from the different perspectives of patients, Healthcare Professionals and Breathe Easy support group members.

Critical Realists advocate that the world 'operates as a multidimensional open system' (McEvoy and Richards, 2006, p.70) and that events are not linear, they do not follow an order, but the outcomes are determined by the interactions between the social structures, mechanisms and human factors. This thesis begins to examine these complex interactions between the social world, the causal mechanisms associated with them, whilst also situating them within the context of the human aspects of patients and Healthcare Professionals. McEvoy and Richards (2006) suggest that the causal mechanisms have the 'potential to make impact' (p.70) but that the conditions in which the mechanisms operate need to be suitable for the mechanism to be activated. In relation to this thesis, this chapter will begin to identify the causal mechanisms associated with behaviour change in self-management by combining the data from the focus groups and survey responses. Consideration will be made in relation to how these mechanisms operate and how they influence the success of behaviour change in self-management.

7.3. Methodological Triangulation

Methodological Triangulation allows for enhanced validity of the research by combining analysis of different often complimentary research methods to gain new insights into the research question (Robson, 2002). Risjord *et al* (2002) advocate that Methodological Triangulation is employed for three purposes: completeness, confirmation, and abductive inspiration. These terms were described in relation to the current study within the Methodology in Chapter 3. However, these terms will be revisited for the purpose of this Chapter. Risjord *et al* (2002) suggest that mixed methods research allows for complimentary perspectives on the research question which contributes to completeness. Within Critical Realist philosophy, completeness using mixed methods allows for the reality in question to be observed and understood from different perspectives (McEvoy and Richards, 2006). Whereas confirmation allows for increased validity and reliability by combining data from different sources to support a more robust conclusion than each data could provide separately (Robson, 2002). Abductive Inspiration is the process in which new explanations for a phenomenon are found, often through using one method to enhance the development of another (Risjord, 2002). In this thesis, the data obtained from the focus groups influenced the development of the survey questions and this chapter will focus on how both sets of data contribute to a deeper understanding of the causal mechanisms involved in behaviour change and self-management.

To conceptualise behaviour change in relation to the causal mechanisms associated with self-management, the focus groups, in the first instance, served as a means of 'confirmation' of the barriers and enablers from the different perspectives of the participant groups and also confirmed elements from existing literature. Secondly, a mixed methods approach used with the focus groups and survey, contributed to the 'completeness' of the data collection. This allowed for a deeper understanding of the phenomenon of behaviour change in relation to self-management from multiple perspectives. However, to conceptualise and identify the casual mechanisms it was necessary to examine the data focussing on the causal relationships and understand the meaning of the data at a deeper level in relation to 'the Real' and 'the Actual'. This process is called 'Retroductive Reasoning'.

7.3.1. Retroductive Reasoning

Critical Realists primarily aim to understand why certain events happen in the way they do but ultimately, Critical Realism is used to discover the deeper levels of explanation and understanding of why they happened in that way (McEvoy and Richards, 2006). The process for this is 'Retroduction'; in which the underlying mechanisms and structures associated with creating a phenomenon are discovered. To do this, the focus group data and survey data formed the basis by outlining the lived experience of self-management. In addition, combining the data allows for deeper thinking around the underlying structures and mechanisms involved.

7.4. Causal Mechanisms

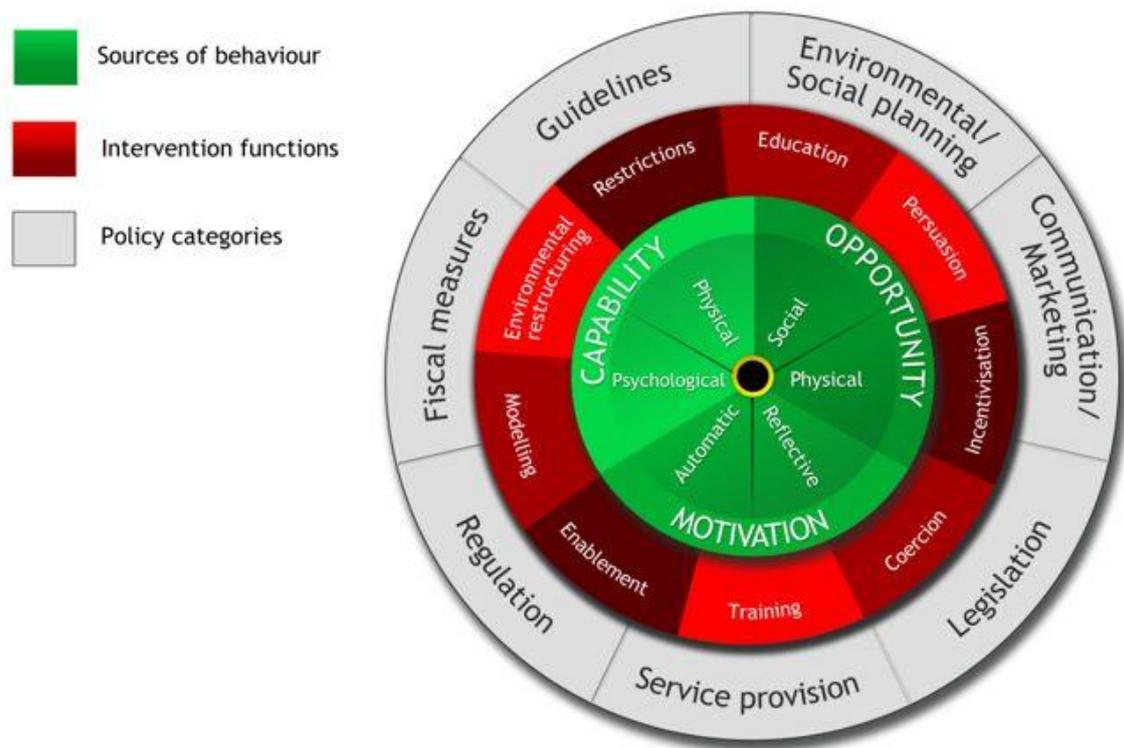
Causality is often referred to in medical-based research. Randomised controlled trials that are well conducted often claim that there is a significant level of evidence to suggest that a certain treatment caused a particular outcome. However, much of contemporary research in health and social sciences are based upon non-experimental often qualitative-based research. Causality in Critical Realism means the process of identifying the causal mechanisms, investigating how they work and understanding how they are activated and if they have been activated (Sayer, 2000). Dalkin *et al* (2015) emphasise the importance of explaining why relationships come about and establishing the mechanisms within a system that influence the outcomes. Causal mechanisms are often influenced by the environment and context and are rarely universal. Bhaskar believed that 'causal mechanisms sit primarily within the structural component of the social world and reside in the power and resources that lie with the great institutional forms of society' (Dalkin *et al*, 2015, p.2). In relation to this combined data analysis chapter, the Behaviour Change Wheel and COM-B models will enable further analysis on the causal mechanisms presented in the focus groups and survey responses. The Behaviour Change Wheel and the COM-B model allow for detailed analysis on the components of Pulmonary Rehabilitation and specifically in relation to behaviour change and self-management.

Health behaviours are complex in nature and as outlined in Chapter 1, behaviour change is the cornerstone to successful self-management. Consequently, an in-depth investigation into health behaviours and the mechanisms involved in behaviour change is key to be able to improve support for self-management. This thesis begins to unravel the causal mechanisms associated with self-management and behaviour change in relation to Pulmonary Rehabilitation, as a complex intervention.

7.5 Background to the Behaviour Change Wheel as a framework

The Behaviour Change Wheel (Figure 7.1) can be used to develop interventions from scratch, build on or modify existing interventions or to help chose from existing interventions. For the purpose of this thesis, the Behaviour Change Wheel was used to investigate an existing intervention: Pulmonary Rehabilitation. But, in addition, specific focus can be placed upon identifying causal mechanisms associated with behaviour change with self-management. The data from the focus groups and survey responses were used to identify the sources of behaviour in relation to self-management behaviour change. The Behaviour Change Wheel was used to identify which components of behaviours need to be changed to promote successful behaviour change in self-management.

Figure 7.1: The Behaviour Change Wheel (Michie *et al*, 2011)



7.6. The COM-B model analysis

The COM-B model at the centre of the Behaviour Change Wheel provided the first level of data analysis by determining the components presented within the focus groups and survey responses, which were related to self-management behaviour. The COM-B model comprises six components that are hypothesized to drive behaviour: physical capability (e.g. skills), psychological capability (e.g. knowledge), physical opportunity (e.g. time), social opportunity (e.g. social cues), reflective motivation (e.g. intentions), and automatic motivation (e.g. emotional reactions) (Michie *et al*, 2011).

The survey findings in relation to the 14 domains within the Theoretical Domains Framework were mapped to the COM-B system to categorise behaviour change into 3 components: Capability, Opportunity and Motivation. Richardson *et al* (2019) advocate triangulation of findings. Therefore, the data from the Thematic Networks

from the focus groups and the Theoretical Domains Framework analysis of survey responses were mapped onto the COM-B system. The process of analysing the data by using the 14 domains of the Theoretical Domains Framework, the COM-B system and the Behaviour Change Wheel allows the researcher to identify the sources of behaviour to understand how they influence behaviour change. In addition, identifying key intervention types targeted at behaviour change is beneficial when conceptualising behaviour change in relation to self-management. Table 7.1 shows the COM-B model for self-management. Key words from the combined data from the focus groups and survey response data analysis were mapped onto the COM-B model. This was done to be able to categorise the data into the three elements of the Capability, Opportunity and Motivation surrounding self-management behaviours.

Table 7.1: COM-B model analysis for self-management:

Behaviour	Capability	Opportunity	Motivation
Self-Management	<p>Physical:</p> <ul style="list-style-type: none"> • Skills • Tools • Strength / fitness • Physical limitations • Exacerbations • Disease severity • Breathlessness <p>Psychological:</p> <ul style="list-style-type: none"> • Knowledge • Information / Advice • Education • Cognitive awareness • Anxiety/Depression • Embarrassment • Confidence 	<p>Physical:</p> <ul style="list-style-type: none"> • Time • Transport to a PR venue • Work commitments • Dependants, carer responsibilities <p>Social:</p> <ul style="list-style-type: none"> • Socioeconomic background • Buddy / peer support • Expert patient • Friendship 	<p>Reflective:</p> <ul style="list-style-type: none"> • Goal setting • Self-efficacy • Adherence • Compliance • Empowered <p>Automatic:</p> <ul style="list-style-type: none"> • Fear • Anxiety/Depression • Enjoyment

For this thesis, 'self-management' is the behaviour under investigation. However, it is clear from the focus group and survey data as well as previous literature, that the success of self-management is situated within a system of other competing or contributing behaviours and there are influences from other causal mechanisms at play. This thesis begins to examine these causal mechanisms to be able to understand the influences on the success of self-management. Understanding the behavioural relationship between Healthcare Professionals and patients is an essential step towards being able to identify the causal mechanisms involved.

From the COM-B analysis, it is possible to look at the different elements and consider which are the objective and tangible components. These are often the physical elements such as the physical capabilities and physical opportunities, which may be more easily influenced by support for behaviour change. Elements which are often more difficult to influence, are associated with psychological capabilities and motivation factors. These are often more complex in origin with multiple components. The components within the capability, opportunity and motivation analysis categories in Table 7.1 can be seen as independent variables but they also interact with each other to influence the outcome of self-management as a behaviour. There is a complex web of interactions between each of the components which represent the causal mechanisms associated with self-management in Pulmonary Rehabilitation. These mechanisms and behaviours may or may not be present or activated for all patients and / or Healthcare Professionals. For example, there needs to be investment in time to support motivation through goal-setting, self-efficacy and empowerment to be able to influence the physical and psychological aspects of the capability including education, knowledge and skills, as well as the influence of breathlessness and physical ability. Alongside the motivation and capability, there needs to be the opportunity to change. This includes the influence of socioeconomic backgrounds and organisational barriers such as access and locations of programmes.

The context of Pulmonary Rehabilitation within a primarily biomedical model of Healthcare creates an environment in which mechanisms can influence the ability of an individual to engage with the programme. For example, organisational and structural aspects such as funding, staffing levels and competencies / training as well as venue availability and location and assistance with transport to access programmes influence the uptake attendance and completion of Pulmonary Rehabilitation.

Pulmonary Rehabilitation as a complex intervention is a challenging area to investigate and there are additional layers of complexity due to the dynamic nature of Healthcare delivery in which mechanisms interact in different and unpredicted ways (Stockley and Graham, 2022). This thesis demonstrates that there are influences from both the patient and the Healthcare Professional which advances previous literature which primarily focusses on the barriers associated with the patient or only from the patient's perspective (Cox *et al*, 2017 and Keating *et al*, 2011b). This thesis aimed to enhance understanding of the factors associated with behaviour change in self-management from the different perspectives of the patient, service user and Healthcare Professionals. The current model of Pulmonary Rehabilitation is quite restrictive in terms of its evidence-based recommendations for face-to-face delivery models as a preferred choice. This limits the opportunity for development in models of delivery.

7.7. Intervention Functions

Following using the COM-B model, the next section of the Behaviour Change Wheel, to consider involved mapping the intervention functions identified during the focus group and survey responses data analysis in relation to self-management as a behaviour. This is a necessary step towards shaping interventions to support behaviour change in self-management. The data from the focus groups and survey responses were analysed to categorise how the intervention types were represented within the focus groups and survey responses to be able to show how the intervention functions were used in relation to self-management in clinical practice

Table 7.2: Intervention Types highlighted from focus groups and survey responses:

Behaviour: Self-Management	
Intervention Type	How intervention types were represented in focus groups and survey responses
Education	Structured education, face-to-face and printed materials during Pulmonary Rehabilitation
Persuasion	Empowering, expert patient, peer support
Incentives	Verbal praise during Pulmonary Rehabilitation encourages patients. Discussion around improved health status and outcomes to encourage patients.
Coercion	Explaining the risks / negatives of a lack of physical activity, not taking medications and not treating exacerbations early
Training	Skills and tools were frequently referenced as essential for self-management. Pulmonary Rehabilitation facilitates practice of these skills. Patients recognise the value of being supervised with their training in Pulmonary Rehabilitation
Restriction	Goal setting and pacing allow for the individual to work within their ability. Healthcare Professionals support this progression of physical activity during Pulmonary Rehabilitation.
Environmental restructuring	Transport and accessibility for Pulmonary Rehabilitation, goal setting including walking targets
Modelling	Role models, expert patients, demonstrating techniques such as exercises, airway clearance and inhaler technique during Pulmonary Rehabilitation
Enablement	Goal setting – importance of patient led discussion

These intervention types are useful to be able to categorise the components of behaviour change in relation to self-management to be able to better understand the interaction between the different elements. The representation of the intervention types from the focus groups and survey begins to suggest elements where causal mechanisms influence the outcome of behaviour change and shapes the understanding of the complexities associated with self-management behaviours.

These elements have been cited previously as barriers and facilitators to completion of Pulmonary Rehabilitation within the literature, but this thesis begins to draw together the thoughts and opinions from a range of individuals. This is unique in relating these to the Theoretical Domains Framework and is specifically related to behaviour change in self-management. To conceptualise behaviour change in relation to self-management, it is essential to situate the complex web of interactions between the elements of the behaviour, the capability, the opportunity and the motivation within the intricacies of the intervention types. This, alongside the understanding of the ontological domains, allows for a deeper understanding of the causal mechanisms associated with behaviour change in self-management.

7.8. Policy Categories

The outer layer of the Behaviour Change Wheel represents the wider context and influence of policy. This specifically relates to key policies and guidelines for Pulmonary Rehabilitation. For example, The British Thoracic Society (BTS) Pulmonary Rehabilitation Guidelines (2013), the BTS Quality Standards for Pulmonary Rehabilitation in adults (2014), The BTS and RCP national clinical audit reports (2015 and 2017), the NICE guidelines on Behaviour Change (2007) and The National Service Framework (NSF) for Long Term Conditions (2005). The organisational structure and local policy also influence the provision and delivery of Pulmonary Rehabilitation.

Despite having a robust evidence base and clinical guidelines for its effectiveness, there remains a lack of consistent recommendations regarding behaviour change interventions in Pulmonary Rehabilitation.

In order to situate the contemporary issues surrounding behaviour change in self-management, it is essential to be able to understand the policy background and service provision models and guidelines. Clinical guidelines and standards may need reconsideration to ensure they are fit for purpose.

The relationship between the three layers of the Behaviour Change Wheel is an important step to consider when investigating the causal mechanisms. It is not as simple as addressing one aspect to be able to influence behaviour change. It is the relationships and interactions between causal mechanisms that need further investigation. It is also necessary to understand if causal mechanisms have been activated or not and if so, how they have been activated. The data mapped to the COM-B model and intervention functions showed that the components for behaviour change are present in Pulmonary Rehabilitation, but it was clear in both the focus groups and survey responses, that there were conflicting opinions on what self-management means.

7.9. Defining Self-Management

To understand the mechanisms associated with the lived experience of behaviour change in self-management, it is first appropriate to look again at the definitions of self-management from both the literature and the focus group and survey responses data. This will contribute to more detailed understanding of the barriers and facilitators to behaviour change. The Theoretical Domains Framework allowed for greater understanding of the findings in relation to the domains related to behaviour change. There appeared to be a conflict in opinions on what self-management means to the individual from a Healthcare Professional, a patient and Breathe Easy support group

member. By using the process of Triangulation, the lived experience of self-management can be postulated by viewing the data from the focus groups and survey responses through a Critical Realist lens. As stated earlier in this thesis, self-management can be described in many different ways, but one relevant definition is:

'the provision of interventions to increase patients' skills and confidence, empowering the individual to take an active part in their disease management' (Murphy, 2017, p.276).

It is apparent, however, that this definition does not acknowledge the complexities of behaviour change which are inherently essential to appreciate and understand to be able to facilitate long-term successful behaviour change. This definition is a commonly applied definition in healthcare and reflects a biomedical model approach to self-management. For example, the emphasis is upon providing interventions to increase skills and confidence and this will allow the patient to take an active role in their disease management. Several survey responses indicated that providing short-term strategies such as providing education, knowledge, tools and advice would improve self-management. There is little or no reference to patient-centred care and shared decision-making in relation to behaviour change. To draw upon examples of definitions of self-management from the survey responses, this approach seems to be mirrored within clinical practice among the participants. Key responses to describe what self-management means include:

"The patient is provided with the skill sets to have an understanding of their condition and enable them to manage an exacerbation effectively"
[Participant 2]

“Providing those with a chronic condition with the appropriate information / education and necessary tools to be able to manage their condition independently” [Participant 4]

“Giving a patient the tools to treat themselves independently” [Participant 8]

“Encouraging the patient to take responsibility of preventing exacerbations and deterioration of their lung disease” [Participant 26]

In the focus groups, some responses surrounding self-management from the Healthcare Professionals groups focussed around a more biomedical model management approach. For example:

“...a lot of it is about ownership as well because what we know is that if they don't own it they're not going to sustain it.....guidance and education is about how you sustain it after the programme.” [HCP, 1]

However, some recognised the importance of considering the patient as an individual with particular attention to the psychological aspects:

“looking at psychological needs....not just the physical needs because sometimes the psychological needs are actually a barrier to getting them to do the exercise programme” [HCP, 1]

“...there’s quite a big responsibility to trying to sort of work out people’s personality types and what they’re going to respond to best.” [HCP, 2]

“it’s about how that person will interpret whether you are being helpful or telling them what they need to be doing” [HCP, 3]

There appeared to be a conflict in views regarding the role of the Healthcare Professional in Pulmonary Rehabilitation. There was a conflict between what patients understood the role to be compared with what Healthcare Professionals viewed as their role. Often the Healthcare Professionals described their role as educating and supporting patients to achieve self-management as a process with an end point. For example, patients would be supported to learn how to self-manage their condition but then would be expected to manage independently after a period, which was usually after a course of Pulmonary Rehabilitation.

“So, we’re trying really hard to get them to take kind of charge of their own rehab and their own exercise programmes and I think that they like that aspect of having somebody to push them and somebody to come and see and check in with and that aspect of it, I think they enjoy.” [HCP, 7]

“It’s the transition from doing Pulmonary Rehabilitation to them maintaining it in the community so then them actually doing it themselves. I think they quite like the structure of coming to something and somebody doing it for them. They are not always maintaining what they were doing as from an exercise point of view on their own. I think they quite like the input from us.” [HCP, 4]

Many of the survey responses in relation to what self-management means to them, included key words such as “empowering”, “confidence”, “independently” and “taking control”. These indicate that the Healthcare Professionals believe their role is to allow the patient to manage their condition themselves. The Healthcare Professionals tended to adopt approaches to self-management which align with the intervention functions. For example;

“Empowering the patients to help them to maintain their own personal well-being.” [Participant 1]

“Providing those with a chronic condition with the appropriate information / education and necessary tools to be able to manage their condition independently.” [Participant 4]

Whilst the patients and Breathe Easy Support group members appeared to mourn the loss of the Healthcare Professional support and often described a lack of support from Healthcare Professionals as being due to funding and staffing issues. This suggests that they feel the need for on-going support from Healthcare Professionals. They often felt abandoned following a course of Pulmonary Rehabilitation.

“And since that it all sort of stopped” [PR, 3]

“We should have more courses. I definitely think more sessions would help. But I presume it’s the cost and the hospital is very short staffed, having to get agency staff in and such like. And this is the most of the NHS and they can’t spend the time. They’ve got to spend the time with the hospital patients, so I understand they can only do it once a year.

But if we could do it twice a year or being greedy - three times a year we'll be really good.” [PR, 4]

“You'd think maybe they'd keep it up themselves but it's like once it finishes, maybe a 2 week break and it started again but like you say it's funding and everything” [PR, 1]

The Breathe Easy support group participants also reported that they were waiting for the hospital led Pulmonary Rehabilitation programme, but decided to set up their own exercise class instead. One participant said that their class helped each other to keep motivated.

“It's the fact, well, we all suffer from the same sort of problem with the lung conditions. You get together and it makes you do the exercises and because we know that at home we don't. So, it's the fact that you are actually coming somewhere to do it, it makes you want to do it if everyone else is doing it as well. And that is the benefit.” [BE, 8]

The elements presented from the COM-B model and intervention functions using the data from the focus groups and survey responses show that there are many different elements to behaviour change. Conflicting views on the on-going role of the Healthcare Professional were apparent. This shows that there is a need for a deeper understanding of the factors and casual mechanisms associated with behaviour change in self-management.

The barriers and facilitators are the objective tangible aspects of behaviour change. For example, the structural elements such as the venue, transport issues, educational resources as well as psychological aspects such as anxiety and depression. However,

the key to understanding behaviour change on an individual basis is to consider how these elements interact with the unique psyche of each patient individually. It is at this higher level of analysis and understanding that the ontological domains of the real, the actual and the empirical are crucial to be able to support effective long-term behaviour change. These ontological domains will be revisited in Chapter 8: Discussion and Conclusion. The focus groups allowed for more in depth discussion from both sides of the relationship between the patient and the Healthcare Professional. This allowed for 'confirmation' of the literature within the data and during this Chapter of data analysis it is important to be able to move backwards and forwards between the focus group and survey data as they complement each other. It also provides an opportunity to be able to pull together similarities, whilst also recognising conflicting views, leading to 'completeness'.

Within the context of this thesis, self-management can be defined from the different perspectives of the Healthcare Professional and the patient(s). In summary from the survey responses, from a Healthcare Professional perspective self-management means 'empowering patients to manage their own condition through providing education on skills and tools encouraging patients to take ownership of their own condition'. In contrast, during the focus groups, patients described self-management as 'feeling supported in Pulmonary Rehabilitation but view it as a short-term intervention which they would want more of if there were more NHS staff to run it and more funds to deliver more programmes'. This suggests that they feel abandoned following a course of Pulmonary Rehabilitation and wish to be able to attend further courses. These contrasting views highlight the conflict in understanding of the term self-management in Pulmonary Rehabilitation which impacts the long-term benefits of the programme. It is difficult to succeed at self-management without having effective support mechanisms. This is applicable to both Patients and Physiotherapists. Staff need support to be able to guide patients on self-management as well as patients needing support mechanisms to be able to successfully self-manage. Support mechanisms suggested from both the focus groups and survey responses include colleagues, friends, family, other members of the Pulmonary Rehabilitation group as

well as resources such as patient information and educational content. This thesis demonstrates a conflict between what a patient wants and needs with regards to support for self-management and what the Healthcare Professional believes is within their role in supporting self-management. There is often a tone of blame from the Healthcare Professionals when a patient doesn't fit within the biomedical model of delivery and outcomes (Harrison *et al*, 2017 and Goodwin *et al*, 2010). Pulmonary Rehabilitation services are driven by outcomes and influenced by high volume of patient referrals so biomedical model of delivery aims to deliver a structured programme but it is apparent from this thesis that the one-size fits all approach is not appropriate in delivering patient-centred Pulmonary Rehabilitation.

7.10. Chapter Summary

This chapter has used the principles of Triangulation to pull together the data analysis from the focus groups and survey responses, whilst applying to the principles of the Behaviour Change Wheel as a framework to shape the findings. Critical Realism has been used to be able to situate the findings in relation to the philosophical underpinnings of this thesis. One of the key elements related to these findings is that the definitions of self-management, behaviour change and adherence need to be explored further in relation to the findings from this thesis. This will be discussed further in the Discussion and Conclusion Chapter. The relationship between Healthcare Professionals and patients is a crucial element in achieving successful behaviour change.

Chapter 8: Discussion and Conclusion

8.1. Overview of Chapter

The aim of this thesis was to explore the opportunities and challenges associated with behaviour change in self-management within the context of Pulmonary Rehabilitation from a Critical Realist perspective. This final chapter will review the purpose of this thesis and re-examine the key areas of self-management and behaviour change with particular focus on the influence of Physiotherapists' behaviours on patients' behaviours and outcomes in Pulmonary Rehabilitation. The findings will be presented in relation to the wider context of behaviour change relating to sources of behaviour as well as relevant National policy context. Relevant contemporary literature surrounding new models and evaluations of practices due to the COVID-19 pandemic will also be presented and related to the findings.

The philosophical framework of Critical Realism underpins this thesis and has been a continuous thread used to be able to understand the data through a Critical Realist lens. The causal mechanisms identified in this study will be discussed in relation to the ontological domains of the Real, the Actual and the Empirical to provide an understanding of the barriers and facilitators to successful behaviour change in self-management within the context of Pulmonary Rehabilitation.

The limitations of the current study will be discussed within the context of the methodological underpinnings and philosophical approach to this thesis. The chapter will conclude by considering the future directions for Physiotherapy research and practice within self-management in Pulmonary Rehabilitation.

8.2. Review of the Research Objectives

To achieve the aim, these research objectives outlined the different elements of the study. These will be revisited to be able to conceptualise the causal mechanisms associated with behaviour change.

1. To compare and contrast how behavioural factors associated with self-management in Pulmonary Rehabilitation influence successful behaviour change amongst different stakeholder groups including from a patient, service user and Healthcare Professional perspective.
2. To determine how Physiotherapists behaviours influence patient behaviours and abilities to self-manage in Pulmonary Rehabilitation.
4. To develop an enhanced conceptual understanding of the causal mechanisms influencing behaviour change in self-management among patients and Healthcare Professionals, with a particular focus on Physiotherapists to provide recommendations for clinical practice.

These objectives reflect the qualitatively-driven mixed methods approach to the different research methods employed. Focus groups explored the behavioural factors from varying perspectives, including those of Healthcare Professionals, Pulmonary Rehabilitation patients and Breathe Easy support group members. Respiratory Physiotherapists were targeted using survey methods to gain a deeper understanding of contemporary issues and perspectives on barriers and facilitators to and understanding of self-management. Findings from both the focus groups and the survey were then mapped to Behaviour Change theory to begin to identify causal mechanisms associated with behaviour change.

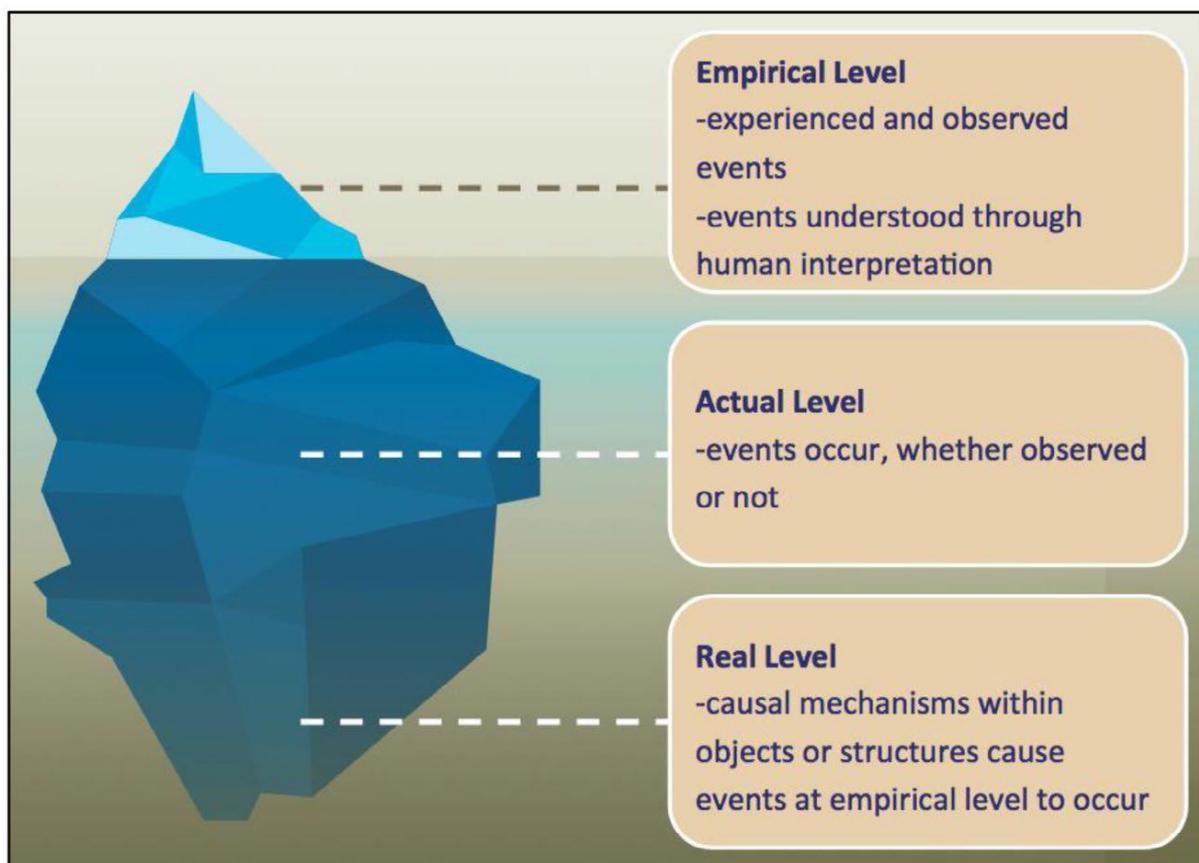
8.3. Critical Realist Ontological Domains

One of the main reasons for applying Critical Realism as the philosophical underpinnings of this thesis was that behaviour change has numerous elements which influence it. The complexity of chronic respiratory disease and the impact upon an individual's daily life meant that it was essential to understand how Physiotherapists in Pulmonary Rehabilitation approach behaviour change in self-management by investigating the influence of the social world. The social world comprises different social behaviours which can be derived from culture, beliefs, institutional influences and economic factors which make it heterogeneous and complex compared to the natural world. Previous research surrounding barriers and facilitators to adherence in Pulmonary Rehabilitation has generally been conducted using more positivist methods such as randomised controlled trials and systematic reviews. Critical Realism allows for the truths about the complex interplay between the social and the natural worlds to be investigated (McEvoy and Richards, 2006). From a practitioner-researcher perspective, the experiences as a clinician forged an interest in understanding the complexities associated with behaviour change in Pulmonary Rehabilitation. To be able to achieve successful behaviour change, there are deeper issues which need addressing with individual patients. It is much more than just considering objective factors such as transport, venues, the influence of the referring clinician and anxiety and depression (Keating *et al*, 2011b). This thesis employed a qualitatively-driven mixed methods approach to Critical Realism by combining the qualitative data from the focus groups and the quantitative and qualitative data from the survey responses to be able to identify the underlying structures and mechanisms. This was particularly key in relation to identifying the enduring entities associated with an event (Mingers, 2013).

The ontological domains of the Real, the Actual and the Empirical will be used as a framework to conceptualise the findings from the current study. Fletcher (2017) presented the "Iceberg Metaphor" to visually demonstrate the human knowledge of reality. The Iceberg diagram (Figure 8.1) depicts the ontological domains on a visual

level to be able to understand how the different domains are actualised. They are all part of one reality but only the Empirical is experienced or observed. The Actual and the Real are part of the same reality but may not be directly experienced or observed. For the purpose of the current study, Figure 8.1 illustrates how causal mechanisms situated in the Real domain are not directly observable, but they occur and have influence in the Empirical domain. All three domains represent the world in which patients and Healthcare Professionals live but it allows for the ‘unseen’ aspects surrounding behaviour change and self-management to be understood. This is an important step when considering the impact of behaviour change on successful self-management in Pulmonary Rehabilitation.

Figure 8.1: An “Iceberg Metaphor” depicting the ontological domains taken from Fletcher (2017).



To be able to conceptualise the mechanisms influencing behaviour change in self-management, the ontological domains will be revisited in relation to the current study:

- The Empirical – what happens when implementing Pulmonary Rehabilitation and the experiences of Healthcare Professionals and patients as a result of delivering and participating in these programmes. This is visible in clinical practice and therefore is situated ‘above the surface’ of reality.
- The Actual – implementation of Pulmonary Rehabilitation in practice and events which may or may not be observed. These aspects are not clearly visible in clinical practice and therefore ‘sit below the surface’ of reality.
- The Real – the factors and mechanisms influencing self-management and behaviour change in Pulmonary Rehabilitation. Often these aspects are not clearly visible and therefore ‘sit below the surface’ of reality.

Understanding the world in which we live is an essential step towards paving the way for advances in approaches to support for behaviour change in relation to self-management. The unique contribution from this thesis is a focus mainly on the elements within the Real domain which is an area less well documented within Pulmonary Rehabilitation literature. Often the elements within the Real domain are not clearly visible, particularly in a biomedical focussed model of Pulmonary Rehabilitation delivery, therefore, there is a tendency to focus purely on the aspects which are more clearly visible which tend to sit within the Empirical domain. One of the key starting points is to consider the causal mechanisms which are associated with current practice in Pulmonary Rehabilitation. This thesis investigated factors associated with barriers and facilitators to adherence and self-management to be able to identify causal mechanisms, primarily within The Real domain, which influence successful behaviour change. The ontological domains of the Empirical, the Actual and the Real are often out of phase and there is no clear distinction between where

one begins and one ends (Patomaki and Wight, 2000). Therefore it is inherently difficult to clearly define elements of behaviour change in self-management. For example, mechanisms may only be known by their effects and may not be directly experienced. This contributes to the notion that peoples' experiences of events can be fundamentally different (Bhaskar, 2008). The unique approach to this thesis by applying the philosophy of Critical Realism and moving between the ontological domains whilst also using reflexivity allowed for a richness and complexity of philosophical theory than could have been gained from a purely positivist approach to this research. The COM-B analysis of the focus group and survey data highlighted the complex web of interactions between the components of Pulmonary Rehabilitation which emphasised that mechanisms may or may not be present or activated for all patients or Healthcare Professionals. This extends the understanding beyond what is already known from the self-management and behaviour change literature presented within the Introduction and Literature Review chapters.

A qualitatively-driven mixed methods approach produced rich data from a range of perspectives on the issues relating to behaviour change in self-management and the complexities associated with them. The application of Critical Realism as a philosophical framework within this chapter will facilitate understanding of the underlying mechanisms by analysing their impact and roles of the ontological domains.

This thesis has investigated the personal accounts of behaviour change in self-management from varying perspectives but with a focus on Healthcare Professionals, to be able to better understand the world in which the participants live. Healthcare Professional behaviours have been less well investigated compared to the behaviours of the patients. It is essential to look closer at the mechanisms involved in individual decision-making to be able to understand ways to better support behaviour change (Sayer, 2000). It is particularly key to appreciate how individuals understand the world in which they live and consequently how this may impact their ability to change their behaviours. Not only is it important to consider how the patient understands the world

in which they live, but as behaviour change is often a partnership with a Healthcare Professional, it is also key to understand how their approach to behaviour change may influence its success.

This unique approach to the issues surrounding behaviour change in Pulmonary Rehabilitation utilises the value of a qualitatively-driven mixed methods approach using Critical Realist underpinnings to understand the inherent mechanisms at play. Social structures operate at many different levels, and it is particularly important to appreciate that individuals experience events on many different levels which are often the accumulation of varying influences (Angus, 2012). Often causal mechanisms are embedded in social structures, and they are usually expressed through people's actions. Therefore, the focus groups and survey were an opportunity to unpick these intricacies (Kazi, 2003).

Behaviour change is complex, this is shown by the intertwined thematic networks from the focus groups analysis, as well as the varied approaches to self-management in the survey responses. To be able to better understand its properties in relation to self-management, the findings from this thesis can be understood by considering the ontological domains within Critical Realism. Although these 3 domains are separate entities within the structure of the social world, they influence each other. It is important to be able to understand the concept of behaviour change from a Critical Realist perspective to be able to unpick the components and develop strategies to facilitate more comprehensive support for behaviour change in self-management in Pulmonary Rehabilitation. The findings from this thesis highlight that events are subject to human interpretation and influenced by social structures from both patient and Healthcare Professional perspectives. With this in mind, it is crucial to recognise the factors associated with each of these domains to be able to understand the mechanisms involved in clinical practice in Pulmonary Rehabilitation.

Critical Realism allows for the understanding of social reality in relation to the three ontological domains: the Real, the Actual and the Empirical. These ontological domains sit amongst what are perceived and what are hidden aspects of reality. These elements are difficult to interpret as they are not stand-alone tangible elements. However, they are important to decipher to be able to effectively support behaviour change.

This thesis began with observations in both clinical practice and research evidence-base that adherence within Pulmonary Rehabilitation impacted the effectiveness of the intervention. In addition, this thesis provides valuable and honest individual accounts of the underlying issues surrounding adherence in Pulmonary Rehabilitation and contributes to the enhanced understanding of an individual approach to support for self-management. This thesis focusses on the underlying mechanisms which impact upon adherence in self-management, these are situated within the Real domain and include the psychological impact of chronic respiratory disease, the fluctuating nature of the disease, knowledge and understanding of the purpose and value of Pulmonary Rehabilitation, motivation to exercise and the impact of education on the individual. Many of these aspects have several associated mechanisms themselves which contribute to the complex nature of adherence in self-management. This demonstrates how difficult it is to simply implement a 'one size fits all' approach to behaviour change in self-management. This thesis demonstrates that not only do patients need individualised support with self-management but Healthcare Professionals, in particular, Physiotherapists, need to recognise and understand their own beliefs and assumptions when supporting behaviour change in self-management.

A paradigm shift has been evolving in moving away from a biomedical approach to healthcare towards a more psychosocial model. But, although there have been advances in the evidence for the need to evolve there has been less evidence of its implementation in clinical practice, particularly in Physiotherapy (Søndenå *et al*, 2020). Within this thesis there has been several references to ensuring a patient-centred care

approach is adopted, this is both evident in the findings from the focus groups and survey responses. Focus groups and survey responses often considered that support for self-management involved providing patient-centred care by empowering, educating and supporting them through Pulmonary Rehabilitation. From a Critical Realist perspective, the importance of recognising the underlying mechanisms which influence behaviour change is crucial in evolving practice to be able to support self-management in a person-centred way. A person-centred approach is more aligned with facilitating an individual to have a meaningful life in contrast to the patient-centred approach which facilitates an individual to have a functional life (Eklund *et al*, 2019). This thesis has shown a conflict in understanding and responsibility regarding ownership of self-management and often there can be tensions between the Healthcare Professional aiming to be patient-centred and shifting responsibility by giving the patient the opportunity to be active in their decision-making. Healthcare Professionals often had a tone of blame when patients don't adhere to or maintain the behaviour change. Power relations are challenged when the Healthcare Professional and the patient have different interpretations of self-management (van de Bovenkamp and Dwarswaard, 2017). This is common in patients with COPD in Pulmonary Rehabilitation because the patients personal experiences of symptoms such as breathlessness hugely impact upon their ability to engage in behaviour change.

8.4 Defining causal mechanisms

This thesis provides an in-depth exploration of behaviour change in self-management within the complex intervention of Pulmonary Rehabilitation. This theory-driven qualitative study sought to explain what works within Pulmonary Rehabilitation, which elements are used in clinical practice and explored the experiences of varying perspectives which allowed for an in depth understanding of the complexities of behaviour change in self-management. The unique contribution to knowledge from this thesis is a focus on the underlying structures and mechanisms which sit within the Real domain which are often less visible and less documented in existing literature.

Triangulating the data analysis from the focus groups (thematic networks) and survey responses (Theoretical Domains Framework) using the COM-B model and the Behaviour Change Wheel as theoretical frameworks provided additional insights into the complexities of the causal mechanisms associated with behaviour change in self-management in Pulmonary Rehabilitation. For example, the mechanisms associated with motivation in self-management and the impact of the physical capabilities and opportunities. By using behaviour change theory and Critical Realism to explore the barriers and facilitators in Pulmonary Rehabilitation, this thesis explores the potential causal mechanisms within the ontological domains. Combining the findings related to behaviour change theory, identifying the capability, opportunity and motivation associated with behaviour change as well as highlighting the intervention functions associated with self-management in Pulmonary Rehabilitation allowed for a unique in-depth analysis. This goes beyond previously documented barriers to adherence in Pulmonary Rehabilitation which are factors which generally sit within the Empirical domain, these are often more visible and well-recognised.

The causal mechanisms associated with behaviour change in self-management in Pulmonary Rehabilitation will be presented and explored more widely through the ontological domains of the Real, the Actual and the Empirical throughout this chapter. The causal mechanisms demonstrate that some aspects are visible whilst others have physical, emotional, psychological, structural and societal components which are not clearly visible in the real world, but these aspects influence the outcomes in Pulmonary Rehabilitation. In realist ontology there is an assumption that although things can't always be seen, they are no less real, and even if they can't be seen they can still influence reality (Hunter *et al*, 2022). Further consideration will be made to these aspects relating to the ontological domains of the Real, the Actual and the Empirical. The events (the Actual) that are experienced (the Empirical) are generated by the interaction of systems and mechanisms (the Real) (Mingers and Standing, 2017).

8.4.1 The Real

The Real exists regardless of our understanding of it and constitutes the realm of objects, their structures, and powers. The Real comprises social structures which are not tangible and therefore are inherently difficult to interpret and consequently be able to change. In the context of this thesis, the Real refers to the factors influencing self-management and behaviour change, often referred to within the literature as the barriers and facilitators. These barriers and facilitators are often visible objective aspects which sit within the Empirical domain but they are influenced by causal mechanisms which may be expressed differently for different patients or Physiotherapists. Therefore, due to their complexity, these mechanisms aren't visible and so 'sit below the surface' of reality. In relation to this thesis, the relationship between the Healthcare Professional and the patient is an example of how the human imagination creates structures which influence how that individual interprets a situation or event. For example, the social, socio-economic, and educational backgrounds can influence an individual's interpretation of a given event, such as behaviour change in self-management. Drawing on examples from the focus groups, in relation to a patient with COPD, their experiences of living with a chronic lung disease with breathlessness, medication burden, possible anxiety and depression and a lack of knowledge of strategies or support available all impact upon their ability to engage in supported self-management in a Pulmonary Rehabilitation programme.

The governance and structure of the NHS healthcare system, the organisational structure of Local policy for Pulmonary Rehabilitation and National policy on standards for Pulmonary Rehabilitation and long-term conditions management policy and practice all influence a Healthcare Professional's approach to self-management with COPD patients. The governing structures are not always visible in clinical practice but they influence the content, structure and delivery of Pulmonary Rehabilitation, therefore, these structures sit within the Real domain. The House of Care model (The Kings Fund, 2013) approach to long-term conditions management aimed to develop

services to change the hierarchical biomedical model of healthcare by shifting the focus from a didactic approach to more of a partnership model of healthcare. A collaborative approach to shared decision-making with particular focus on a personalised approach is advocated within this The House of Care Model. However, it was apparent within both the focus groups and survey responses that often a didactic approach was still used, which highlights that a change in approach is needed to be able to facilitate better support for self-management. For example, providing education on knowledge and skills on how to self-manage sit within the Empirical domain but patients in the focus groups expressed their need for more than short-term didactic education and required more long-term support with their self-management.

A biomedical model approach was apparent particularly within the focus group discussions. There is often a disparity between what the patient understands with regards to self-management and what the Healthcare Professionals intend to advise which is an example from the Real domain. Many of the survey participants responded that self-management meant providing with information, tools and advice, as well as skills and understanding of their condition, these objective interventions often sit within the Empirical domain. These reflect quite a didactic approach to education which is contrary to what the Healthcare Professionals described as effective techniques in support for self-management. Survey participants noted a more personalised, collaborative approach with an individualised treatment plan. Patients may not understand the information or be able to follow through with the advice due to physical, emotional or cognitive barriers (Blackstock *et al*, 2015). The role of education in self-management requires review to move away from a didactic approach to education sessions towards a more patient-centred model (Blackstock *et al*, 2015). Blackstock *et al* (2018) discuss that the educational component of Pulmonary Rehabilitation has been studied less than the exercise component. However, the educational component is an essential part of Pulmonary Rehabilitation, particularly in relation to self-management and behaviour change. Focus group and survey participants tended to adopt a more traditional biomedical approach to the educational content which focussed around giving information and advice and assuming that this led to behaviour

change in relation to self-management. There remains doubt as to whether didactic-style education and information giving leads to long-term behaviour change. Blackstock *et al* (2018) suggest that there should be more emphasis on supporting the process of learning to look beyond the simple giving of information and move towards supporting skills development, understanding the values and beliefs and habits of the patient to be able to effectively influence behaviour change which sits within the Real domain.

From a Critical Realist perspective, knowledge is a social product which is produced through engagement and interaction with previous social products (Patomaki and Wight, 2000). This thesis demonstrates that even when Healthcare Professionals recognise that self-management education should be delivered on an individualised approach, it is still often delivered in a hierarchical model approach with the Healthcare Professional in control. This is due to the organisational structure and current service models of delivery of Pulmonary Rehabilitation programmes within the NHS. For example, commonly cited barriers in both the focus groups and survey responses included time, programme structure, pressures of waiting lists and the complex needs of a varied patient group which all limit their ability to deliver individualised education and support for self-management. It has been recognised within a systematic review by Roberts *et al* (2018) that support for self-management should include education not just for knowledge transfer but to facilitate sustained behaviour change. This systematic review highlighted that the educational content of Pulmonary Rehabilitation programmes is still very poorly described and many lacked any assessment of individual patient needs and delivery methods were commonly didactic in approach. This further adds to the value of this thesis study which recognises the essential need to understand the underlying mechanisms associated with behaviour change in relation to self-management and that the traditional methods of educational content delivery in Pulmonary Rehabilitation are questioned. Once again, a 'one size fits all' approach is not appropriate in achieving behaviour change. Education alone is not sufficient for on-going self-management and particularly behaviour change. Some survey participants reported using motivational interviewing as a strategy to improve

successful self-management. Apps *et al* (2013) combined education and motivational interviewing through the means of a self-management manual: the self-management programme of activity, coping and education for chronic obstructive pulmonary disease (SPACE for COPD). Whilst the SPACE for COPD manual is a comprehensive educational package, it is not clear how behaviour change was measured or achieved through the programme. Education in Pulmonary Rehabilitation is a key element in achieving behaviour change but it was apparent during the focus group discussions and the survey responses that the approach to education in relation to self-management needs further consideration.

It is essential to unpick the Real domain as it is the ontological gap between what is experienced and what is understood. Patients within Pulmonary Rehabilitation are often a medicalised patient group in which both the patient and Healthcare Professionals focus on objective measures and symptoms. It is difficult to understand and determine reasons why patients do not change their health behaviours through Pulmonary Rehabilitation. It was apparent within the Pulmonary Rehabilitation patients' focus group that some of the patients appeared to prefer to adopt a more biomedical management approach. This poses a question as to whether patients are reliant upon a medicalised approach because Healthcare Professionals adopt this approach when delivering Pulmonary Rehabilitation and also the way in which Pulmonary Rehabilitation is delivered. In a post COVID-19 world, this approach may not be fit for purpose and more time should be spent in supporting patient-centred care models to be able to support long-term behaviour change.

During the focus groups, it was apparent that there was a difference in understanding and appreciation for these types of control. The Healthcare Professionals tended to see themselves as the expert in a position of authority. They tried to control patients' behaviours through giving them things. For example, providing education and tools and advice as well as motivating them to change their behaviours with the ultimate goal of disease control. Furthermore, when disease control was not achieved, it was

seen as the fault of the patient rather than the clinician. Whereas the patients and Breathe Easy support group members seemed to suggest that disease control was dependent on the clinician being there to support them and they often found that they were unable to control their disease symptoms on their own, despite completing a course of Pulmonary Rehabilitation. This suggests that the course is either not long enough or that the self-management support is not sufficient to change patient behaviours within the time frame of the course. These considerations present as the underlying mechanisms which sit within the Real domain. This highlights the need to ensure an individualised approach and collaborative shared decision making between clinicians and patients which is a more successful way to support disease control. However, for this to be successful, clinicians need to be able to change their own behaviours and recognise how they support patients with self-management. Within the biomedical model of healthcare, there is an emphasis on Healthcare Professional-led control (Mudge *et al*, 2015). For example, Healthcare Professionals cited in the focus groups and survey responses that patients should follow their recommendations to manage their condition independently and as consequently there would be less healthcare utilisation. For the future workforce, there should be thorough training and reflection on their approaches to self-management. But there is also a need to ensure that undergraduates are taught novel approaches to patient-centred care and collaborative decision-making to ensure that the future workforce for long-term conditions management is sustainable. If Healthcare Professionals continue to work within a biomedical model of care, then patients will continue to expect to be treated in that way and the conflict between responsibilities for disease management will remain. This will create further dependency upon NHS healthcare resources and contribute further to the current challenges of high number of referrals and long waiting times for interventions such as Pulmonary Rehabilitation. A service model change is required to move away from a paternalistic model of Healthcare which breeds dependency and move towards patient-led and personalised treatment interventions with appropriate support mechanisms.

This thesis has shown that a psychosocial model of care is essential to recognise the impact of the behavioural and social aspects impacting disease management. But it is also key to remember that COPD is a fluctuating condition that does require elements of a medical management approach, particularly during an acute exacerbation. The fluctuating nature of the disease contributes to the sometimes daily variances in the underlying mechanisms influencing a patient's ability to engage in behaviour change. For example, the aspects relating to their capability such as the physical impact of breathlessness and its influence on the psychological impact of fear and anxiety and depression demonstrate mechanisms within the Real domain which influence the patients ability to engage in Pulmonary Rehabilitation which is observed in the Empirical domain. Therefore, this is where a conflict can lie between what the Healthcare Professionals expect from self-management and what the patient expectations are of their care. A collaborative approach to disease management within COPD and Pulmonary Rehabilitation is required to be able to support patients effectively. This extends on the work of George Engel in which the biopsychosocial model approach is recommended to include recognition of the social, psychosocial, and behavioural dimensions of healthcare (Farre and Rapley, 2017). Whilst the biopsychosocial model aims to recognise the impact of disease and illness from a broader perspective, it also recognises the importance of understanding the underlying contributing factors. From a Critical Realist perspective, these factors include the causal mechanisms and structures within the Real domain that influence an individual's ability to self-manage. Engel proposed that all entities (systems) have influence upon and are structurally connected to each other (Farre and Rapley, 2017). This has parallels with a Critical Realist approach when considering the hidden elements of reality such as the mechanisms and structures and the events that happen. However, there are some criticisms of the biopsychosocial model. These include, the model being vague and generic with no specific model or framework, so it is difficult to put into practice. It has been suggested that the biopsychosocial model should be part of the toolbox of techniques to use alongside a biomedical model of care.

Several of the survey participants responded that self-management meant empowering patients to manage their own condition, as well as providing them with knowledge and skills and educating them on self-management. Although survey participants responded that they 'empowered' patients, it was not clear how this was achieved. Empowerment has become a common term used in healthcare policy and practice, particularly in relation to self-management. However, there is a lack of consistency in the meaning of the terminology. Survey respondents referred to empowerment as a way to facilitate patients to achieve self-management, to have the skills and knowledge, to understand their condition and to feel confident. There was no specific detail as to the mechanisms required to empower patients to achieve successful self-management. Self-management as an intervention, features in current policy and guidelines and is often thought to be a solution to improving quality of life. The exact understanding of the definition of self-management in Pulmonary Rehabilitation remains variable within the literature and clinical practice. The mechanisms associated with self-management sit within the Real domain. They have an influence on the reality but are not clearly visible as individual elements. Often it is the interaction of varying mechanisms that influence the outcome.

In clinical practice there is often a conflict in competing paradigms. The pressures of the acute hospital setting including focus on safety, assessment and early discharge is in conflict with the individual needs of the patient. Similarly in Pulmonary Rehabilitation there are organisational constraints such as waiting lists, venue availability and service standards and structures. These all impact upon the ability of the Physiotherapist to engage with patients in a patient-centred way which can lead to them naturally adopting an authoritative role of the expert and trying to control patient outcomes (Killingback *et al*, 2021). The biomedical model of healthcare and the culture within healthcare settings is often a key factor limiting Physiotherapists from adopting a more patient-centred approach with patients in their support for self-management in patients with long-term conditions.

Through retroduction, this thesis found that there are many different connecting mechanisms associated with self-management in Pulmonary Rehabilitation. For example, the mechanisms influencing motivation and capability can include factors associated with self-efficacy, goal setting, adherence, compliance and empowerment as well as the influence and impact of psychological aspects such as anxiety and depression and fear. The mechanisms identified have varying properties, characteristics and powers which influence self-management. For example, the socioeconomic background of the patient and Healthcare Professional can influence the outcome of self-management. This social structure cannot be directly observed but it exists in the interactions between the patient and the Healthcare Professional. There is potential for multiple mechanisms influencing self-management in Pulmonary Rehabilitation due to the interaction between the patient and Healthcare Professional. Human beings have their own complex range of powers and mechanisms associated with their own beliefs, assumptions, experiences and social identity therefore, each person brings their own causal mechanisms (Mingers and Standing, 2017). Critical Realism within the context of this thesis allows for the researcher to look beyond what is directly observable within the Empirical domain and to identify causal mechanisms and how they work and understand if they have been activated (Bergin, *et al*, 2008). In addition, it is fundamental to appreciate that humans are complex, and outcomes are the result of many varying underlying structures and mechanisms that can't be solely described as a causal link with the visible events (Kazi, 2003).

Within the context of patients with COPD, some aspects of the disease causes can be attributed to structures within the Real domain, such as the socio-economical background. For example, smoking status, educational background, and working environments. It has been suggested that COPD is more prevalent in those from poorer socio-economic backgrounds. This has links to aspects such as educational status, working environments and social support structures. When considering socio-economic status, it is also necessary to consider the impact of the individual's ability to engage and successfully change their behaviours in relation to self-management. Uptake and participation in Pulmonary Rehabilitation programmes is often poor in

poorer socio-economic backgrounds. They may have more barriers to attending such as transport and location, but it is important to appreciate the associated elements such as educational ability which may influence the impact of the programme. Hence, within this group it is key to ensure a personalised approach to support for self-management. Socio-economic status has been shown to impact upon physical ability in functional outcomes, such as exercise capacity (Porta *et al*, 2018).

8.4.2 The Actual

The “Actual” domain reflects the unobservable Real domain, although it is not possible to know exactly which causal mechanisms exist. The “Actual” refers to actions that people perform or do not perform which lead to events happening or not. These are not always clearly visible and are a combination of what happens as a result of support for self-management and the causal mechanisms that influence the outcomes. These actions sit ‘under the surface’ of reality so are not always observed. Within the context of the current study, the “Actual” refers to the implementation of support for self-management by Healthcare Professionals and how the patient engages with self-management in Pulmonary Rehabilitation. This may include educational content, delivery and educational resources as well as the environment and context in which support for self-management is delivered. The term ‘successful self-management’ is often referred to, but it is necessary to determine what constitutes successes and which components are associated with it. Behaviours can influence an individual’s success or failure to self-manage. However, the Healthcare Professional and patient may not be aware of their behaviours and / or how these influence adherence to self-management. For example, within the focus groups and survey, adherence and compliance were frequently discussed. These are examples from the Actual domain – an individual is adherent / compliant or not which influences the outcome of behaviour change in self-management. Nevertheless, the underlying structures and reasons (the Real) may not be realised but they influence the outcome.

This thesis has explored the importance of an individualised patient-centred approach to support behaviour change in self-management by using behaviour change theory to analyse the data. Education on self-management was frequently cited within the data but as previously discussed there was often a focus around a more Healthcare Professional-led didactic approach to self-management education. For example, education on disease management and education on skills and tools to be able to self-manage their condition. This extends the work of Newham *et al* (2017) which aimed to identify the most effective components of interventions and using behaviour change theory to classify specific active ingredients as components of the intervention. Newham *et al* (2017) found that the most cited behaviour change techniques focussed around providing information including: 'instruction on how to perform the behaviour', 'information about health consequences' and 'demonstration of the behaviour'.

Motivation was a common theme in the focus groups and was cited as a key behaviour by survey participants as a key requirement for 'disease control' in relation to self-management. Particularly in relation to motivation to exercise. However, motivation was expressed differently by Healthcare Professionals and patients. This demonstrates that the underlying mechanisms and structures vary between patients as well as Healthcare Professionals, this emphasises the importance of understanding the mechanisms involved. Motivation forms part of the COM-B analysis. In relation to this thesis, motivation in the COM-B model includes focus on the role of goal setting, self-efficacy, adherence and compliance and empowerment. This extends on previous research by Mudge *et al* (2015) who found that clinicians felt that motivation was essential for successful self-management and that education and instruction were key strategies used to motivate patients. This does reflect a more biomedical model approach to support for self-management.

It is within the Actual domain that the perceptions and understanding of self-management can influence the success of long-term behaviour change. For example, the understanding and approach to support for self-management from Healthcare

Professionals can influence patient outcomes. There were a range of definitions of self-management from the survey participants, but frequently cited aspects were around education, provision of information and skills, as well as improving knowledge of their condition. Although these methods may improve a patients ability to self-manage their condition, there is little evidence or recommendations on how best to approach delivery of these. Considering the mechanisms in which these interventions are delivered and received is a key component of effective support for self-management. For example, this thesis has shown that the underlying structure of Pulmonary Rehabilitation as an intervention, the beliefs and assumptions of the Healthcare Professional and the patient, the influence of the patients motivation and their capability to achieve behaviour change in self-management are crucial to consider when supporting self-management.

A biomedical model approach which was frequently referred to in the focus groups as a hierarchical approach in which the Healthcare Professional adopts a didactic role of instructing patients to do certain elements, such as taking their medication and complying with exercise recommendations to be able to achieve self-management (Franssen *et al*, 2019). This was also highlighted within the focus groups in which Pulmonary Rehabilitation patients and Breathe Easy support group members referred to as “needing” the on-going support from Healthcare Professionals after completing Pulmonary Rehabilitation and often referring to specific medications and treatments as solutions to their chronic respiratory disease problems. This hierarchical biomedical model of care is not sustainable or effective at supporting long-term behaviour change, as it creates a dependency upon the Healthcare Professional to ‘fix’ elements of chronic disease rather than promoting behaviour change. It is, therefore, essential that Healthcare Professionals adopt a whole system approach to changing the way in which we manage long-term conditions. In particular, meaningful conversations, individualised assessment and treatment and support for individualised behaviour change should be facilitated and recognised as effective and positive attributes to in engagement and interaction with patients. Turner *et al* (2014) found that patients still showed improvement in patient activation, health status, quality of life

and psychological health following a 7-week self-management programme using both Healthcare Professional and lay-person (an expert COPD patient). There were significant improvements in COPD mastery and self-management abilities. This indicates that the support and structured guidance from someone, not specifically a Healthcare Professional can still lead to benefits.

Empowerment was frequently referred to within both the focus groups and survey responses, but it was not clear of the mechanisms for empowering patients. In relation to empowerment in support for self-management, the Actual domain refers to the actions which patients or Healthcare Professionals may or may not perform to influence change. Healthcare Professionals cited that the empowered patients but there was little detail into how this was achieved, or what specific interventions were used to empower patients. Holmstrom and Roing (2010) note that patient motivation has an influence on both patient-centeredness and patient empowerment. They suggest that for patient empowerment to be successful, the Healthcare Professional needs to be able to 'surrender their need to control' (p.170). This links to the common issue within a biomedical model of healthcare where often the Healthcare Professional has an authoritative role within a hierarchical structure. Healthcare Professionals frequently cited that they 'empower' their patients suggesting that empowerment is a process, and that Healthcare Professionals have 'empowered' the patient to make changes to their self-management. Comparatively, the role of empowerment can be to prepare patients to make informed choices about their health (Holmstrom and Roing (2010). There needs to be a greater distinction between whether empowerment is a 'process' or a 'state'. For successful support for self-management in the future healthcare within the NHS, there is a drive towards changing how Healthcare Professionals actively 'empower' their patients. Shared decision-making and patient-centred care are key components for successful empowerment.

Motivation in relation to the COM-B analysis included consideration of adherence and compliance. To be able to conceptualise behaviour change, it is important to revisit

the definitions of compliance, concordance and adherence to be able to consider their relevance to behaviour change. Interactions and relationships between Healthcare Professionals and patients are key opportunities to develop an equal partnership relationship in which a joint decision can be made about treatment options. Compliance, concordance and adherence have been well documented and discussed within the literature. However, current National agenda of shared decision-making (NICE, 2019) and behaviour change (PHE, 2018) prompts further investigation into changing the way in which Healthcare Professionals approach long-term conditions management. Healthcare Professional and patient relationships are an ideal opportunity to allow for a conversation where goals can be mutually agreed. Compliance is described as ‘the extent to which the patient’s behaviour matches the prescriber’s recommendations’ (Horne *et al*, 2005, p.12). Whereas adherence is described as ‘the extent to which the patient’s behaviour matches agreed recommendations from the prescriber’ (Horne *et al*, 2005, p.12). Although dated references, these definitions are still referred to in contemporary literature (Scullion, 2020). The key difference is that with adherence recommendations are agreed upon between the patient and the prescriber. Concordance is more aligned with contemporary approaches to shared decision-making and personalised care and is described as ‘a consultation process in which the doctor and patients agree therapeutic decisions that incorporate their respective views’ (Horne *et al*, 2005, p.12). Therefore, it can be suggested that behaviour change conversations should ideally be more focussed around a concordance approach in which both parties are actively involved in the decision-making process. Although there was reference to understanding the patient on an individual basis during the Healthcare Professionals focus groups, there was little reference to instilling a collaborative and personalised care model from the survey responses. This further demonstrates the lack of links between understanding what support the patient may need in self-management and how Healthcare Professionals practice their support for self-management in a largely biomedical model of healthcare delivery.

8.4.3 The Empirical

The “Empirical” refers to how the individual experiences their own reality with their chronic condition, particularly in reference to self-management. This relates to what happens because of implementing self-management in Pulmonary Rehabilitation and the experiences of both the Healthcare Professionals and patients. This is often not fully understood by Healthcare Professionals which highlights the importance of a Critical Realist approach to understand the mechanisms at play in the Real domain. A prominent finding within the focus groups was a disparity between what Healthcare Professionals thought self-management should be compared to what the patients and Breathe Easy support group participants felt they needed. The conflict in understanding of the intentions and purpose of self-management undoubtedly has an influence on the outcomes within a complex intervention such as Pulmonary Rehabilitation.

The themes from the “Empirical” domain are often more visible ‘above the surface’ of reality as represented in the Iceberg diagram. The focus groups, in particular the Pulmonary Rehabilitation group participants, allowed for a greater understanding of the individual problems or obstacles in relation to behaviour change in self-management. The Empirical reflects the psychological experience of symptoms related to the disease. Some factors discussed in the focus groups included fear, anxiety and depression, confidence and embarrassment in relation to their experience of the symptoms of COPD such as breathlessness. However, in a more biomedical model orientated Pulmonary Rehabilitation model, there is less focus on the psychological impact of chronic illness. The qualitatively driven mixed methods approach of the current study allowed for personal accounts of their experiences in Pulmonary Rehabilitation to understand the personal impact of these symptoms on successful behaviour change. A feeling of a lack of control was noted in the focus group discussions with the Pulmonary Rehabilitation patients and Breathe Easy support group participants as a barrier to exercise, due to the fear and anxiety as well

as physical limitations associated with breathlessness. This is similar to findings from Lewis *et al* (2014) in which participants described a feeling of floating in which they felt like they had no control over the direction of their condition, not knowing what to expect or how they would feel in relation to their breathlessness. Within this thesis, these fears and anxiety were described as barriers to them engaging in continued physical activity, as they associated worrying thoughts and potentially unpleasant memories, when they become breathless which then leads to an activity avoidance.

It was apparent throughout this thesis study that living with COPD is challenging as it is a long-term condition with a fluctuating disease pattern. This poses challenges for patients and their carers as well as Healthcare Professionals with regards to consistent self-management of their condition. Several of the focus group participants commented that they found it more difficult to engage and participate in Pulmonary Rehabilitation during an exacerbation. The fluctuating nature of the disease impacts behaviour change in self-management. The often-unpredictable nature of COPD can impact upon the physical, social and psychological needs of the individual (Fromer, 2011). This demonstrates a need to continually adapt self-management interventions for a truly patient-centred approach. Currently, the traditional model of Pulmonary Rehabilitation incorporating 6-8 weeks of twice weekly supervised exercise does not match the needs of those patients who become unwell during a course. The impact of exacerbations and illness were frequently cited issues amongst focus group participants both from the patient and Healthcare Professional perspective.

Empowerment was cited frequently within the survey responses, but there was a lack of detail on how Physiotherapists empower their patients. Although, it was clear that Healthcare Professionals recognised the need to have individual conversations and to listen to their personal needs. It is evident in the literature that self-management is often described by Healthcare Professionals as patients being compliant with a biomedical advice or recommendations (Dwarswaard, 2015), which is more aligned to a biomedical model of healthcare. Piper (2010) explored the definition that nurses

gave to health promotion – empowerment was a prominent theme. Piper (2010) discusses that empowerment is the individual's conscious decision to change as well as being linked to informed choice, shared decision-making and patient involvement. These aspects all sit within the Empirical domain. They found during focus group discussions with Nurses that empowerment was seen to be a holistic process balancing the psychological needs of the patient whilst also developing a supportive and trusting relationship with the nurse. In their literature review, Holmstrom and Roing (2010) compared the relationship between the concepts of patient empowerment and patient-centeredness. Despite their differences, patient empowerment and patient-centeredness have some similarities. This includes a shared responsibility, a partnership between patient and Healthcare Professional which is based upon trust and respect.

The biomedical model of healthcare demonstrates a hierarchical structure in which Healthcare Professionals are 'in control' of the decision making and direction of care. The biomedical model of healthcare was commonly referred to within this thesis study. For example, some of the Breathe Easy support group members were focussed on their medications and on-going supervision and support from Healthcare Professionals, more than managing their own condition. During the focus groups, patients expressed their need and desire for on-going support from Healthcare Professionals particularly in relation to on-going supervision with Pulmonary Rehabilitation. Whilst Healthcare Professionals expressed their desire to enable patients to independently manage their condition by empowering them to do so. It was evident during the focus groups and survey responses that clinicians exercise their authority with patients through education and instruction with the view to control disease and change behaviour. Mudge *et al* (2015) explored the concept of control in their systematic review of clinicians' view on their role in self-management. This systematic review was broad in nature and covered papers from a range of clinical backgrounds and chronic conditions. However, the principles of self-management support and Healthcare Professionals views can be applied across conditions. They used thematic analysis to analyse the papers. The three main themes were: 'Who is

in control?', 'Changing clinician views' and 'Overcoming challenges to change'. This hierarchical structure is often observed in Pulmonary Rehabilitation with the Healthcare Professionals educating, motivating, empowering, and providing them with tools and advice and consequently, the patients are being educated, motivated, empowered and are provided with all the tools and advice to self-manage their own condition. In reality, patients need support to achieve self-management goals in a collaborative way with Healthcare Professionals who listen to their individual needs and set goals with shared decision making on an individual basis. This conflict was apparent within the focus group discussions, a mismatch of what patients feel they want and need and what Healthcare Professionals think they need.

As outlined previously, there are many different reasons for difficulties in achieving behaviour change in self-management in Pulmonary Rehabilitation and it is often suggested that increased funding is required to improve outcomes by funding more Pulmonary Rehabilitation services and more staff to work within programmes (NHS Right Care, 2020). An increase in staffing and funding would benefit many services, but it is first necessary to understand how to support and approach the complexities surrounding behaviour change in relation to self-management. The structure and models of Pulmonary Rehabilitation programmes may need to be adapted to be able to effectively support behaviour change. Moreover, now, more than ever, there is a need to address the current situation and ascertain whether Pulmonary Rehabilitation services are fit for purpose in a post COVID-19 world. The traditional face-to-face Pulmonary Rehabilitation model has previously only been available to those who could attend sessions on a certain day and time and many others were unable to access services due to issues relating to transport, location, work commitments and social support. The digital advances required during the COVID-19 pandemic opened the accessibility of Pulmonary Rehabilitation to those who previously couldn't access services. Many individuals have been able to take leadership on their own condition at a time that suited them.

It was apparent within the focus groups that there was disparity between the views of the purpose of Pulmonary Rehabilitation from the patient and Breathe Easy support group members compared to the views held by Healthcare Professionals. For example, the patients and Breathe Easy support group members remained quite reliant upon the support from Healthcare Professionals. This reflects that these patients felt that they needed the on-going support from the Healthcare Professionals and appeared to attribute the lack of on-going classes to the funding and staffing issues associated with the programme, rather than the fundamental purpose of Pulmonary Rehabilitation to be able to continue self-management techniques independently. There appears to be a disparity between the patient's impression of the purpose of Pulmonary Rehabilitation and the Healthcare Professional's expectations for the patients to be fully independent with self-management and continued exercise after completing a 6-week course. Previous qualitative research has suggested reasons for this, including a lack of perceived benefit from attending (Keating *et al*, 2011) as well as issues relating to attributing value to Pulmonary Rehabilitation (Bulley *et al*, 2009). During the Pulmonary Rehabilitation patient focus group discussion, participants admitted that they did not know what to expect from the programme and they felt that this could impact upon attendance and uptake. Both patients in that focus group discussion, previously had contact from a Physiotherapist for other health complaints and the care of a close family member, so they had positive experiences which influenced their uptake of the programme. Despite this, they both admitted that they were pleasantly surprised that they enjoyed the programme. Lewis *et al* (2014) expanded upon previous literature regarding barriers such as transport, the influence of the referring clinician, providing continued support and competing commitments by investigating the lived experience of COPD and referral to Pulmonary Rehabilitation. Lewis *et al* (2014) conducted interviews with patients after they had been referred to Pulmonary Rehabilitation but before commencing on a programme. They found that uncertainty was a prominent theme which related to the uncertainty of the development of their condition, a lack of knowledge on their condition, as well as fear and anxiety associated with their breathlessness. This led to uncertainty about the benefits that Pulmonary Rehabilitation could give them.

Self-management, as previously described, is a complex phenomenon in which there are many different mechanisms which influence an individual's ability to self-manage their condition. During the focus group sessions, there was a tendency to describe self-management from a biomedical model perspective, rather than an individual patient-centred perspective including behaviour change. This was echoed within the survey responses to what self-management means and the identification of key behaviours of self-managing patients, as well as Physiotherapists, who support patients to self-manage their condition. For those, Physiotherapists described that self-management means that patients should be able to manage their own condition with less healthcare utilisation, once they have provided them with the information, knowledge and tools and advice. They recognise that there are barriers and that patients want to be more dependent upon them, but describe that service limitations such as funding, staffing and resources are barriers to on-going healthcare professional input. There seems to be a missing link in the process of supporting a patient how to self-manage their condition. It is apparent that this missing link is effective support for long-term behaviour change. The hierarchical biomedical model of care isn't congruent with the self-management model of patients having ownership and control of their own condition. By recognising the underlying mechanisms associated with achieving behaviour change, Healthcare Professionals may be able to support self-management more effectively. In a biomedical model of care the Healthcare Professional often exerts greater power and control over decision making. Whereas in a patient-centred holistic model of care, the patient should have greater control over decisions relating to their health. Patients and Breathe Easy Support group members often described their condition in medical terms and focussed on the value of the support from Healthcare Professionals but also seemed to have a reliance upon them. Many said that they lacked motivation and drive to continue their exercises without the support from a Healthcare Professional. McCusker *et al* (2019) explored how patient activation influenced self-management. The influence of the patient's mood and readiness to engage in support for self-management was explored and it

was suggested that a collaborative approach to supporting self-management is required.

It is evident from the focus group and survey findings that, both locally and nationally, there is a tendency to adopt a biomedical management approach which emphasises a hierarchical model of care in relation to self-management. Whereas in reality, self-management actually encompasses a range of elements such as medical management, including medications and education on disease, psychological support, particularly related to anxiety and depression and also support for behaviour change, including exercise and lifestyle adaptations. Lorig *et al* (2003) promote the three tasks related to self-management: medical management, behavioural management and emotional management. This encompasses both the physical and psychological impact of long-term conditions management which were highlighted as key aspects of self-management during the focus group discussions. Although a dated reference, this three-task approach is still relevant in contemporary Pulmonary Rehabilitation programmes. The British Thoracic Society (BTS) Pulmonary rehabilitation guidelines (2013) outline recommendations including assessment of exercise ability, self-efficacy in relation to behaviours, anxiety and depression measures.

One of the key barriers from a patient perspective in relation to self-management, is the psychological impact of breathlessness. This thesis has examined the literature and indeed, there is a link between anxiety and depression and the psychological impact of breathlessness which affects the patient's ability to effectively self-manage their condition. Anxiety related to breathlessness was a prominent theme throughout the focus groups and survey responses. Personal accounts of anxiety due to breathlessness were explored in the Pulmonary Rehabilitation group focus groups, as well as in the Breathe Easy Support group focus group. Whilst the Healthcare Professionals acknowledged that breathlessness and perceived breathlessness could impact physical and psychological ability. Breathlessness is a complex symptom which often requires both pharmacological and non-pharmacological treatment. Often

there is not a direct relationship between disease severity and level of breathlessness and each individual can perceive breathlessness differently. In their paper introducing 'The Breathing, Thinking, Functioning model', Spathis *et al* (2017), present that there must be other elements at play when breathlessness is not congruent with disease severity. These other elements are similar to the causal mechanisms associated with behaviour change in self-management. Some of these can be seen for example, the Empirical aspects, whilst others, the Actual and the Real, are hidden from view but have an impact on the outcome or behaviour of the individual. Illness perceptions have been highlighted within the literature within this thesis but Kaptein *et al* (2017) investigated how participant's illness perceptions were depicted in their drawings of their own lungs. Although this study had a small sample size, it demonstrated that patient perceptions of their condition can hold great value in how they are able to articulate their own perceptions. This relates to the way in which an individual experiences their own reality, within the Empirical domain. It is possible to explore the nature of the mind and consider its relationship with the physical world. One of the Breathe Easy support group members admitted that she was struggling psychologically and that it influenced her ability to attend on the maintenance exercise class. Illness perceptions and disease severity influence an individual's ability to engage in both the physical and psychological components of Pulmonary Rehabilitation. Motivation and empowerment were prominent themes amongst survey responses in relation to self-management, but there was less focus on specific strategies to support behaviour change from a psychological perspective.

A common assumption within the literature focussing on barriers to adherence and self-management is that the barriers are either structural or environmental or they are aspects associated with the patient, particularly in relation to behaviour change (Russell *et al*, 2018). There is a lack of detailed analysis into the impact of Healthcare Professionals' behaviours and their influence upon successful behaviour change. Key messages surrounding behaviour change are often focussed on the need for patients to change their behaviours. It is rarely suggested that Healthcare Professionals need to change their behaviours. However, a paper by Stoilkova-Hartmann *et al* (2015)

investigated the attitudes of Healthcare Professionals providing Pulmonary Rehabilitation and noted that there needed to be a shift from Healthcare Professionals managing patients towards a collaborative partnership in disease management, with particular focus on guiding structured behaviour change. A collaborative approach to decisions regarding self-management involves sharing power, influence and responsibilities throughout the decision-making process and patients are empowered to make informed treatment choices (Stoilkova-Hartmann *et al*, 2015). Empowerment was a prominent theme among the survey responses regarding defining self-management. Survey participants also responded that alongside empowerment, participants used knowledge / education, reassurance, giving confidence and motivating patients to make an informed choice on a treatment plan.

Living with chronic illness is often underestimated (Toms and Harrison, 2002). The impact of chronic illness and its associated symptoms determines how the individual experiences their reality. The current study allowed for in depth understanding of varying perspectives on reality associated with behaviour change in self-management. There is often a gap between what patients experience in their own reality in comparison to how Healthcare Professionals might view the patient's reality. Critical Realism allows for a critical lens when interpreting the findings from the focus groups and survey responses. Sometimes, due to different perspectives, there are inconsistencies in the effectiveness of management strategies. An example of this was discussed in the focus group with the Breathe Easy support group members who set up their own exercise class to continue their exercises following attendance on a Pulmonary Rehabilitation course. Their desire to maintain social contacts and support mechanisms from their peers was also a key factor in setting up the group. Some of the Breathe Easy support group members said that they attended the exercise class but did not always exercise due to illness or increased breathlessness and yet they found comfort in the social support of the group environment. Similarly, Toms and Harrison (2002) provide a key example of a maintenance exercise group after Pulmonary Rehabilitation in which the members had been part of the group for many years, some remaining consistent, some leaving but then later returning with disease

progression. Their perceptions of the purpose of the group were inconsistent. The members were still engaged in the exercise group, but the Healthcare Professionals felt that they had failed to equip these patients with the coping skills and knowledge to be able to self-manage their condition. Whilst the authors interpreted it as either 'the desire to remain on the programme was a sign of dependency in weak, poorly coping individuals or was it a sign of highly motivated individuals keen to maintain the health behaviours that helped them?' (Toms and Harrison, 2002, p.606). This is where there can be conflict between the varied perspectives on the individual patient needs.

Healthcare Professionals, as demonstrated in the focus groups and survey responses, tended to believe that patients should be able to manage their own condition, even during an exacerbation, once they had sufficient knowledge, skills and tools to do so. Whereas in reality, the patients and Breathe Easy support group members tended to want to have the supervision and contact with the Healthcare Professionals. This is where there are inconsistencies in the Healthcare Professional perspective. They often suggested a move away from a biomedical model of care to a more patient-centred model but at the same time continued to exert power and authority over providing didactic-style education. Compared to patients who often are more familiar with a biomedical model of care, with a focus on medications and treatments. They often seek out medical professional support when they are unwell with an exacerbation. With this in mind, the current model of Pulmonary Rehabilitation practice needs to be reviewed to see whether the traditional twice a week for six weeks model of care meets the needs of those with a long-term condition such as COPD.

Pulmonary Rehabilitation is an ideal setting for structured support for behaviour change in relation to self-management, but its success relies on an effective relationship between the patient and Healthcare Professional. On-going difficulties exist regarding uptake and adherence to the course. Participants from the Pulmonary Rehabilitation group focus group spoke of their enjoyment during the course and suggested ways in which they could promote its benefits. One participant admitted

that his perception of Pulmonary Rehabilitation changed through engaging on the course. He initially did not appreciate the benefits, but once he attended a session, he understood the value in attending. Understanding the benefits of Pulmonary Rehabilitation is key to improving uptake and participation. This is crucial to have an impact upon the growing number of people living with chronic lung disease as a long-term condition. This has been previously outlined in the literature as uncertainty prior to attending Pulmonary Rehabilitation with regards to experiences and expectations of referral into the programme (Lewis *et al*, 2014). Behaviour and particularly behaviour change in self-management was the global theme from the focus groups. This theme was further investigated within the survey. Survey participants were asked specifically about behaviours, behaviour change techniques and what self-management means. Both the focus group and survey data enabled an understanding of the current context and climate for behaviour change in relation to self-management in Pulmonary Rehabilitation at a local and national level.

8.5 Policy Context

Within the context of the current study, the key standards and guidelines for Pulmonary Rehabilitation will now be revisited to be able to explore how behaviour change interventions are currently outlined as well as suggesting where improvements could be made. Within the Quality Standards for Pulmonary Rehabilitation (2014) document, there is no specific reference to behaviour change. However, Standard 6 refers to 'Pulmonary rehabilitation programmes include a defined, structured education programme'. Within the detail of this standard, it refers to the BTS Guideline on Pulmonary Rehabilitation (2013), in which it is stated that education should include, among others, education on behaviour change. The purpose of the education sessions is described as: 'The intention of the educational element is to support the lifestyle and behavioural change and assist self-management to promote decision-making and self-efficacy' (BTS, 2013, p.ii12). It would be beneficial to Healthcare Professionals if the specifics of behaviour change were highlighted within an update

of the guidelines. This could include reference to The Theoretical Domains and Behaviour Change Techniques. For example, the commonly cited Theoretical Domains from the survey responses were knowledge, skills, goals and environmental context. Behaviour change techniques including goal setting, self-efficacy, and follow-up with feedback were commonly cited as techniques used by Physiotherapists in clinical practice from the survey responses. These represent the 'active ingredients' of Pulmonary Rehabilitation but the detail on their application needs to be further explored. There needs to be consideration on how these can be implemented in relation to the Real, the Actual and the Empirical domains. The most referenced domains within the Theoretical Domains Framework across the focus groups and survey were 'environmental context and resources' as well as 'social influences' and 'social / professional role and identity'. This indicates that the individual's environment and social identity is at the foundation of behaviour change. From a Critical Realist perspective that the world exists independently of our perceptions of it, it is also important to recognise that an individual's perception of the world is constructed from their own experiences and perspectives. Therefore, understanding the influence of the social and environmental context for the individual is a necessary step in understanding how they might perceive the world in which they live. This is an essential aspect of understanding and influencing behaviour change in chronic respiratory disease.

When supporting behaviour change in patients with chronic respiratory disease, it is important to have an understanding of the patient as an individual. There is a national drive within the NHS long-term plan to adopt a personalised care approach towards patients, especially those with chronic respiratory disease. Healthcare Professionals strive to provide an individualised model of care, but in reality, there are barriers such as time, resources and expertise which prevent this being fully achieved. These were well recognised with both the focus groups and survey responses. There has been debate recently surrounding the difference and explicit implications of patient-centred verses person-centred care models. Describing interventions as patient-centred has a paternalistic tone which is orientated around a biomedical hierarchical model of care.

In contrast, a person-centred care model seeks to remove the element of vulnerability and dependence upon Healthcare Professionals and aims to represent a partnership of care which focusses on understanding the person in their own reality (Eklund *et al*, 2019).

It was recognised that Healthcare Professionals are key players in tackling the barriers and improving the relations between patients and the healthcare system relating to long-term conditions management. The World Health Organisation (WHO, 2003) document entitled 'Adherence to Long Term Therapies' set out pathways to change the ways in which Healthcare Professionals approach adherence among patients with long-term conditions. This World Health Organisation document recognised and made clear that issues relating to compliance often have a tone of blame and suggest that the term adherence captures the complexities of long-term conditions management. These same messages are still apparent in the issues relating to behaviour change in self-management in Pulmonary Rehabilitation. This highlights the difficulties in changing healthcare systems as well as how Healthcare Professionals interact with patients. The application of The Behaviour Change Wheel in this thesis, allowed for a wider view of behaviour change, including the policy context. There is a need to support effective behaviour change amongst patients but also more importantly amongst Healthcare Professionals. Their approaches to support for self-management are vital. The relationship between the Physiotherapist and patient can be complex but it is important to address issues to achieve a successful therapeutic alliance. The concept of a therapeutic alliance is slowly being adopted within Physiotherapy (Søndenå *et al*, 2020). A therapeutic alliance aims to move away from the biomedical model of care towards a more biopsychosocial model. This thesis has highlighted a conflict between desires to move away from a biomedical model of care within a predominantly biomedical orientated disease management structure. In addition, this thesis has shown that often patients sometimes expect and prefer a biomedical model approach to their care. The conflict lies within the relationship between the Healthcare Professional and the patient in a power-balance in shifting responsibility in self-management.

Within the United Kingdom, health inequalities are closely linked to the social and economic position of individuals (NICE, 2007). Both the social and economic position can impact upon health behaviours, both by preventing changing behaviours as well as reinforcing damaging behaviours. NICE (2007) suggest that health behaviours are the product of complex interactions within the biological, social, psychological and economical realms. It is recognised that behaviour change interventions need to be targeted at different levels to bring about sustained behaviour change. Current National agenda and policy reflects the need for Healthcare Professionals to change their approach to self-management. For example, the rising number of the population who have a long-term condition and are living longer due to advances in biomedical treatments. However, undergraduate as well as postgraduate training needs further development to be able to train the future as well as current workforce so that they can deliver effective support for self-management and long-term behaviour change. A workforce transformation is required to be able to adapt approaches to support for behaviour change in self-management particularly in long-term conditions management.

Some survey respondents reported using self-efficacy as a tool in Pulmonary Rehabilitation. This aligns with some of the other responses relating to the value in helping patients to believe in their own abilities to manage their own condition. Measuring change in relation to behaviour change is challenging but the role of self-efficacy is referred to in the BTS Pulmonary Rehabilitation guidelines (2013) as an important outcome measure in adherence. The Pulmonary Rehabilitation Adapted Index of Self-Efficacy (PRAISE) tool was developed to measure levels of self-efficacy in behaviour in Pulmonary Rehabilitation and has been shown to be sensitive to change in this patient cohort (Vincent *et al*, 2011). Liacos *et al* (2019) found that the PRAISE tool can show improvement in sedentary behaviours and can be used as a screening tool to predict those who may require additional support with self-efficacy to gain benefits from Pulmonary Rehabilitation. However, to date, this tool is not yet widely used.

8.6. The Impact of COVID-19 on Pulmonary Rehabilitation

Although the data from this thesis was collected prior to the COVID-19 pandemic, the data analysis was conducted during the pandemic, but the findings are relevant in a post COVID-19 world. Within the field of Pulmonary Rehabilitation clinical practice and literature, the COVID-19 pandemic has exposed pre-existing as well as augmented some health inequalities (Gardiner and Singh, 2022). It is evident that the key messages are contemporary and the new world in which we find ourselves in is an ideal blank canvas to be able to implement change including a workforce transformation to be able to situate behaviour change in self-management at the heart of Pulmonary Rehabilitation. Some of the underlying mechanisms including objective barriers such as transport, time, funding and accessibility of classes that have previously impacted upon successful attendance and completion in Pulmonary Rehabilitation are no longer barriers in a remote Pulmonary Rehabilitation model (Holland and Hill, 2011). However, the more complex mechanisms such as the psychological impact of breathlessness and the relationships between patients and Healthcare Professionals, in particular, Physiotherapists, require further investigation into how they influence behaviour change in self-management in post COVID Pulmonary Rehabilitation programmes. Factors associated with health inequalities such as culture, beliefs and assumptions as well as digital literacy also have been exposed (Gardiner and Singh, 2022).

Prior to COVID-19 the World Health Organisation (2017) produced a report on a call for action to improve rehabilitation services. Key aspects of this report focus around ensuring that rehabilitation services are accessible, sustainable and affordable to be able to support the ever-increasing unmet need for rehabilitation services in long-term conditions. The increasing population including an increase in non-communicable diseases and the number of people aged over 60 is expected to double by 2050 and the demand for rehabilitation services is only going to continue to increase (WHO, 2017). The issues presented within this thesis in relation to the impact of causal mechanisms on successful behaviour change in self-management highlight that a

paradigm shift from a biomedical to psychosocial model of healthcare is essential to meet the predicted demands of the future population. In a post COVID-19 world, there is even more of a demand upon rehabilitation services. So, it is crucial to be able to ensure investment and recognition in rehabilitation services from a global and national perspective. The focus of this thesis is within the field of Pulmonary Rehabilitation but the issues highlighted in relation to behaviour change and self-management are relevant across many other long-term conditions which are expected to increase.

The impact of COVID-19 will have lasting effects on the current healthcare system as well as changing the landscape for Pulmonary Rehabilitation. It is expected that it will take 5-10 years for the NHS to recover from the impact on acute services (Alderwick *et al*, 2021) as well as community-based services such as Pulmonary Rehabilitation, as a result of changing service models, suspending services impacting waiting lists and an increase in referrals (ACPRC, 2020). A post COVID-19 world is emerging, and traditional Pulmonary Rehabilitation models have been questioned as being fit for purpose in this new world (ACPRC, 2020). There is scope for improved accessibility for programmes for current patient groups, using remote and digital models for patients who may have previously not been able to attend a centre-based programme. This thesis has highlighted that there are multiple complex mechanisms influencing behaviour change and self-management. COVID-19 has provided additional challenges and influences on existing mechanisms whilst simultaneously providing an opportunity to develop system-wide change. There are limitations to digital models. Not only due to a lack of internet access but also because of the level of digital literacy can be poor among COPD patients. It is estimated that 7% of UK households do not have access to the internet and 10.7 million people in the UK have limited digital literacy skills (Majeed, Maile, & Coronini-Cronberg, 2020). In a recent survey of Pulmonary Rehabilitation service-users, of which 170 responded, 31% reported never having accessed the internet whilst 29% reported they had no interest in accessing Pulmonary Rehabilitation digitally (Polgar *et al*, 2020). It is also important to recognise that the digital literacy among Healthcare Professionals has been challenged. The rapid change in services to remote delivery has highlighted the need for training and

support in digital delivery. Staff as well as patients need to be able to utilise remote delivery options to be able to deliver an effective digital service model (Smith *et al*, 2020). Health inequalities and digital literacy and access to Pulmonary Rehabilitation programmes in relation to COVID-19 possess additional causal mechanisms as well as augmenting pre-existing ones. For example, patients had less opportunity to have face-to-face conversations with Healthcare Professionals and there were less opportunities for peer-support within group environments and adherence issues within this patient group were influenced by the difficulties associated with digital access and resources. The relationships between variables and the mechanisms associated with them are key to understanding complex interventions (Dalkin *et al*, 2015). Despite the success and advances in digital delivery of Pulmonary Rehabilitation services, this technology and way of delivering Pulmonary Rehabilitation needs further investigation. One size does not fit all and a hybrid model of blended self-management interventions in Pulmonary Rehabilitation needs to be explored and adopted. A hybrid model of self-management interventions includes a menu of choices of options for methods of accessing Pulmonary Rehabilitation to be able to offer both remote and face-to-face models to ensure that services are accessible for all.

The COVID-19 pandemic had a profound impact upon the psychological states of many people with Chronic Obstructive Pulmonary Disease (Phillips *et al*, 2020). This thesis demonstrates the complex interplay between the physical and the psychological impact of chronic respiratory disease on the patient's ability to manage their condition. During the pandemic this has been and is likely to continue to be an issue when engaging patients in behaviour change in self-management interventions such as Pulmonary Rehabilitation. The relationship between breathlessness and anxiety was demonstrated within this thesis study and these issues are likely to be more apparent with a reduction in physical functioning leading to increased breathlessness.

The lasting effects of the COVID-19 pandemic can be seen in patients with long-term conditions, in particular those with Chronic Obstructive Pulmonary Disease. Due to

physical and social isolation, many individuals with Chronic Obstructive Pulmonary Disease experienced a reduction in their physical ability as well as their activities of daily living (Fettes *et al*, 2021). The implications of this are a cohort of patients who may require support from Pulmonary Rehabilitation services who would have previously been managing themselves independently. There is likely to be an increasing demand placed upon Pulmonary Rehabilitation services, many of which already have long waiting lists due to staff re-deployment and suspension of services. A combination of fear of attending the GP surgery or hospital led to more patients being managed at home with courses of antibiotics as well as a lack of usual routine. A lack of support from Healthcare Professionals contributed to the detrimental effects of social and physical isolation. The reliance upon Healthcare Professionals found in this thesis demonstrates that those with Chronic Obstructive Pulmonary Disease actively seek and value the support from Healthcare Professionals. A shift in towards a more biopsychosocial model of care has naturally occurred during the pandemic and this is a good starting point to be able to investigate alternative models of support for self-management.

Studies had already been investigating the effectiveness of alternative models of Pulmonary Rehabilitation delivery before the COVID-19 pandemic (Holland and Hill, 2011) but there was an expansion of the literature and home-based Pulmonary Rehabilitation was more widely accepted as an option in remote delivery options (Cox, 2021, Houchen-Wolloff *et al*, 2021 and ACPRC, 2020). It had been previously suggested that home-based Pulmonary Rehabilitation was inferior to centre-based programmes. Difficulties in determining its effectiveness were partly due to a lack of evidenced-based outcome measures for physical ability and an inability to conduct exercise assessments such as the incremental shuttle walk or the 6-minute walk test in the home environment. There have been similar studies within the field of Cardiac Rehabilitation, due to the similar nature of the programmes, parallels can be made between Cardiac and Pulmonary Rehabilitation. A systematic review by Heron *et al*, (2016) reviewed randomised controlled trials relating to home based Cardiac Rehabilitation with a particular focus on behaviour change techniques. They found

that social support, goal setting and knowledge formation were the most cited behaviour change techniques within the studies they reviewed.

The COVID-19 pandemic demanded alternative options for assessing outcomes, as well as programme delivery. Behaviour change in self-management within the context of COVID-19 is particularly important when considering how the NHS healthcare workforce will be able to support this patient group into the future. There are challenges as well as opportunities following the COVID-19 pandemic. This approach is often recommended as a model of long-term conditions management but as this thesis demonstrates, it is often difficult to implement in practice due to the complex nature of chronic disease and long-term conditions management. Now, more than ever, there is an increased demand to adopt a person-centred approach with specific consideration to the underlying mechanisms associated with the individual's barriers to behaviour change in self-management and in particular attention needs to be on whether mechanisms are activated or not.

The COVID-19 pandemic has exemplified that health behaviours are complex and gave Pulmonary Rehabilitation services permission to develop different models of delivery that would not have been possible if the pandemic had not happened. The effectiveness of the traditional biomedical model of Pulmonary Rehabilitation has been challenged and the potential for adapted service models has been unlocked. Whilst the NHS will take a long time to recover from the impact from COVID-19, Pulmonary Rehabilitation services face new opportunities to develop service models to improve access for those who previously couldn't engage in the intervention due to common barriers such as transport, access and availability of programmes. The digital front door has been opened for the future development of alternative service models which offer greater patient choice than has ever previously been available to this patient population. With this opportunity there needs to be focussed attention on re-modelling services with particular attention to person-centred approaches and investment in

ensuring the current and future workforce are equipped with the necessary skills to be able to support effective behaviour change in self-management.

8.7. PhD journey - Researcher reflections

At the outset, pre-existing assumptions regarding the issues surrounding behaviour change and self-management instigated and determined the direction of this thesis. These included the difficulties with current service models to meet the needs of the patients. For example, if a patient did not engage in Pulmonary Rehabilitation they were consequently discharged from the service. It would be much more beneficial to be able to understand the individual barriers to each patient's ability to engage in services. The stigma of previously defined barriers such as smoking history and socioeconomic status inevitably creates a negative perception of the patient's engagement in Pulmonary Rehabilitation. A pre-existing paternalistic tendency which is common in Physiotherapy practice (Mudge *et al*, 2014) undoubtedly influenced my initial assumptions at the start of this thesis. The journey through this PhD has developed from thinking purely about objective adherence problems, to investigating and understanding the deeper mechanisms associated with adherence problems to be able to more effectively support long-term behaviour change. For example, truly understanding how the patient 'sees' the world in which they live is key to facilitating engagement and behaviour change in self-management.

Conducting this thesis has enabled me to reflect on my own clinical practice which is primarily situated within a biomedical model of care and to move forwards towards a more psychosocial model. The dual role of practitioner-researcher has allowed for a critical review of current working practices within Pulmonary Rehabilitation. Critical Realism has been a valuable mechanism to be able to investigate and reflect upon the current issues surrounding difficulties in achieving behaviour change in self-management. It has allowed for reflection on the underlying structures to determine what is visible and what lies beneath the surface of reality. My own practices and

ways of working have been challenged and I am able to recognise the impact of a predominantly biomedical model approach and consider alternative ways of working in a newly defined post-COVID world.

Working within the NHS is a demanding task, juggling high expectations from both staff and patients and striving to deliver the best service for the patients but often with limited resources. It is apparent that in relation to behaviour change in particular related to self-management, there needs to be a whole system approach. A workforce transformation is ultimately required. This should start from undergraduate training for the future workforce as well as embedding cultural changes within Healthcare Professionals already in the workforce. On reflection from the focus groups and survey responses, the Healthcare Professionals primarily have the patient's outcome at the heart of their approach to support for self-management, but it is clear that there are elements of the intervention approach that are not congruent with each other. Clinicians should take a step back and think about how best to approach each patient as an individual but to also look at the service model should be reviewed, and provision made to understand if it is fit for purpose.

As a clinician embarking on a research journey it has been a challenge to juggle clinical priorities as well as research relating to this thesis but as set out in Chapter 1, the value of a researcher-practitioner approach often adds value by investigating real problems from clinical practice. There is scope for researcher bias when completing research in your own clinical field which is why it is essential to adopt a reflexive approach and take a step back to understand the research as well as the clinical experience of the issues. The true value of practitioner research is that clinicians are committed to understand and solve real life problems. The difficulty arises when trying to implement research findings into clinical practice due to the inherent complexity of Healthcare Systems. However, clinicians are ideally placed to implement change to have the most effective impact.

From a personal perspective, I am ideally placed to be able to have impact upon the future approach to behaviour change in relation to self-management through my clinical role and wider peer support groups such as the Association of Chartered Physiotherapists in Respiratory Care, as well as being part of Working groups for the National agenda on Pulmonary Rehabilitation and co-authoring key documents related to Pulmonary Rehabilitation during the COVID-19 pandemic.

The COVID-19 pandemic challenged my professional, research and personal lives and experiences, but opened the opportunity to delve deeper into the complex nature of chronic disease management and behaviour change. My clinical role and position on the Association of Chartered Physiotherapists in Respiratory Care (ACPRC) Committee allowed for me to actively engage and contribute to guidelines and position statements related to COVID-19 Pulmonary Rehabilitation. This contributed positively to my engagement in contemporary literature in relation to this thesis and being able to situate the pre-pandemic research findings into a new landscape for Pulmonary Rehabilitation. This thesis has allowed for a critical review of the current practice of support for self-management in Pulmonary Rehabilitation, using Critical Realism as a lens to understand the data. Both Pulmonary Rehabilitation as an intervention and support for self-management are perhaps even more complex than first thought. The COVID-19 pandemic has allowed for a blank canvas for developing the future models of Pulmonary Rehabilitation. It has opened the digital front door for improving access compared to traditional models of face-to-face Pulmonary Rehabilitation. The interactions with causal mechanisms associated with behaviour change in relation to self-management are not congruent with the traditional model of Pulmonary Rehabilitation because of the constraints of the NHS organisational structure and the outcomes-based approach to Pulmonary Rehabilitation delivery. Being able to adopt a reflexive approach, moving between clinical practice, contemporary literature and revisiting and engaging in my data analysis allowed for a thorough understanding of the issues surrounding behaviour change and self-management in Pulmonary Rehabilitation. The dawn of a new era of Pulmonary Rehabilitation is an exciting, yet challenging time which I hope to be able to draw upon my research findings to be able

to contribute to the development of advances in service models which are fit for purpose in a post-COVID world. Finally, on reflection of the in-depth exploration of support for self-management in Pulmonary Rehabilitation and considering the limitations and conflicts associated with the current NHS climate and organisational structure as well as the complexity of interactions between Physiotherapists and patients, it is unclear whether the traditional model of Pulmonary Rehabilitation is fit for purpose. Current practice in Pulmonary Rehabilitation often adopts a 'one-size fits all' approach orientated around outcome-based measures of success which doesn't easily allow for a patient-centred model of delivery.

8.8. Strengths and Limitations of the Study

8.8.1. Strengths of the study

The use and application of a mixed methods approach to this study was an asset. This added new knowledge by investigating several participant groups to gain in depth understanding of the varied elements and opinions regarding self-management. This highlighted some key areas which have been previously identified within the literature, but the range of data obtained has contributed to further understanding of the gaps between the literature and evidence-base, the current design and provision for Pulmonary Rehabilitation programmes as well as variances between Healthcare Professionals and patients perceptions and experiences of self-management in Pulmonary Rehabilitation.

This mixed methods study was qualitatively-driven which enabled opportunities to obtain valuable data from participants. However, both recruitment methods included self-selecting samples which holds an element of bias. Despite this, the participants included in this study were engaged, interested and thus provided a richness within the data. At the outset, the predicted response rate for the survey was unknown. This was partly due to an unknown number of people who would respond from the ACPRC members. Some factors associated with improved uptake to focus groups include

face-to-face recruitment, arranging convenient dates for the focus group and incentives (Tausch and Menold, 2016). The value of qualitative research methods and in particular mixed methods approaches have become increasingly recognised as valued methods, commonly associated with a more interpretivist paradigm. The aim of the current study to explore the opportunities and challenges associated with behaviour change in self-management required a qualitatively-led study to be able to further understand the underlying structures and mechanisms involved. Whilst some would argue that a positivist paradigm offers more robust results, it is important to recognise the value in a more interpretivist approach to issues surrounding self-management, behaviour change and the complexities associated with them (Ryan, 2019). Randomised controlled trials are more appropriate when comparing single interventions but when analysing complex interventions such as Pulmonary Rehabilitation there are more variables to consider (Marchal *et al*, 2013).

A key strength of this study is that participants were recruited from a range of groups which encompass those involved in support for self-management. The focus groups allowed for patients as well as Healthcare Professionals to describe their thoughts and views regarding the difficulties in supporting and achieving behaviour change in self-management.

The complexities of behaviour change, particularly in self-management in Chronic Obstructive Pulmonary Disease, inevitably mean that it is a challenge to study the component parts and mechanisms associated with it. Despite this, the investigation in the current study provides rich data from varied perspectives which together enabled a detailed understanding of the issues surrounding behaviour change in self-management. The application of behaviour change models and theory within this thesis including The Behaviour Change Wheel and The COM-B model as well as The Theoretical Domains Framework has contributed to the developing field of behaviour change in relation to self-management in Pulmonary Rehabilitation.

The application of Critical Realism as a philosophical framework allowed for the researcher to explore the issues surrounding behaviour change in self-management through a critical lens of the social world and its structures. This contributed to the uniqueness of this thesis by using critical realism to approach real-life issues surrounding behaviour change in self-management which adds new insights into its complexities.

8.8.2. Limitations of the study

A limiting factor with this study was the relatively small sample sizes, primarily with the survey responses. The survey was sent to ACPRC members via a link in the monthly Newsletter. The survey was directed towards a specific participant group of Respiratory Physiotherapists working in or with a knowledge and interest in Pulmonary Rehabilitation. But this was an unknown proportion of ACPRC members. The participant group is quite a niche group of Physiotherapists. However, in qualitatively-led research, Yardley (2000) emphasises the importance of theoretical worth rather than statistical generalisability. Yardley (2000) claims that data analysis can be important not purely for the purpose of providing complete and accurate data but by developing novel perspectives on the empirical data. In Critical Realist research the goal is less to determine generalisability through a more positivist approach but to develop more detailed explanation and understanding of the underlying structures and mechanisms influencing the phenomenon being investigated (McEvoy and Richards, 2006).

Pulmonary Rehabilitation has become more widely discussed and there are several national specialist discussion groups and working groups which developed since the planning and conduct of this survey. If this data collection method were to be used again, it would be more appropriate to target a more specific group. This would be a representative sample which would provide specific examples from contemporary

clinical practice specifically within the field of Pulmonary Rehabilitation. For example, there is now a Yorkshire and Humber regional Pulmonary Rehabilitation group which would have been a relevant group to survey for a local perspective as well as the Pulmonary Rehabilitation working group within the Taskforce for Lung Health.

There were recruitment difficulties in the Pulmonary Rehabilitation group patients' focus groups. This could be attributed to a lack of engagement, lack of time or ability to attend a focus group or simply disinterest in contributing to the research. Whilst these aspects are acknowledged, in qualitative methodology with a discreet patient population, the varied participant groups within the focus groups and the survey participants proved to have rich content on a specific topic area. In qualitative research there is less emphasis upon large sample sizes such as those required in quantitative randomised controlled trials and the richness of personal accounts proves more valuable. Therefore, the small sample sizes did not appear to impact upon the quality of the data obtained from both the focus groups and survey responses. It must also be noted that the participants included in the focus groups and survey responses were actively engaged and willing to contribute.

For the purpose of this thesis, respecting the limitations of conducting research whilst in a clinical role, focus group participants were recruited from those who responded to an invitation to participate in the study. Pulmonary Rehabilitation patients invited were already attending a Pulmonary Rehabilitation course so were potentially already more engaged than those who declined to attend a Pulmonary Rehabilitation course. It is acknowledged that there is an important cohort of participants who were not recruited, those who did not respond to the invitation to participate in either Pulmonary Rehabilitation or the focus groups. This group of participants would have provided valuable and a further insight into the barriers and facilitators to engaging in Pulmonary Rehabilitation. There is a wealth of data and information that could have been obtained from both patients and Healthcare Professionals who did not respond to taking part in the focus groups and survey. There is likely to be rich data to be obtained

from a sample of patients who did not engage in Pulmonary Rehabilitation in the first instance. Their responses would be invaluable in understanding the underlying mechanisms associated with why they did not accept a referral or respond to an invitation to attend Pulmonary Rehabilitation. Making research within this field more accessible and providing more information is key to improving successful recruitment (Taylor *et al*, 2007).

It is vital to acknowledge the importance of being explicit in reflecting on how reflexivity impacted upon this thesis. The process of carrying out this thesis study has had a profound impact upon me, and my clinical practice especially related to my thoughts and clinical practice surrounding support for self-management. At the inception of this thesis study, although perhaps not knowingly, I was primarily approaching support for self-management in a largely biomedical model way. Working within a busy NHS environment following clinical practice guidelines on delivering effective Pulmonary Rehabilitation through education and supervised exercises. It is only through conducting this thesis study whilst also engaging in relevant literature that I have become more acutely aware of the contrasting elements within the biomedical and psychosocial models. My initial approach stemmed from my undergraduate and post-graduate training as well as further educational courses which were all directed towards a more biomedical approach. Moving forwards, my future approach will include reflection and consideration of the spectrum of approaches including both biomedical and psychosocial models.

The Researcher-practitioner approach carried with it both positives and negatives to the study. One organisational difficulty encountered was related to conflicts on time and availability to conduct the focus groups. The focus groups required a level of organisation such as booking the venue as well as arranging the participants' attendance. There were also some difficulties in arranging a suitable time for the moderator to attend for all six focus groups. This led to me as the researcher moderating one of the focus groups. This posed a risk to bias but it was decided that

there was greater opportunity to discover rich data in a specified timescale rather than not be able to conduct the focus group at all. There was a potential for researcher bias due to some participants knowing me in my Physiotherapist clinical role. This could have influenced the responses during focus groups due to being present, both as a moderator in some focus groups but also as a silent moderator in others, due to most participants knowing me as a Physiotherapist. This was mitigated by introducing the purpose of the focus group for advances in research as well as it being a confidential environment at the start and ensuring anonymity.

The extended duration of a part-time PhD in itself can pose risks to the data being contemporary upon completion. Whilst the journey to completion for the current study was elongated, the development within the field of behaviour change theory as well as the COVID-19 pandemic and its implications to the topic area have allowed for the data to be situated within contemporary literature and therefore allows for greater impact on the relevance of the findings in clinical practice.

8.9. Summary and future recommendations for Physiotherapy research and practice

This thesis has shown a complex interplay between what happens at both a patient and Healthcare Professional level in relation to behaviours and mechanisms at play and their influence on behaviour change in self-management. The unique contribution to knowledge this thesis provides is a complex investigation into behaviour change and self-management from varied perspectives using behaviour change theory and models alongside the principles of Critical Realism to situate the findings in relation to the domains of the Real, the Actual and the Empirical. The benefit of using these methods has allowed for critical reflection on whether the current model of Pulmonary Rehabilitation delivery is fit for purpose. Through this thesis pre-existing barriers and facilitators have been further explored to understand the missing links between the intentions and actions of Healthcare Professionals in relation to the needs of the

patients within self-management in Pulmonary Rehabilitation. At the end of this thesis study there are some recommendations for future research and practice which are aimed at enhancing current practice within Pulmonary Rehabilitation. These will now be outlined:

Recommendations for Physiotherapy research and practice are outlined here:

Recommendation 1:

To successfully support behaviour change in self-management, there needs to be greater focus and emphasis upon identifying the underlying structures and mechanisms influencing barriers to engagement in Pulmonary Rehabilitation. Future research should include investigating how to identify individual mechanisms influencing behaviour change during the patient assessment in Pulmonary Rehabilitation programmes.

For example, moving away from a traditional biomedical model of care and adapting Pulmonary Rehabilitation services to be able to develop a more biopsychosocial model using patient-centred approaches to self-management. Listening to patient needs and fostering a collaborative conversation to support effective behaviour change in self-management. There needs to be effective ways of discussing and documenting behaviour change conversations as part of the assessment process in Pulmonary Rehabilitation programmes.

Recommendation 2:

Healthcare Professionals, in particular Physiotherapists, need to explore their own understanding of behaviour change theory and practice. To be able to transform approaches to behaviour change in Pulmonary Rehabilitation, Physiotherapists need to firstly be able to recognise their own beliefs and assumptions. Future research should explore understanding of behaviour change theory and practice amongst Physiotherapists working in Pulmonary Rehabilitation to be able to identify individual learning needs.

An important first step is understanding our own beliefs and assumptions in relation to behaviour change in self-management and begin to understand how this may influence approaches to supporting patients in Pulmonary Rehabilitation. This may include developing and accessing relevant training and resources at both undergraduate and postgraduate level. Planning for the future workforce is key to ensuring transformation of services to meet the needs of the patients in relation to self-management.

Recommendation 3:

In a post COVID-19 world, the Pulmonary Rehabilitation programme service model requires a review to determine how different models effectively support behaviour change in self-management. Future research should focus on how behaviour change approaches can be integrated into and successfully delivered using remote and digital models of Pulmonary Rehabilitation.

As we navigate through the newly emerging post-COVID world, there is an imminent demand for alternative approaches to support for self-management. The impact on the NHS and accessibility of digital resources requires further research to investigate approaches to supporting behaviour change between Physiotherapists and patients in Pulmonary Rehabilitation. Understanding different models of practice and questioning pre-existing beliefs will enable Physiotherapists to develop Pulmonary Rehabilitation services. A menu of options for Pulmonary Rehabilitation has been offered during the COVID-19 pandemic compared to the traditional face-to-face model which was most commonly delivered prior to the pandemic. Remote and digital models were appropriate as an alternative model of delivery during the pandemic when it was not possible to conduct face-to-face programmes. However, these models of programme need to be evaluated to determine whether they are fit for purpose in a post COVID-19 world.

8.10. Conclusion

Behaviour change in self-management within the context of Pulmonary Rehabilitation is complex and although this thesis has explored the causal mechanisms from a Critical Realist approach, there remains a need to develop interventions to support long-term behaviour change. Whilst many Healthcare Professionals, in particular Physiotherapists report to adopt a patient-centred approach to self-management, the current study revealed that there remains a missing link between what Physiotherapists think they are providing and what the patient feels they gain from their support and intervention. Further qualitative and quantitative research methods are required to develop behaviour change interventions specific to both Healthcare Professional and patient use in self-management in Pulmonary Rehabilitation. This is particularly required to address the underlying structures and mechanisms which are within the Actual and the Real domains that are not always visible to the eye. Each individual person brings their own causal mechanisms which include their beliefs, assumptions, experiences and social identity. The Healthcare Professional's role in supporting behaviour change in self-management is to listen to the individual,

understand their unique needs and preferences and provide support in a collaborative relationship. Looking forwards to a future model of healthcare, it is more than ensuring approaches are patient-centred or person-centred, including shared decision-making and personalised care models. The underlying structure of support for behaviour change in self-management needs to firstly seek out and understand each individual's set of beliefs and their own causal mechanisms. Healthcare Professionals, particularly, Physiotherapists are ideally placed to be able to effectively support behaviour change in self-management.

Appendices

Appendix I: Focus Group Invitation Letter:

Self-management and adherence to maintenance exercise programmes for patients with Chronic Obstructive Pulmonary Disease (COPD)

Mrs Frances Butler, Dr Lisa Robinson, Prof Pam Dawson

Dear Participant,

You have been invited to take part in a research study which is looking into self-management and adherence to maintenance exercise programmes for patients with Chronic Obstructive Pulmonary Disease. You have been selected as you have either taken part in the pulmonary rehabilitation course run by York hospital, or you work within or refer to pulmonary rehabilitation or you are a member of the York Breathe Easy support group.

Please read the enclosed 'Participant Information' sheet and respond with the enclosed reply slip if you wish to take part.

Please don't hesitate to contact me via the details below if you have any further questions or require any further information.

Yours Sincerely,

Frances Butler

PhD Student - Northumbria University

Advanced Clinical Specialist Physiotherapist

York Teaching Hospital NHS Foundation Trust

Wigginton Road

York

YO31 8HE

(01904) 725528

Appendix II: Focus Group Participant Information Sheet

Self-management and adherence to maintenance exercise programmes for patients with Chronic Obstructive Pulmonary Disease (COPD)

Mrs Frances Butler, Dr Lisa Robinson, Prof Pam Dawson

Participant Information Sheet

You are being invited to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

Ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

Chronic Obstructive Pulmonary Disease (COPD) is a debilitating respiratory condition. Patients with COPD account for the most common reason for emergency admissions to hospital.

Pulmonary rehabilitation is an exercise and education program which is designed to maximize the exercise ability and quality of life in individuals with COPD. Although pulmonary rehabilitation has shown positive improvements in exercise ability and reduced hospital admissions; the benefits obtained in exercise performance, quality of life, and symptoms tend to diminish over time. Previous research has shown that there are several reasons why patients have poor adherence to exercise

Focus group discussions will be carried out with patients who have previously attended pulmonary rehabilitation, health care professionals who either deliver or refer to pulmonary rehabilitation and members of the local Breathe Easy support group who attend their exercise programme. Discussions will focus around adherence to maintenance exercises as well as methods to improve commitment to long-term exercise.

The Researcher (Frances Butler) is currently undertaking a part-time Doctor of Philosophy (PhD) degree at Northumbria University exploring the factors influencing adherence to maintenance exercise programmes for people with COPD.

The aims and objectives of the study are:

- To identify factors influencing uptake and adherence to pulmonary rehabilitation and maintenance exercise programmes from a patient, service user and healthcare professional perspective.
- To evaluate the findings to gain a deeper understanding of reasons for poor uptake and adherence to pulmonary rehabilitation and maintenance exercise programmes.
- To establish the feasibility of using a relevant intervention among service users targeted at improving adherence to maintenance exercise.

Why have I been chosen?

Focus group discussions will be targeted at three groups of people. Firstly, patients who have recently taken part in the Pulmonary Rehabilitation programme through York Hospital. Secondly, health care professionals who work in pulmonary rehabilitation and / or refer patients to pulmonary rehabilitation. Thirdly, members of the local Breathe Easy support group who attend the Breathe Easy exercise class.

Do I have to take part?

Participation is, of course, entirely optional. If you agree to take part in this study you will be given this information sheet to keep and asked to sign a consent form. However, you are free to withdraw from the study at any time without giving a reason.

What will happen to me if I decide to take part?

You will be contacted by the Researcher (Frances Butler) and invited to discuss your experiences in a small peer group setting. The focus group will last approximately 2 hours. With your permission, your views will be tape-recorded and the recordings stored in a secure location.

Expenses and payments

Transport costs to and from the focus group can be reimbursed if required.

What do I have to do?

If you are interested in taking part in the study, please complete the reply slip at the end of this information sheet and return it to:

Frances Butler
Advanced Clinical Specialist Physiotherapist
York Teaching Hospital NHS Foundation Trust
Wigginton Road
York
YO31 8HE

What are the benefits of taking part?

It is anticipated that the findings of the focus groups will be utilized to define strategies to promote adherence to maintenance exercise programmes for people with COPD. Your opinions and experiences of prescribing or participating such programmes will help to shape local service delivery and improve physiotherapy interventions provided for people with COPD.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed by the research team and dealt with as appropriate. Please refer to complaints section below for more information.

Will my taking part in this study be kept confidential?

Yes. All the information about your participation in this study will be kept confidential. All personal identifiable details will be removed from any written information once the data has been transcribed. Personal identifiable details will be kept in a locked filing cabinet in a coded locked room at York Hospital physiotherapy department for the duration of the study period which should be approximately 6 months and will then be destroyed confidentially. Audio recordings will only be listened to by the researcher who will transcribe the audio recording. Participant names will not be used in this transcription; participants will be allocated pseudo names or codes.

Complaints:

If you have any concerns about any aspect of this study, you should ask to speak to the Research Team who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

Frances Butler
Advanced Clinical Specialist Physiotherapist
York Teaching Hospitals NHS Foundation Trust
Wigginton Road
York
YO31 8HE
(01904) 725528

Prof Pamela Dawson
Associate Dean
Strategic Workforce Planning and Development
Coach Lane Campus West
Northumbria University
Newcastle upon Tyne
NE7 7AX
0191 2156050

Dr Lisa Robinson
Physiotherapy Clinical Specialist and Honorary Senior Lecturer
Postgraduate Taught Office, Faculty of Medical Sciences
Third Floor, Ridley Building 1
Newcastle University
Queen Victoria Road
Newcastle upon Tyne
NE1 7RU
0191 2085199

Harm:

In the event that something does go wrong and you are harmed during the research study, there are no special compensation arrangements. If you are harmed and this is due to someone else's negligence then you may have grounds for compensation against the York Teaching Hospitals NHS Foundation Trust but you may have to pay your legal costs. The normal NHS complaints mechanisms will still be available to you (see above).

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Any information that leaves the hospital will have your name and address removed so that you cannot be recognized from it. For healthcare professionals only, with your consent, your manager will be informed of your participation in this research project. This is to ensure they agree to your time spent on the focus group discussion. All personal information and any transcribed data will not be available to them.

What will happen to the results of the research study?

The findings may be presented at the Northumbria University and York Hospitals NHS Foundation Trust. Abstracts and papers may be submitted to peer-reviewed journals for publication throughout the course of the research study. You will not be identified in any report or publication.

Who is organizing and funding the research?

The research has been organized by Northumbria University and York Hospitals NHS Foundation Trust. The Principal Investigator (Frances Butler) will not receive any payment for including you in this study.

Who has reviewed this study?

This study was given a favourable ethical opinion for conduct in the NHS by NRES Committee South West – Central Bristol reference number: 15/SW/0240, approval given on 10th September 2015.

Thank you for your interest in this study

If you have read the information above and would like to be involved in the study please return the attached slip in the envelope provided.

Expression of interest form

I would like to take part in the research study and am happy to be contacted by:

Telephone

Email

(Please indicate preference)

Name:

.....

Telephone number:

.....

Email Address:

.....

Best time to call:

.....

Participant Group:

Ex-pulmonary Rehabilitation Patient / Breathe Easy Member / Healthcare Professional

(Please delete as appropriate)

Appendix III: Focus Group Consent Form

Self-management and adherence to maintenance exercise programmes for patients with Chronic Obstructive Pulmonary Disease (COPD)

Mrs Frances Butler, Dr Lisa Robinson, Prof Pam Dawson

Consent Form

Please initial box

I confirm that I have read and understand the information sheet dated 7 th September 2015 (version 4.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation is entirely voluntary and that I am free to withdraw at any time, without giving reasons and without my medical care or legal rights being affected.	
I understand that the Research Team will hold all information and data collected securely and in confidence and that all efforts will be made to ensure that I cannot be identified as a participant in the study (except as might be required by law). I give my permission for the Research Team to hold relevant personal data.	
I agree to the focus groups being audio taped.	
I agree to the use of anonymised quotes from the focus groups being used in reports or publications resulting from this study.	
If I withdraw from this study for any reason, I give my permission for the Research Team to utilise information already collected.	

I agree to take part in the above-named study.	
--	--

Name of Participant Date Signature

Name of person taking consent Date Signature
(If different from researcher)

Researcher Date Signature

Appendix IV: Focus Group Topic Guide

Ex-PR patients and Breathe Easy Support Group	Healthcare Professionals
1. Can you tell me about your experiences of participating in exercise?	1. What are your experiences of referring patients for or working with patients in pulmonary rehabilitation?
2. Do you think it is important to exercise?	2. What do you class as exercise?
3. What do you class as exercise?	3. What do you think makes it difficult for a patient to maintain and adhere to exercise?
4. What makes it difficult for you to participate in exercise?	4. What factors do you think make it easy for a patient to maintain and adhere to exercise?
5. What makes it easy for you to participate in exercise?	5. Have you ever used strategies or considered using strategies to promote motivation and adherence to exercise programmes?
6. What do you think affects motivation and adherence with exercise?	6. How do you think patients should continue their exercises once they have finished pulmonary rehabilitation?
7. Have you found any ways to improve your motivation and adherence to exercise?	7. Do you offer any support to patients who have been through the pulmonary rehabilitation programme?
8. What support do you think you need in order to maintain commitment to exercise?	

Appendix V: Confirmation of permission to contact Association of Chartered Physiotherapists in Respiratory Care (ACPRC) members

Hi Fran,

More than happy for you circulate via our newsletter - please take this email as approval.

BW

Ian Culligan
ACPRC VICE CHAIR (2018 chair-elect)

Appendix VI: Integrated Research Application System (IRAS) Ethical Approval Permission letter

Study title: Self-management and adherence to maintenance
exercise programmes in patients with Chronic
Obstructive Pulmonary Disease (COPD).
REC reference: 15/SW/0240
IRAS project ID: 167849

Thank you for your letter of 8th September 2015, responding to the
Proportionate Review Sub-Committee's request for changes to the
documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA
website, together with your contact details. Publication will be no earlier than three
months from the date of this favourable opinion letter. The expectation is that this
information will be published for all studies that receive an ethical opinion but should
you wish to provide a substitute contact point, wish to make a request to defer, or
require further information, please contact the REC Manager Naaz Nathoo,
nrescommittee.southwest-bristol@nhs.net. Under very limited circumstances (e.g. for
student research which has received an unfavourable opinion), it may be possible to
grant an exemption to the publication of the study.

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.

Appendix VII: NHS Ethics Permission

York Teaching Hospital

NHS Foundation Trust

Research & Development
Learning and Research Centre
York Hospital
Wigginton Road
York
YO31 8HE
Direct line: (01904) 726996

R&D Unit reference: YOR-

A02482 15th October 2015

Mrs Frances Butler
Advanced Clinical Specialist Physiotherapist - Pulmonary
Rehabilitation York Hospital

Dear Mrs Butler

NHS Management Permission to undertake a research study

Trust/Site: York Hospital

Study Title: Adherence in Pulmonary Rehabilitation

Thank you for submitting details of this trial for NHS Management Permission from the above-named Trust,

On behalf of the Trust I confirm that Management Permission to conduct the study at this site is granted. The Sponsor should accept this as confirmation that all necessary governance checks have been made. Please note that this NHS Permission is based on the documents included on the following list and any subsequent amendments must be notified to the R&D Unit.

Protocol	Version 4.0
Consent Form(s)	Version 3.0
Participant Information Sheet(s)	Version 4.0

Please notify the R&D Unit when you recruit your first participant to the study. The Trust is required to record this information as soon as it is available.

I hope the study goes well and please remember that the R&D Unit are here to assist you if

we can

Yours sincerely

Damon
Foster
Head
of
R&D

cc: Mags Szewczyk; Jon Thompson

R&Dff04 -
Version 6.0

Appendix VIII: Northumbria University Ethical Approval Letter

From: EthicsOnline@Northumbria <EthicsOnline@Northumbria>

Sent: 03 April 2018 15:43

To: frances.butler <frances.butler@northumbria.ac.uk>

Subject: Research Ethics: Your submission has been approved

Dear frances.butler,

Submission Ref: 4432

Following independent peer review of the above proposal*, I am pleased to inform you that **APPROVAL** has been granted on the basis of this proposal and subject to continued compliance with the University policies on ethics, informed consent, and any other policies applicable to your individual research. You should also have current Disclosure & Barring Service (DBS) clearance if your research involves working with children and/or vulnerable adults.

* note: Staff Low Risk applications are auto-approved without independent peer review.

The University's Policies and Procedures are [here](#)

All researchers must also notify this office of the following:

- Any significant changes to the study design, by submitting an 'Ethics Amendment Form'
- Any incidents which have an adverse effect on participants, researchers or study outcomes, by submitting an 'Ethical incident Form'
- Any suspension or abandonment of the study.

Please check your approved proposal for any Approval Conditions upon which approval has been made.

Use this link to view the submission: [View Submission](#)

Research Ethics Home: [Research Ethics Home](#)

Please do not reply to this email. This is an unmonitored mailbox. If you are a student, queries should be discussed with your Module Tutor/Supervisor. If you are a member of staff please consult your Department Ethics Lead.

Appendix IX: Survey Participant Information Sheet

How do Physiotherapists' behaviours influence patient's behaviours and ability to self-manage and adhere to maintenance exercise programmes in patients with Chronic Obstructive Pulmonary Disease (COPD)?

Mrs Frances Butler, Dr Katherine Baker, Dr Lisa Robinson, Prof Pam Dawson

Participant Information Sheet

You are being invited to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

Ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

Chronic Obstructive Pulmonary Disease (COPD) is a debilitating respiratory condition. Patients with COPD account for the most common reason for emergency admissions to hospital.

Pulmonary rehabilitation is an exercise and education program which is designed to maximize the exercise ability and quality of life in individuals with COPD. Although pulmonary rehabilitation has shown positive improvements in exercise ability and reduced hospital admissions; the benefits obtained in exercise performance, quality of life, and symptoms tend to diminish over time. Previous research has shown that there are several reasons why patients have poor adherence to exercise

The Researcher (Frances Butler) is currently undertaking a part-time Doctor of

Philosophy (PhD) degree at Northumbria University exploring the factors influencing adherence to maintenance exercise programmes for people with COPD.

The aims and objectives of the study are:

- To find out if respiratory physiotherapists use behaviour change models / techniques in their delivery of self-management strategies / education within Pulmonary Rehabilitation sessions.
- To determine what outcome measures are used to evaluate whether behaviour change models are effective.
- To determine if standardised approaches are used and whether they are validated tools / outcome measures.
- To find out if national policy / drivers influence the delivery of self-management education

Why have I been chosen?

An electronic link will be sent out to all Association of Chartered Physiotherapists in Respiratory Care (ACPRC) via email. This will focus on determining how Healthcare Professionals; specifically Respiratory Specialist Physiotherapists, recognise and use behaviour change methods or models within their daily practice with patients with long term respiratory conditions.

Do I have to take part?

Participation is, of course, entirely optional. If you agree to take part in this study you will be given this information sheet to keep and will be asked to give your consent at the beginning of the survey.

However, you are free to withdraw from the study at any time without giving a reason.

What will happen to me if I decide to take part?

You are invited to complete the online survey via the link within the email.

Expenses and payments

There should be no expenses accrued.

What do I have to do?

If you are interested in taking part in the study, please click on the link within the email and complete the consent form at the beginning of the survey and then complete the survey.

If you would like to contact the researcher please use the following contact details:

Frances Butler
Advanced Clinical Specialist Physiotherapist
York Teaching Hospital NHS Foundation Trust
Wigginton Road
York
YO31 8HE

What are the benefits of taking part?

It is anticipated that the findings of the survey will be utilized to define strategies to promote adherence to maintenance exercise programmes for people with COPD. Your opinions and experiences of how behaviour influences an individual's ability to

self-manage will help to shape local service delivery and improve physiotherapy interventions provided for people with COPD.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed by the research team and dealt with as appropriate. Please refer to complaints section below for more information.

Will my taking part in this study be kept confidential?

Yes. All the information about your participation in this study will be kept confidential; completing the survey will be anonymous. Any personal identifiable details will be removed from any written information once the data has been analysed. Personal identifiable details will be kept in a locked filing cabinet in a coded locked room at York Hospital physiotherapy department for the duration of the study period which should be approximately 6 months and will then be destroyed confidentially.

Complaints:

If you have any concerns about any aspect of this study, you should ask to speak to the Research Team who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

Frances Butler
Advanced Clinical Specialist Physiotherapist
York Teaching Hospitals NHS Foundation Trust
Wigginton Road
York
YO31 8HE

(01904) 725528

Dr Katherine Baker
Senior Lecturer in Physiotherapy
Department of Sport, Exercise & Rehabilitation
Faculty of Health & Life Sciences
Northumbria University
0191 2156723

Dr Lisa Robinson
Consultant Allied Health Professional - Major Trauma Rehabilitation
The Newcastle upon Tyne Hospitals NHS Foundation Trust
Rehabilitation Department
Royal Victoria Infirmary
Queen Victoria Road
Newcastle upon Tyne
NE1 4LP
0191 2824266

Harm:

In the event that something does go wrong and you are harmed during the research study, there are no special compensation arrangements. If you are harmed and this is due to someone else's negligence then you may have grounds for compensation against the York Teaching Hospitals NHS Foundation Trust but you may have to pay your legal costs. The normal NHS complaints mechanisms will still be available to you (see above).

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential.

What will happen to the results of the research study?

The findings may be presented at the Northumbria University and York Hospitals NHS Foundation Trust. Abstracts and papers may be submitted to peer-reviewed journals for publication throughout the course of the research study. You will not be identified in any report or publication.

Who is organizing and funding the research?

The research has been organized by Northumbria University and York Hospitals NHS Foundation Trust. The Principal Investigator (Frances Butler) will not receive any payment for including you in this study.

Who has reviewed this study?

This study was given a favourable ethical opinion by Northumbria research ethics committee on 3rd April 2018.

Thank you for your interest in this study

If you have read the information above and would like to be involved in the study please follow the links to the survey.

Appendix X: Survey Consent Form

How do Physiotherapists' behaviours influence patient's behaviours and ability to self-manage and adhere to maintenance exercise programmes in patients with Chronic Obstructive Pulmonary Disease (COPD)?

Mrs Frances Butler, Dr Katherine Baker, Dr Lisa Robinson, Prof Pam Dawson

Consent Form

Please initial box

I confirm that I have read and understand the information sheet dated 21 st February 2018 version 1 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation is entirely voluntary and that I am free to withdraw at any time, without giving reasons and without my medical care or legal rights being affected.	
I understand that the Research Team will hold all information and data collected securely and in confidence and that all efforts will be made to ensure that I cannot be identified as a participant in the study (except as might be required by law). I give my permission for the Research Team to hold relevant personal data.	
If I withdraw from this study for any reason, I give my permission for the Research Team to utilise information already collected.	
I agree to take part in the above named study.	

Name of Participant

Date

Signature

Name of person taking consent Date Signature
(If different from researcher)

Researcher Date Signature

Appendix XI: Survey Questions

Survey:

- I confirm that I have read and understand the information sheet dated 21st February 2018 version 1 for the above study. – tick box
- I understand that my participation is entirely voluntary and that I am free to withdraw at any time, without giving reasons and without my medical care or legal rights being affected. – tick box
- I agree to take part in the above named study. – tick box

Demographics:

- Age – age ranges will be included for participant to select
- Gender – male/female/transgender – participant to select
- Year's since qualifying in their Physiotherapy degree – year ranges will be included for participant to select
- Clinical or Research role or both – drop down box with options
- Types of patients they work with – drop down box with common options and other – please state option
- Age of patients they work with – drop down box for options of adults or paediatrics
- Work base location – drop down options of acute or community
- Do they work alongside other healthcare professionals – Yes, drop down box with list of options and other – please state, or No.

Questions:

- Do you educate patients / clients on self-management within the context of Pulmonary Rehabilitation? – Yes/No
- Do you see patients in an individual or group setting? – Drop down options for group or individual

- What do you think self-management means? – free text
- Do you use any strategies for behaviour change? – drop down options; CBT, self-efficacy, goal setting, health coaching, follow-up contacts, other – please state
- What do you think the enablers and barriers are to successful self-management from a patient's perspective? – motivation, exacerbations, support mechanisms, psychological impact, knowledge, transport, other – please state
- What do you think the enablers and barriers are to successful self-management from a service perspective? – motivation, exacerbations, support mechanisms, psychological impact, knowledge, transport, other – please state
- In your experience / opinion, please state no more than 3 key behaviours of the successful self-managing patient – free text

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