# Improving referral from primary care to Pulmonary Rehabilitation for patients with COPD

By

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## Abstract

### Introduction

Pulmonary Rehabilitation (PR) is an essential non-pharmacological intervention for patients with chronic obstructive pulmonary disease (COPD), yet rates of referral across the UK are persistently low. There is little research on the perspectives of health care referrers which could highlight avenues for interventions that could improve referral rates.

### Methods

Drawing on the principles of implementation science and including psychological theory offered by the Theoretical Domains Framework (TDF) and the Capability Opportunity Motivation and Behaviour model (COM-B), a multiphase mixed methods approach has been used. This commenced with a systematic review to identify previously tested PR referral uptake and adherence enhancing interventions. Then an inductive qualitative research study was carried out, followed by a second deductive approach where the TDF was applied to the original qualitative findings. This supported the generation of belief statements which informed a survey for distribution amongst a wider primary health care professional population. This sought to test the generalisability of the qualitative findings and used a sequential exploratory mixed methods approach. The findings from all individual approaches were then integrated to highlight key practice based referral barriers and enablers and inform intervention development, which utilised COM-B and its associative Behaviour Change Wheel (BCW).

### Results

The systematic review showed there is a paucity of controlled studies that have evaluated referral, uptake and adherence interventions. Patient held COPD scorecards and training respiratory healthcare professionals in motivational interviewing alongside personalised care planning may be effective referral enhancing strategies.

The combined Primary Health Care Practitioners (PHCP) qualitative and quantitative investigations showed referral to PR is complex. There are multiple barriers and very few enablers, which relate to three populations: patients, PHCPs and PR providers, individually and collectively. Key findings highlight that PR knowledge and awareness is important, but intrinsic and extrinsic factors pertinent to patients, systems and providers affect subsequent referral behaviours, both positively and negatively. However, PHCPs with respiratory qualifications report having greater confidence in answering patient's questions and to refer more frequently than those without.

Intervention design using COM-B and the BCW is time consuming and challenging. However, its use highlighted PHCPs 'unconscious beliefs (termed 'automatic motivation') around a

number of perceived patient factors affected referral behaviours. Nevertheless, PHCPs consider PR beneficial for patients with COPD and describe wanting to refer more patients.

**Conclusion**

PHCPs decisions to refer patients with COPD to PR are influenced by many factors before and during the physical PR referral process. Interventions need to consider how to enhance collaborative working across patients, PHCPs and PR providers in order to increase PR awareness, uptake and completion. It must also consider intervention fidelity. Adopting targeted strategies to increase PR awareness that address patients and PHCPs motivations and enhancing PR provider engagement are likely to help. Testing these interventions within a cluster RCT are recommended next steps.

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## Contribution Statement

All the chapters in this thesis are the product of my own work. My supervisors have contributed to the design, format, data analysis, interpretation of findings and reviewed and commented on draft protocols, publications and on the thesis.

Professor Kate Jolly contributed to design of the protocol informing the systematic review in chapter 2. Both Professor Kate Jolly and Ms Lucy Gardiner supported search processes, data extraction and interpretation of data outcomes, as well as commenting on draft works of chapter 2. Elizabeth Stold, Cochrane Library assisted with the search strategy and search process used in chapter 2.

Professor Ivo Vlaev, University of Warwick assisted with the topic guide that informed the interviews for chapter 3 and contributed to the TDF data analysis alignment where clarification was sought both in chapter 3 and chapter 4.

## Thesis Format

Chapter 1 of this thesis is an overview and introduction of COPD and pulmonary rehabilitation. It considers patients and HCP perspectives on current challenges and sets out the thesis investigative plans.

Chapter 2 of this thesis is the systematic review pending publication: Watson, JS. Jolly, K. Jordan, RE. Gardiner, L. Adab, P & Greenfield, S. Interventions to promote referral, uptake and adherence to pulmonary rehabilitation for people with chronic obstructive pulmonary disease (COPD). Cochrane Library. The protocol is available online at: https://www.cochrane.org/CD012813/AIRWAYS_interventions-promote-referral-uptake-and-adherence-pulmonary-rehabilitation-people-chronic

Chapter 3 of this thesis is the published qualitative study: Watson, JS. Adab, P. Jordan, RE. Enocson, A & Greenfield, S. Referral of patients with chronic obstructive pulmonary disease to pulmonary rehabilitation: a qualitative study of barriers and enablers for primary healthcare practitioners. British Journal of General Practice Online First. 2020. Available online at: DOI: https://doi.org/10.3399/bjgp20X708101

Chapter 4 of this thesis is the paper pending publication in BML Open. Watson, JS. Jordan, RE. Adab, P. Vlaev, I. Enocson, A & Greenfield, S. Investigating primary health care practitioners' barriers and enablers to referral of patients with COPD to Pulmonary Rehabilitation: a sequential mixed methods study using the Theoretical Domains

Framework. Available as a pre-print online at: https://www.researchsquare.com/article/rs-87076/v1

Chapter 5 of this thesis is a presentation of PHCPs views on PR referral enhancing interventions. This data was collected in the original survey (presented here in chapter 4), but was not published in the mixed methods paper.

Chapter 6 of this thesis is intervention design and development. This brings together the findings of chapters 2, 3, 4 and 5 and also follows the Behaviour Change Wheel (BCW) model along with a logic model for intervention development.

Chapter 7 of this thesis is a summary of the key findings, alignment to research, policy and practice also considers thesis strengths and limitations and offers recommendations for further research.

## Contents

## List of Abbreviations

| Abbreviation | Descriptor |
|---|---|
| COPD | Chronic Obstructive Pulmonary Disease |
| PR | Pulmonary Rehabilitation |
| HCP | Health Care Professional |
| PHCP | Primary Health Care Professional |
| UK | United Kingdom |
| NHS | National Health Service |
| ANP | Advanced Nurse Practitioner |
| GP | General Practitioner |
| PN | Practice Nurse |
| MDT | Multidisciplinary Team |
| CPD | Continuing Professional Development |
| CCG | Clinical Commissioning Group |
| QoF | Quality outcomes Framework |
| MRC | Medical Research Council dyspnoea scale |
| mMRC | modified Medical Research Council dyspnoea scale |
| CRQ | Chronic Respiratory Questionnaire |
| SGRQ | St Georges Respiratory Questionnaire |
| AECOPD | Acute Exacerbation of COPD |
| BCW | Behaviour Change Wheel |
| TDF | Theoretical Domain Framework |
| COM-B | Capability, Opportunity, Motivation - Behaviour |
| BCT | Behaviour Change Technique |
| RR | Risk Ratio |
| OR | Odds Ratio |
| CI | Confidence Interval |
| FEV1 | Forced Expiratory Volume in 1 second |
| FVC | Force Vital Capacity |
| RoB | Risk of Bias |
| RCT | Randomised Control Trial |
| CCT | Clinical Control Trial |
| STP | Sustainability and Transformation Partnership |
| BTS | British Thoracic Society |
| BCCT1 | Behaviour Change Taxonomy version 1 |

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## Publications

Watson, JS. Adab, P. Jordan, RE. Enocson, A & Greenfield, S. Referral of patients with chronic obstructive pulmonary disease to pulmonary rehabilitation: a qualitative study of barriers and enablers for primary healthcare practitioners. 2020. British Journal of General Practice Online First. 2020. Available online at: DOI: https://doi.org/10.3399/bjgp20X708101

Watson, JS. Jolly, K. Jordan, RE. Gardiner, L. Adab, P & Greenfield, S. Interventions to promote referral, uptake and adherence to pulmonary rehabilitation for people with chronic obstructive pulmonary disease (COPD). Cochrane Library. 2017 The systematic review protocol is published and available online at: https://www.cochrane.org/CD012813/AIRWAYS_interventions-promote-referral-uptake-and-adherence-pulmonary-rehabilitation-people-chronic

Levack, WM. Watson, JS. Hay-Smith, J. Davies, C. Ingham, T. Jones, B. Cargo, M. Houghton, C & McCarthy, B. Factors influencing referral to and uptake and attendance of pulmonary rehabilitation for chronic obstructive pulmonary disease: a qualitative evidence synthesis of the experiences of service users, their families, and healthcare providers. 2018 Cochrane Library. The systematic review protocol is published and available online at: https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD013195/full

## Pending Publication

Watson, JS. Jordan, RE. Adab, P. Vlaev, I. Enocson, A & Greenfield, S. Investigating primary health care practitioners' barriers and enablers to referral of patients with COPD to Pulmonary Rehabilitation: a sequential mixed methods study using the Theoretical Domains Framework. 2021. BMJ Open. Pre-print online at https://www.researchsquare.com/article/rs-87076/v1

## Oral Presentations

Watson, JS. Jordan, RE. Adab, P. Greenfield, S. Enocson, A & Vlaev, I. Referral to Pulmonary Rehabilitation for COPD patients by primary health care staff - a qualitative study using the Theoretical Domains Framework to develop theory-informed behaviour change interventions. Primary Care Respiratory Society Conference, Telford. Sept 2019

Young, JS. Jordan, RE. Adab, P. Greenfield, S & Enocson, A. Barriers & enablers for primary health care practitioners when referring patients with Chronic Obstructive Pulmonary Disease to Pulmonary Rehabilitation. International Primary Care Respiratory Group, Porto. May 2018

## Poster Presentations

Watson, JS. Jordan, RE. Adab, P. Greenfield, S, Enocson, A & Vlaev, I. What motivates primary healthcare practitioners to refer patients with Chronic Obstructive Pulmonary Disease (COPD) to Pulmonary Rehabilitation? A survey using the Theoretical Domains Framework. European Respiratory Society Conference, Virtual Sept 2020.

Watson, JS. Jordan, RE. Adab, P. Greenfield, S. Enocson, A & Vlaev, I. Referral to Pulmonary Rehabilitation for COPD patients by primary health care staff - a qualitative study using the Theoretical Domains Framework to develop theory-informed behaviour change interventions. Primary Care Respiratory Society Conference, Telford. Sept 2019

Watson, JS. Jordan, RE. Adab, P. Greenfield, S & Enocson, A. Understanding referral to Pulmonary Rehabilitation for COPD patients by Primary Health Care Staff – a qualitative study using the Theoretical Domains Framework. European Respiratory Society International Conference, Paris. Sept 2018

Young, JS. Jordan, RE. Adab, P. Greenfield, S & Enocson, A. Barriers and enablers for primary health care practitioners when referring patients with Chronic Obstructive Pulmonary Disease to Pulmonary Rehabilitation: a qualitative study. Primary Care Respiratory Society Conference, Telford. Sept 2017. Awarded Best Original Poster.

# Chapter 1: INTRODUCTION

## 1.1 **Summary**

Chronic Obstructive Pulmonary Disease (COPD) is a common disease that has considerable impacts on global economies and health service provision (1). For patients, COPD has significantly debilitating health and life impacts, associated with which are frequent feeling of guilt based on smoking behaviours, which often results in patients with COPD being stigmatised (2).

This thesis aims to identify the barriers and enablers to referral of patients with COPD to Pulmonary Rehabilitation (PR) from the Health Care Practitioners (HCPs) perspective and to identify intervention(s) that will increase referral rates. This chapter will introduce and describe COPD and its impact on patients, society and health services. It will discuss current treatment approaches, consider what is effective, what is not and then focus upon PR. It will examine the literature on the effectiveness of PR, moving onto reviewing current PR referral factors including patient and HCPs perspectives on PR. This will then identify the PR referral gap) and set the scene for the research projects I have conducted to address this gap.

## 1.2 **Description and pathophysiology of COPD**

COPD is a debilitating disease (3) defined by the Global Obstructive Lung Disease (GOLD) as

*'a common, preventable and treatable disease that is 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 and influenced by host factors including abnormal lung development.'* (3) (pg. 4)

Chronic pulmonary inflammation is a key pathological feature of COPD affecting predominately the small distal airways (also termed bronchioles) (4). This pulmonary inflammation causes recurrent inflammation of cells and tissues which leads to the production of excess mucus. Furthermore, repeated pulmonary inflammation causes innate repair processes which lead to major airway remodelling and narrowing which collectively obstruct the airways (5). Additionally, innate repair processes reduce usual lung recoil and increase airflow resistance, which leads to pulmonary air trapping, decreased gas transfer and hyperinflation of the lungs (6). Pulmonary inflammation extends outside the small airways and causes destruction of the lung parenchyma and alteration and thickening of arteries adjacent to the bronchioles, thus impacting also upon the vascular and cardiac system (4). COPD and associative widespread systemic inflammatory effects are increasingly recognised, highlighting extensive pathological derangements and physiological effects outside of the pulmonary system (5, 7).

Exacerbations are events that are caused by complex interactions driven by viral and/or bacterial respiratory infections and air pollution (8, 9) , which increase both pulmonary and systemic inflammation (10). An exacerbation of COPD is defined clinically as

"*episodes of increasing respiratory symptoms, particularly dyspnoea, cough and sputum production, and increased sputum purulence*." (11) (pg. 2)

Exacerbations accelerate underlying disease decline, increase airflow limitation, thus worsening symptoms and outcomes for patients (10, 12). Moreover, exacerbation frequency increases with worsening disease (12).

## 1.3 **Impact of COPD and prevalence**

COPD is one of the most common chronic respiratory diseases whose global prevalence is increasing largely as a result of ageing populations (1). It is a particularly debilitating disease that has high symptom burden which worsens over time. COPD consequently presents major public health challenges, accounting for 3.19 million global deaths annually (1). The global burden of disease studies reported steady increases in COPD mortality (1, 13). This was a trend that was anticipated to continue (14), but the most recent global burden of disease study report a reduction in overall annual COPD mortality rates by 2.36% (2.21%-2.50%) (1, 15). Yet in terms of world-wide disability, in 2019 COPD remained in the top fourth and third respective leading cause of disability adjusted life years in age groups 50–74 years and 75 years and older, demonstrating worsening health and high levels of disease burden (16).

In 2012 COPD was the 5$^{th}$ leading cause of death in the United Kingdom (UK) (17), nearly 30,000 people died from COPD which accounted for 5.3% of the total number of all deaths (18). Moreover COPD deaths in England and Wales rose in 2015 to 30,858 (19).

COPD prevalence in England according to Quality outcome Framework (QoF) 2019/2020 data is reported to be 1.94% (20), representing a 0.15% eight year rise where in 2011 it was 1.79% (21). Whilst more than 1 million people in the United Kingdom (UK) are currently diagnosed with COPD (18) it is estimated that prevalence is substantially higher given the large number of undiagnosed individuals living with COPD both in the UK and indeed worldwide (22). Whilst approximately 90% of all clinical contacts occur in primary care (23),

all cause health care interactions across England are high and increasing. Emergency hospital admissions have increased by 28% in a ten year period since 2008 to nearly 6.5 million (24). All cause primary care consultations have also increased by 10.51% in a seven year period, from 2007/8 to 2013/4 (25). Additionally, hospital admissions are 33.6% higher in those patients most deprived in comparison to those least deprived (11), similarly deprivation increases primary care consultations (26).

COPD related health care interactions are increasing across all health systems; annual general practice COPD consultations have risen from a mean of 6.6 per patient in 2002 to 12.7 in 2010 (27) and COPD emergency hospital admissions from 299,365 in 2008/09 (28) to 383,912 in 2018/9 (29). Furthermore frequent hospital readmissions for COPD places additional demands on health services. NHS digital report readmission rates for COPD to be 25.2% within 29 days in 2019 (30) and the RCP report 90 day readmissions rates of 43.2% within 90 days in 2018 (31).

Yet COPD is classed as an ambulatory care sensitive condition for which hospital admissions are considered largely avoidable and can be achieved by effective out of hospital disease management (32). However more recent publications offered by Harries et al and Paul et al contest this (33, 34), reporting opportunities to reduce COPD readmissions numbers are very small and not necessarily avoidable.

Post-acute hospital admission COPD mortality remains consistently high at 12% within 90 days of admission in both 2015 and 2018 (31, 35) across England and Wales. A 15 year UK

observational study undertaken by Lewer et al demonstrated premature death (that being those < 75 years of age) is correlated to deprivation (36). These findings showed deprivation accounted for 1 in 3 deaths (877,082/ 2,465,285), of which 83,593 related to COPD. Furthermore premature mortality is reported to be worse amongst UK women with high levels of deprivation and COPD (36).

## 1.4 **Risk Factors**

In developed countries the inhalation of tobacco smoke is the largest risk factor for COPD. Yet within particularly urban areas of developing countries such as India, the burning of household solid or biomass fuel drives air pollution and causes COPD (37). Additional risk factors that elevate COPD propensity include; outdoor air pollution, exposure to passive smoking and other noxious gases and fumes in the workplace or elsewhere. These factors combined with genetic disposition, maternal tobacco exposure, poor childhood lung growth and childhood respiratory infections are also associated with disease development (3, 14). Increasing age and lower-socioeconomic status are also important risk contributors (36).

Increased exposure to risk factors for COPD (with the rising tobacco epidemic in low and middle income countries) and increasing population longevity contribute to the heavy forecasted societal and economic COPD burden worldwide (14).

## 1.5 **Current and future COPD management strategy**

Global population increases are well reported (14). In the UK it is predicted that amongst those 65 years and over the population will increase by 8.6 million by 2066 (38). In response to population increases and associated health and social care system burdens, policies such as the NHS long term plan (39) set out strategies to increase out of hospital care provision, integrate community and primary care expertise, restructure emergency care systems and increase patient centred care, thus empowering patients to be in greater control and self-manage their long term health conditions including COPD.

For respiratory disease specifically the long term plan sets key targets including early diagnosis, appropriate use of pharmacological agents and increasing the number of patients with COPD being referred to pulmonary rehabilitation programmes (39).

New service models to support these ambitions include integrating NHS and local authority funded services care systems demonstrating the recognised need for health and social unity for optimising personal well-being. The merger of these systems is implemented at local levels and are termed Sustainability and Transformation Partnerships (STP). Additionally primary care networks facilitate the alliance of general practice surgeries in order to increase multidisciplinary team collegian for patient benefit (40).

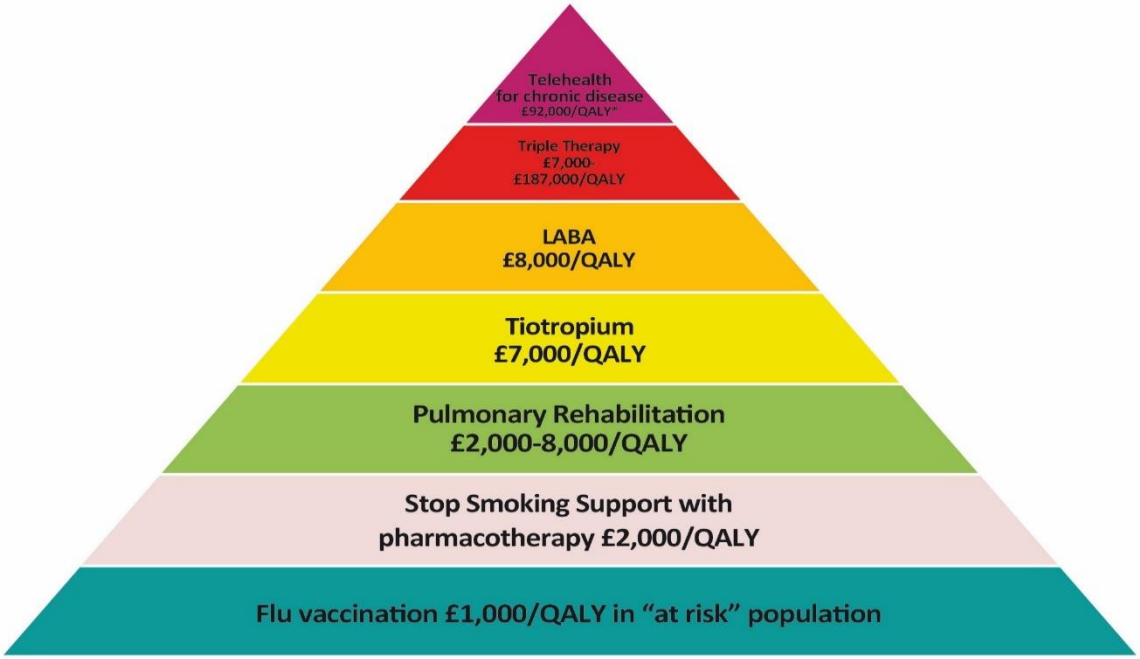
## 1.6 **COPD treatment: Pharmacological and Non-pharmacological**

COPD management when patients are in a stable state is aimed at reducing disease progression, managing symptoms and relieving overall disease burden. All patients should be offered smoking cessation advice at regular intervals, as this is the main disease modifying treatment available at present (41). Pharmacotherapy consists of short-acting and long-acting bronchodilator inhalers, with steroid inhalers added to manage advancing symptoms and prevent exacerbations (3). All patients should also receive influenza, pneumococcal and COVID-19 vaccines and advice about self-management (3, 42, 43).

Patients with breathlessness or self-reported exercise limitation (usually Medical Research Council (MRC) dyspnoea scale (44) grade 3/modified (m) MRC2 or worse dyspnoea (but can include MRC 2/mMRC 1 if patients report functional limitation) are eligible for pulmonary rehabilitation (PR) (3).

The COPD value pyramid (figure 1) demonstrates the high economic and personal value of self-management interventions, including PR as measured in quality adjusted life year's (QALY) (45). Importantly PR interventions consistently offer high value for low cost across all COPD disease severities, from mild to very severe (46).

**Figure 1 COPD Value Pyramid** (reproduced from the London respiratory network (46))




## 1.7 **Pulmonary Rehabilitation**

PR is a structured multidisciplinary programme 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'* (47) (pg. ii4).

One of the main aims of PR is to increase physical activity for those with COPD (48), however increasing and sustaining increases to physical activity requires behaviour change and self-belief. The combined education and exercise content, alongside patient and interdisciplinary collaboration is key to achieving increasing physical activity outcomes in patients with COPD, over exercise-only interventions (49).

PR programmes are most commonly delivered to groups of patients in community or hospital settings, although other models of delivery, including telerehabilitation and home-based programmes, are also available (50). More recent adaptations to PR programmes, in response to the COVID-19 pandemic have included increased use of home based telerehabilitation both individually and in group format (51, 52).

## 1.8 **Pulmonary Rehabilitation Effectiveness**

National and international COPD guidelines repeatedly recommend that that patients with COPD who are functionally limited or who have breathlessness as measured by MRC 3/mMRC 2 should be referred to PR (3, 42, 53).

A systematic review undertaken by Puhan et al analysed the effect of PR post acute COPD exacerbation on I) hospital admissions ii) mortality and iii) quality of life (54). Pooled results highlighted PR significantly improved outcomes in all three measured domains, however statistical heterogeneity was a factor as only nine small studies were included. The systematic review was updated in 2016 and aligned to the same primary outcome measures. Afurther 11 Randomised Controlled Trials (RCTs) were included (55). All acute exacerbations of COPD (AECOPD) exacerbations were diagnosed and initially managed in hospital settings after which patients commenced inpatient or outpatient (hospital, community or home) PR within 6 weeks of diagnosis.

## 1.9 **Mortality**

The SR pooled mortality outcomes post PR (up to 48 months; median 12) which was reported in 6/20 studies. PR was found to not statistically significantly reduce mortality (OR 0.68; 95% CI 0.28 - 1.67) as it had done in the earlier review (54), meaning there is evidence to suggest PR is beneficial in reducing mortality rate, although this was not proven as the estimate was not statistically significant. However a 2018 systematic review undertaken by Ryrso et al (56) (which included an additional four RCTs to that of Puhan et al's 2016 review (55)) reports a statistically significant reduction in mortality at the end of PR in 4/24 studies (RR 0.58 95% CI 0.35-0.98) and no statistical significance at the longest post PR follow up in 3/24 studies (RR 0.55 95% CI 0.12-2.57). In summary, Ryrso et al (56) not only pooled data at different end points to that of both Puhan et al's reviews (54, 55), but Ryrso et al also included a study that had no control (57). Furthermore, Ryrso et al also calculated the pooled results as risk ratio/relative risk (RR) which is the probability an outcome will occur as opposed to an odds calculation which is the ratio of probability (58). It is therefore difficult to agree that PR reduces mortality as reported by Ryrso et al (56).

A national audit undertaken in England 2015/2016 (35) reports favourable post PR mortality outcomes for respiratory patients including those with COPD. It is reported that of those who enrolled and completed PR at 90 days 4/4262 (1%) and at 180 days 21/4262 (0.5%) died in comparison to 46/2873 (1.6%) and 91/2873 (3.2%) patients who enrolled but did not complete PR. The audit also reports mortality increase alongside COPD disease progression as measured by decreases in $FEV_1$. Mortality rates were also higher in those with elevated

MRC dyspnoea scores. However, knowing mortality is higher in those with worsening disease and symptom burden reduces the confidence in the effect of PR as an independent variable and questions the number that are likely to have died irrespective of PR. This is a recognised limitation of audit data where there is no comparison of a group who did not receive the intervention. It may also be an indicator that referring patients with less severe disease to PR should be more widely considered. Consequently current data is unable to definitively conclude PR reduces mortality in patients with COPD.

## 1.10 **Hospital Admission**

The effect of PR on subsequent hospital admissions however reports more favourable outcomes. Puhan et al's meta-analysis of post PR hospital admission for AECOPD was reported in 8 out of 20 included studies (55). Pooled results conclude that PR results in a statistically significant reduction in hospital admissions (OR 0.44, 95% CI 0.21- 0.91), where follow up duration was between 3-18 months (median 9 months).

An additional but wider scoped systematic review conducted in by Moore et al in 2016 (59) included 18 studies; 10 RCTs, five before and after studies and three cohort studies. The principle aim of the review was to investigate post PR hospital attendance for AECOPD amongst those referred to PR where COPD was stable and for patients who had been admitted to hospital for an AECOPD. Reductions in emergency hospital visits were reported in the pooled 10 RCTs of those commencing PR post AECOPD in comparison to control (0.62 hospitalisations/patient year 95% CI 0.33-1.16). Additionally, significantly reduced rates of

hospital admission were found in the control groups of the before and 12 months after studies post AECOPD and in stable disease (before 1.24 hospitalisations/patient year 95% CI 0.33-1.16; after 0.47 hospitalisations/patient year 95% CI 0.28-0.79). However the 3/18 cohort studies pooled results found the opposite effect, albeit marginal. There were less hospital admissions in the reference group as opposed to the PR group, (reference – 0.18 hospitalisations/patient year 95% CI 0.11-0.32; PR – 0.28 hospitalisations/patient year 95% CI 0.25-0.32). Including both patients during acute and stable disease state is a study strength, sensitivity analysis of the seven stable disease studies highlighted that intervention groups had less hospital admissions than those who did not receive PR, but particularly in the before and after studies. In conclusion primary research demonstrates PR reduces hospital admissions in both the stable COPD disease (59) and hospital post AECOPD state (55, 59).

The previously presented PR national audit (35) also measured the rates of post PR hospitalisation. Within the audit it is reported that 1024/4262 (24%) patients had enrolled and completed PR and had one or more post PR hospital admission at 180 days. The audit states '76% of people who complete PR in England avoided hospital admission 6 months after their initial assessment' (35) (pg. 10). Whilst this appears to be a positive outcome, the previously highlighted methodological audit weaknesses remain and the headline statement needs to be treated with some caution.

Published effectiveness of PR on other outcomes, such as post PR clinical interactions across other healthcare settings is limited. This is particularly interesting given the growth of COPD

health care contacts made across primary care settings. One cohort study (60) reviewed the general practice records of 69,089 patients one year pre and one year post PR attendance, it was reported that people who were referred to PR did not have less primary care or hospital diagnosed AECOPD post PR, than those who were not referred. However, given this study only measured referral rates rather than PR attendance this significantly weakens the ability to report an effect on a measure that is not accurately obtained. PR's effect on post PR clinical health care interactions, rather than focusing on predominately hospital admissions would be an area worthy of further research.

## 1.11 Health Related Quality of Life and Exercise capacity

In addition to the likely positive impacts of PR on post hospital admissions Puhan et al (55) also reports statistical significant improvements post PR amongst secondary outcome measures, specifically health related quality of life (measured by HRQL) and exercise capacity (measured by six minute walk). These findings were also captured in an earlier published systematic review undertaken by McCarthy et al, which compared the effectiveness of PR in patients with stable COPD against those receiving usual care (61). The review included both in and out of hospital PR programmes and collated data from 65 RCT's. Primary outcome measures were respiratory quality of life assessment, measured by the validated patient questionnaires Chronic Respiratory Questionnaire (CRQ) (62) and the St Georges Respiratory Questionnaire (SGRQ) (63). Statistically and clinically significant improvements were found within all four chronic respiratory disease domains (dyspnoea, fatigue, emotional function and mastery) and across all three SGRQ domains (symptoms

(frequency and severity), activity and impact (social functioning and psychological disturbances) (MD -6.89, 95% CI -9.26 – 4.52) (61).

A key weakness however in this published research relates to PR programme variation, where PR programmes components differ. Heterogeneity is subsequently a factor and the inability to pool this data reduces systematic review conclusions. These weaknesses are acknowledged by researchers (55, 59). Puhan et al (55) attempted to address this variation by grading the extensiveness of PR programmes based on factors such as number of training sessions and inclusion of self-management education. Large effect sizes were reported in trials where PR programmes were considered extensive and the opposite outcome was reported for those programmes that were less extensive. PR programme heterogeneity is considered to be an influencing factor, particularly in the assessment of PR on hospital readmissions and further research is invited (55).

As such, current national moves to reduce programme variation through standardised and accredited PR services are welcomed (60). This will hopefully lead to greater homogenous PR effectiveness measures. However, given exacerbations increases with disease progression, it is questioned if the desire to reduce is exacerbations realistic. In summary there is consistently good quality evidence that supports PR is an effective intervention for patients with COPD (35, 55, 56, 59, 61). PR is particularly effective at improving HRQL and exercise capacity for all eligible patients (54-56, 61). Furthermore attending PR reduces subsequent hospital admissions for AECOPD, following hospital diagnosed AECOPD (55, 59, 64) and also

where there is stable disease (59). Conclusions however on PR positively reducing mortality, remain uncertain (35, 56).

## 1.12 **Pulmonary Rehabilitation Provision**

Pulmonary Rehabilitation is an intervention that is available worldwide including New Zealand, Australia, United States of America (USA), North America, Latin America and Europe (65-67). There is also a small provision in Africa and the Middle East (66).

Nationally across all four UK countries there is good PR availability. In England and Wales there are approximately 224 PR programmes (68), 23 in Northern Ireland (69) and widespread service provision in Scotland, (although none in the NHS Scottish Borders) (70). Across all four countries, PR programmes are run largely from community venues such as local leisure centres, including a small number from GP surgeries. PR delivery in acute hospital settings accounts for 13% of the total provision across England and Wales, with all providers offering a combination of rolling and/or cohort programmes (68).

There are however, national discrepancies between provision and population need. For example in Scotland maximal PR capacity of 8,952 equates to only 13% of the 68,951 eligible COPD population (70). Similarly in England and Wales there were approximately 446,000 eligible patients in 2013/4 (64) and an estimated PR programme maximal capacity 81,298, representing 18.2% of the eligible patient population (68). Whilst this is an increase from 2004 where PR provision was reported to be available for 1-1.5% of the UK population (71),

provision remains low in 2020 at less than 20%. Moreover, when accounting for undiagnosed and predicted COPD population increases, current PR provision is lower still.

## 1.13 **Referral process and current trends**

Pulmonary Rehabilitation is commissioned by local Clinical Commission Groups (CCG), meaning there is no cost to the service user or the referrer. Referrers are predominately healthcare practitioners based across primary, community and secondary care settings, although the greatest number of referrals (51%) are reported to derive from general practice (72). It is additionally reported that 65/224 (29%) of the providers accept patient self-referral however use of this referral option is very poor with only 41/7413 (0.6%) of patients adopting this route (72).

Whilst referral is recommended for all patients with COPD and an MRC score of 3 $\leq$, or for those who are functionally limited by COPD or breathlessness (3, 42) there are clinical contacts which offer distinct opportunities for PR referral focus and discussion. In recent years a number of acute trusts across England and Wales have implemented COPD care bundles (73). Care bundles offer a list of evidence based actions that seek to improve patient care (74). COPD discharge bundles were designed by the British Thoracic Society (BTS) and NHS Improvement in an effort to improve AECOPD inpatient and discharge care. The bundles include several core care components including the assessment of all patients for PR prior to discharge (74) (see Appendix 1).

Whilst in primary care settings opportunistic PR referral isdescribed by primary care to be best undertaken by practice nurses during chronic COPD disease management clinics (also known as annual reviews) (75, 76). However, since April 2019 in England a change in primary care contract agreements frequently referred to as QoF points saw the reward of QoF points for the offer of referral to PR for patients with COPD. It is postulated that this incentive is likely to offer a clear directive for primary care staff to discuss PR, whilst primary care providers will measure staff's PR referral actions, necessary for point reimbursement.

## 1.14 **Referral rates**

The percentage of eligible national and international patients receiving referral to PR is however very low with rates ranging from 2% in New Zealand (77) to 8.4% in Scotland (70) and 9.3 -15.2% across England and Wales (60, 64).

Nationally, PR programme capacity is however variable with total referral rates outweighing capacity in Scotland, but some providers show under demand and others over demand for available capacity (70). Yet in England and Wales, 2015 audit data showed 61,504 referrals for 81,298 spaces (68), which includes 22% of patients who had attended PR previously. Even accounting for referral increases in 2016 to 68,000 (64), these referral rates highlight capacity within the system. The data within the England and Welsh audit data is however, not detailed enough to extrapolate areas of under and/or over capacity which would have been insightful. Additionally the 22% of PR re-attendees will have diluted the percentage of eligible patients with COPD who have been referred to PR.

A further audit conducted using the national Clinical Practice Research Datalink (CPRD) database reports PR referral rates to be higher in Wales than in England, Scotland and Northern Ireland (78), but this is likely to be attributed to the QoF reward in Wales for PR referral since April 2013, which also contributed to a significant initial rise in referral rates (79).

Published data has demonstrated that referral to PR remains very low across the UK. This is an area of significant concern and as such there are multiple national and international bodies calling for referral rates to be urgently increased (3, 53, 72). In 2015, the BTS and RCP (68) called for PR to be sold better and also called on patient support and voluntary organisations to encourage patients to ask about PR referral. In 2019, NHS England and NHS Improvement set ambitious targets that seek to see referral rates increase to 60% across England and Wales by 2023 (80). It offered financial investment to programme providers and recommend a number of actions to achieve the 60% target, including increasing capacity, engagement and referral acceptance from under-represented groups and also to increase specifically referral rates from primary care.

## 1.15 **PR referral**

Following PR referral, patients are invited to an initial assessment appointment by PR providers, following successful assessment and agreement on PR goals, patients are then enrolled onto a PR program. Referral therefore does not lead directly to programme enrolment but to programme assessment meaning referral rates infrequently reflect the number of patients who enrol, start and complete PR.

Published data, including audits report that between 27 and 31.8% of patients referred from all sources do not attend initial PR assessments (64, 81, 82). Whilst an exploration of patient factors are important, it is first important to consider quality of referral and possible organisational factors that impact on initial assessment attendance. PR referral criteria as listed in table 1 and informed by national guidelines (47) shows a wide inclusion criteria, with very few exclusions.

**Table 1 PR Referral criteria** (Adapted from Bolton et al, 2013 & NICE, 2018 (47, 83)

| PR Inclusion | PR Exclusion | PR Cautions |
|---|---|---|
| Patients should be offered PR if they have COPD.<br><br>Patients with a Medical Research Council (MRC) Dyspnoea score of 3–5 who are functionally limited by breathlessness should be referred for outpatient PR.<br><br>Patients with a MRC dyspnoea score of 2 who are functionally limited by breathlessness should be referred for PR.<br><br>Patient with COPD who smoke should be referred to PR.<br><br>Patients with COPD and anxiety and/or depression should not preclude referral to PR | Patients with unstable cardiac disease or locomotor difficulties that preclude exercise (e.g., severe arthritis or severe peripheral vascular disease) should not be referred for pulmonary rehabilitation.<br><br>Patients who have had a recent myocardial infarction should not be referred to PR.<br><br>Patients with a MRC dyspnoea score of 5 who are housebound should not routinely be offered supervised pulmonary rehabilitation within their home. | A coexistent abdominal aortic aneurysm (AAA) <5.5 cm should not preclude referral to PR, and being included in moderate intensity aerobic exercise training, provided blood pressure is controlled.<br><br>Patients who have COPD and a AAA >5.5 cm, deemed not fit for surgery, pulmonary rehabilitation incorporating mild–moderate intensity aerobic exercise may be considered, but should not include resistance training.<br><br>Careful consideration should be given to patients who have significant cognitive or psychiatric impairment that would lead to an inability to follow simple commands in a group setting |

Table 2 and 3 demonstrate the MRC and mMRC dyspnoea criteria a key component to PR referral and patient eligibility assessment.

**Table 2 MRC Dyspnoea scale** (Adapted from Fletcher, 1952, (84)

| | |
|---|---|
| 1 | Not troubled by breathlessness except on strenuous exercise |
| 2 | Short of breath when hurrying on a level or when walking up a slight hill |
| 3 | Walks slower than most people on the level, stops after a mile or so, or stops after 15 minutes walking at own pace |
| 4 | Stops for breath after walking 100 yards, or after a few minutes on level ground |
| 5 | Too breathless to leave the house, or breathless when dressing/undressing |

Used with the permission of the Medical Research Council (https://mrc.ukri.org/research/facilities-and-resources-for-researchers/mrc-scales/mrc-dyspnoea-scale-mrc-breathlessness-scale/)

**Table 3 modified MRC Dyspnoea scale (mMRC)** (ATS, 1982) (85)

| | |
|---|---|
| 0 | Not troubled by breathlessness except on strenuous exercise |
| 1 | Short of breath when hurrying on a level or when walking up a slight hill |
| 2 | Walks slower than most people on the level, stops after a mile or so, or stops after 15 minutes walking at own pace |
| 3 | Stops for breath after walking 100 yards, or after a few minutes on level ground |
| 4 | Too breathless to leave the house, or breathless when dressing/undressing |

Yet the 2015 PR audit (68) which included 174 providers, reported 33/174 providers (19%) were unable to accept patients meeting MRC 5 criteria. Further providers did not accept patients with an MRC 2 (49/174;28%) or current smokers (7/174;4%) whist 32% (56/174) reported not accepting patients post hospital admission for AECOPD. Just over one third were able to organise hospital transport for eligible patients and 136/174 (78%) of providers reported free parking available at venues.

## 1.16 **Profile of referred patients**

Patient statistical analysis offers detail on the characteristics of patients referred to PR. A cohort study conducted by Moore et al (60) examined rates of hospitalised and general practice treated AECOPD prior to and following PR by using primary care database and hospital episode statistics data. Of 69,089 eligible patients 9.3% (n=6,438) were recorded as having been referred to or had completed PR. The mean age of those referred was 64.5 years, 55.5% were male and 48% current smokers. The majority were classed as having moderate COPD disease ($FEV_1$ 79-50% of predicted) and an MRC score of 2. A primary study outcome reported that patients who were referred had slightly higher exacerbations rates in the 12 months before PR 2.83 (CI 2.66-3.00) versus 2.17 (CI 2.11-2.24) of those not referred. Additionally exacerbation rates were higher post PR at 3.15 (CI 2.97-3.33) than before PR.

Similarly national audit findings between January and April 2015 found of 7,413 patients referred to PR a greater number were males (53%) and overall mean age was 69 years (64). The mean $FEV_1$ was 53% indicating moderate disease (yet this was only known in 62% of cases), and the most commonly recorded MRC score was 3. One in ten patients were receiving oxygen therapy, over three quarters had at least one co-morbidity and 21% had been admitted to hospital for an AECOPD in the 12 months previous.

A lengthier, 48 month Welsh based audit (86) sought to identify and compare the characteristic data between patients with COPD who were referred and those who were not. Logistical regression reports women were 5% less likely to be referred than males, those

with a MRC score recorded in the last 12 months were nearly four times more likely to be referred and patients who had two or more exacerbations in the last year were over three times more likely to be referred than those with none. Further clinical characteristics highlight increasing number of exacerbations and increasing pharmacological requirements, specifically inhaled triple therapy significantly increased the likelihood of PR referral.

In summary patient characteristic data identifies that males are those more likely to be referred compared to females, patient are commonly at or nearing retirement age and patients with high symptom burden, indicated by co-morbidities, exacerbation rates and high levels of pharmacological therapy.

## 1.17 **Quality of referral**

Following referral, assessment of the patients PR suitability is undertaken by providers, yet there is limited data published on this specific stage of PR assessment. Given patient assessment is the second step in the PR journey and the first following referral, it is an important step to review and may highlight important factors that could be addressed at the point of referral.

A review of 250 Welsh GP PR referrals found that 34.8% needed further assessment, 24.4% were clinically inappropriate and 22.4% did not have COPD based on spirometry readings, meaning less than 20% of those referred were able to transition directly from referral to assessment (87). A further consultant analysis of 49 tertiary centre PR referrals (undertaken

because of uncertain PR suitability), reports a lower number of inappropriate referrals (5/49; 10%), but similarly reports high additional assessment need on the remaining referrals based on co-morbidity presence, inappropriate respiratory pharmacological treatments and for 23% of referrals, inaccurate spirometry leading to diagnosis uncertainty. The largest referral group were from general practices, representing 41% of all referrals (88).

Inaccurate COPD diagnosis based on spirometry readings, particularly where diagnosis is undertaken in primary care settings is an ongoing area of concern (89, 90) and as has been shown here impacts on the patients PR journey, in deed some practices reported not having an in surgery spirometer (91).

Co-morbidities also have an impact on PR eligibility and suitability as highlighted in table 1. Coronary artery disease prevalence is high in patients with COPD and has been reported to be present in more than 50% of patients (92), given patients with unstable cardiac disease are excluded from PR, assessment of 'stable' versus 'unstable' cardiac disease is postulated to be potentially a subjective clinical assessment, which may result in unnecessary referral and assessment exclusions (93).

Assessing a patients PR suitability based on referral forms alone can therefore be clinically challenging, particularly given rising national patient clinical complexities. PR providers suggest acute illness, co-morbidities, lack of motivation and transport difficulties negatively affect patient assessment attendance (94) and that in some cases patients are not always aware a referral has been made (95).

In summary there are a variety of clinical and organisational factors that drive inappropriate referral, resulting in lower assessment invitations. However, as a publically funded intervention it is important that time and resources are managed effectively so understanding pre-referral, as well as referral in the context of the PR pathway is critical as it impacts on the subsequent PR journey. Whilst it may be difficult to extrapolate specific features that explain the significant drop between referral and assessment attendance numbers, there is much patient focused research that offers additional insight.

## 1.18 **Patients and PR acceptance**

Patient characteristic data offer female gender, current smokers and those living alone are those less likely to attend assessment (81). A larger observational study reported patients were less likely to attend if they were under 55 years or over 74 years (82). Whilst numerical analysis can offer some, albeit limited referral acceptance to assessment insight, it is qualitative studies that offer greater explanations and insights.

Commonly reported patient themes which influence consideration and acceptance of a referral to PR centre around patient disease burden perceptions and the perceived health benefit of PR (96-102). Coping with and impact of co-morbidities is also a reported PR engagement barrier by patients (101) with many reporting a need to be mentally and physically ready to participate in PR programmes (98). Collectively, for patients deciding to engage in PR is a significant undertaking and this decision is a critical barrier to attending

(103). Fundamentally, for patients with COPD convincing them that exercise within PR is an effective treatment is challenging (99, 104).

## 1.19 **Health Care Professionals, patients and PR referral**

There are a number of surveys and audits that examine HCP delivery of COPD management against national and international acute and chronic COPD clinical guidelines (105-110). Often they report only descriptive statistical measures such as number of referrals to PR and grading HCP awareness of PR, whilst also offering correlations between disease severity and co-morbidity presence on reported PR referral. One USA based survey reports both PR availability and HCP beliefs on the usefulness of PR for patients with COPD has increased over recent years. The mixed USA primary care HCP survey (n=278) sought to examine local programme availability and to measure HCPs PR attitudes and beliefs. Undertaken first in 2007, 32% of surveyed HCPs reported PR as an available intervention, yet only 3% thought it useful to patients. This study was repeated seven years later in 2014 amongst (n=426) USA primary care based HCPs. PR availability had increased to 50% and 81% of HCPs considered PR a useful COPD treatment, compared to a previous 3% (110).

A further cross-sectional survey (109), similarly reports pulmonary specialists consider improving functional exercise capacity and quality of life to be the most important goals of COPD management and more than half of the 590 pulmonary specialists considered PR to be clinically indicated for patients with moderate or greater COPD severity. However, despite these reported positive beliefs, PR referral rates remain persistently low. Study authors

Glaab et al (109) have suggested motivation of the patient and/or the HCP maybe an influencing factor.

Patient and HCP survey data indicate where HCPs communicate the value and effectiveness of PR to eligible patients, and are knowledgeable on referral processes, referral acceptance is likely to increase (111, 112). Additionally, referral suggested by healthcare professionals known to the patient is reported to have a positive effect on acceptance (81, 113).

It is reported that healthcare worker seniority statistically significantly enhances PR referral agreement and subsequent programme uptake when in comparison to a junior doctor or allied health care professional (114). This was however a small audit and contrastingly a larger observational study reported that patients referred by a General Practitioner (GP) are less likely to complete PR (82).

A frequently reported determinate of patient acceptance is the manner by which PR is introduced (104). Indeed patients consider referrer attitude received at the time of referral as more persuasive and influential than PR information on content and value (115). Patients also report some HCPs to be judgmental and critical, resulting in negative health care interactions. This approach is likely to increase patient avoidant behaviours including acceptance of PR referral (102). The referrer is therefore an important influencer who positively or negatively affect the patient's decision to accept or refuse PR referral (75, 102, 111, 113, 115).

Guo & Bruce's (98) exploratory inquiry involving COPD patients and HCP's working within PR programmes, suggest to improved PR acceptance, patients need clear explanations including understanding the advantages and disadvantages to taking part. Introducing PR gradually is also seen as advantageous, as is ensuring time is available for open conversations and for HCP's to be sensitive and compassionate, particularly around patient's perception of self-blame (102).

A recent systematic review undertaken by Cox et al (66) combined 48 published papers to identify the behavioural factors that influence referral, uptake and adherence to PR for patients with COPD and the HCPs who care for them. The behavioural factors, in this case known as behavioural constructs were informed by the Theoretical Domains Framework (TDF) (116) and were presented as barriers and enablers to PR. The TDF is a framework made up of 14 domains (Appendix 2) which seek to understand behaviours theoretically. It includes internal (psychological and physical) and external environmental factors so that behaviour change processes can be effectively targeted to enable change (116, 117).

The 48 included papers included a range of methodologies; surveys, audits and a small number of primary research studies (66), yet just 18 were HCP focused and in relation to 'PR referral' only five qualitative primary research studies were included, three of which are suspected duplicate publications (118-120). Data from the included papers was extracted and content mapped to individual units of data against the 14 domains of the TDF, where just 17% of the total units related to referral. The review concludes the TDF domains with the highest number of both barriers and facilitators to referral were 'Knowledge' relative to

both HCPs and patients, and 'Environmental', which included influence of referrer (positive and negative), ease of referral and previous experiences of successful referrals.

Yet in order to uncover detailed understandings of the factors that influence individual behaviour, asking those who perpetuate, or who would be expected to undertake the activity within their natural setting is an important starting point and one best informed by 'why', 'what' and 'how' areas of inquiry, otherwise referred to as qualitative research inquiry (121).

In this context and given the national call for COPD to be managed in out of hospital settings (39) and for referral rates to be increased from primary care settings (80), alongside international respiratory organisations plea for further research to understand the barriers and facilitators in PR patient referral (53), qualitative research that investigates the experiences of primary health care professionals in the referral of patients with COPD to PR is essential.

To date, only two UK primary care studies (75, 122) have sought to understand Primary Health Care Practitioners (PHCPs) PR referral experiences, (both of which were included in the Cox et al review (66)). These two studies suggest time-constraints, limited knowledge of PR, patient's physicality and personal culpability for COPD inhibit referral acceptance. Similar to patient reported findings, PHCP focused studies and the systematic review suggest PHCP attitudes to PR could be important reasons for low referral numbers (66, 75, 122).

However, one of these studies (75) was based on five focus groups with 21 health professionals from three general practices in a limited geographical area and was conducted over a decade ago when PR availability was limited (123). The second (122), was based on a pre-post evaluation of multiple interventions to overcome low PR referral, using semi-structured surveys with health care professionals. Whilst some potentially useful strategies were identified, the small number of participants (only 9 of 22 responded to follow up), shortcomings in the survey design and data analysis process limit interpretation of the study findings.

Whilst this chapter has highlighted pertinent data relative to PR referral barriers and enablers including patient reported experiences, patient characteristic statistical analysis and organisational factors there remains little insights into the experiences of PHCPs in relation to PR referral.

## 1.20 **Self-management and behaviour change**

The application of self-management is important for all patients living with chronic diseases including COPD and can be defined as,

*'' a strategy to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition. … [the] ability to monitor one's condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life"* (124) (pg. 78)

Whilst education of COPD patients is an important aspect of self-management, when used in isolation it does not achieve all that is desired (125). Self-management skill success is most frequently achieved by combining education with HCP support. Furthermore, HCPs who

recognise patients as experts in living with their illness, are those most likely to motivate and enable patients to become active partners in their care (125, 126).

Recognised interventions specifically for COPD are varied and include; smoking cessation, self-treatment and recognition of exacerbations (with and without action plans), physical activity, diet awareness, medication understanding, breathlessness management and pulmonary rehabilitation (127).

A recent Delphi generated definition of a COPD self-management intervention is offered by Effing et al,

*"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*." (128) (p 50)

However, central to enabling and sustaining self-management lie changing behaviours (125). Support for strategies and interventions to adopt self-management behaviours and thus effective behaviour change is fundamental to many global health priorities largely as a result of population longevity and financial health and social care impacts (129). However, it is often HCPs and the supporting health and social care organisations that need to change clinical behaviours, in order to effect behaviour change in those for whom they care. Understanding behaviour and integrating behaviour-change interventions are central to self-management intervention success (129) whilst utilising intervention frameworks are suggested to offer efficient, investigative approaches (130).

Behaviour change interventions that are informed by psychological theory are proposed to be more effective than interventions based on intuition or opinion and as such theoretically informed interventions are recommended on the basis that they are likely to improve and guide wider implementation (117, 130-132).

The Theoretical Domains Framework (TDF) is a framework derived from a synthesis of 84 behaviour change theories agreed by psychological theory experts (116). The frameworks aim is firstly to identify behaviours that are likely to benefit from change, followed by offering theoretical approaches to possible interventions that seek to change the behaviour(s) (116). The TDF has been used as a framework to analysis data within a number of audits, surveys, primary qualitative studies and a systematic review (66). However the application of the TDF in this manner is unusual as it is most commonly applied to practice-based HCP primary research enquiries (133-136).

A further framework designed and tested to understand behaviours specifically for intervention targeting, including application to policy, evolved from an in depth literature review and expert opinion, is the behaviour change wheel (BCW) framework (137). At the core of the BCW is the capability, opportunity, motivation, behaviour (COM-B) model. The COM-B model provides a basis from where identification of the behaviour change that is sought begins, leading to intervention design (137). Each core component of the model has been defined as;

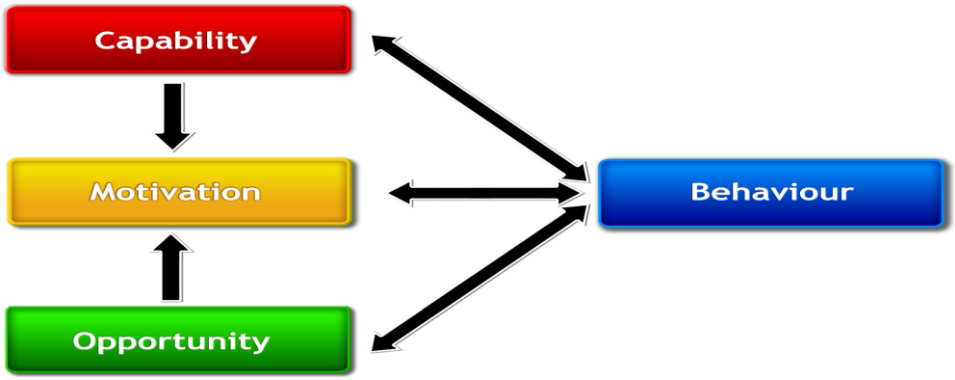
> *"Capability - the individual's psychological and physical capacity to engage in the activity concerned. It includes having the necessary knowledge and skills.*

*Motivation – the brain processes that energize and direct behaviour, not just goals and conscious decision-making. It includes habitual processes, emotional responding, as well as analytical decision-making.*

*Opportunity - the factors that lie outside the individual that make the behaviour possible or prompt it.*" (137) (p 46)

Whilst each of the core components can work independently, for example opportunity can influence motivation so can capability. All three elements  capability, motivation, and opportunity collectively alter behaviour as demonstrated in figure 2.

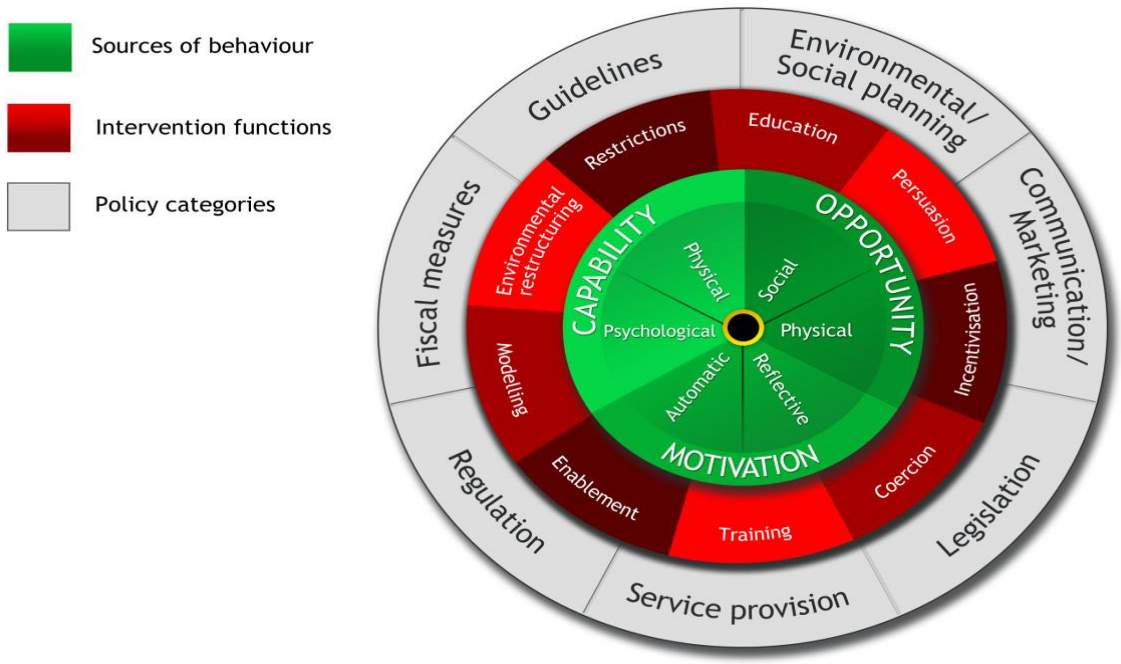
**Figure 2 COM-B Model** (reproduced from Michie et al (137))




The COM-B model seeks to demonstrate how the three core components work to influence behaviour as an independent system, yet when supported by the BCW (figure 3) additional functions relative to intervention and policy interventions can be generated. The BCW demonstrates the relationship of the behaviours by mapping to local and strategic level interventions. This achieves theoretically based sustainable behaviour changes amongst

health care professionals and its application in clinical practice has grown over recent years (138, 139).

**Figure 3 Behaviour Change Wheel** (reproduced from Michie et al (137))




## 1.21 **Aims and Objectives of the PhD**

The aim of this PhD is to inform the design of novel evidence based interventions to improve referral of patients with COPD to PR by primary health care staff, through identification and targeting of barriers & enablers for referral.

The research questions are:

1. What are the barriers and enablers experienced by PHCPs, in referring patients with COPD to PR?

2. What barriers and enablers could be targeted to inform the design of interventions that seek to increase PR referral rates for patients with COPD from primary care?

Specific objectives are:

1. To identify effective previously tested interventions that support referral to, uptake and/or completion of PR for patients with COPD.

2. Identify barriers and enablers to PR referral by PHCPs captured through their descriptive experiences and analysed by two separate data analysis approaches; one inductive and the second deductive, through application of behaviour change theory.

3. Identify current practice of PHCP in terms of PR referral and assess generalisability of qualitative findings using a quantitative survey.

4. Develop new evidence based, theoretically informed interventions that will increase PR referral for patients with COPD from primary health care.

## 1.22 **Multiphase mixed methods research and thesis layout.**

Poor application of clinical guidelines and evidence based recommendations across clinical practice is frequently recognised and their implementation in clinical practice reported to take up to an average of 17 years (140). As has been demonstrated throughout this chapter PR is an evidence-based intervention for patients with COPD, yet it is an intervention that is significantly underutilised. This gap is the key focus of this thesis.

Translating evidence-based finding into clinical practice is an area of high clinical importance, which will improve patient outcomes, advance service efficiency and reduce health care service demands. As such an emerging research field that seeks to understand and improve the translation of research findings to practice application, including the study of HCP and organisational behavioural influences is 'implementation research' (141). Implementation research is inherently complex, particularly where the contextual determinants, that being barriers and enablers affecting desired behaviours are largely unknown, as in the case of PR referral for patients with COPD by PHCPs. Yet clinical interventions that are tailored to overcome identified barrier and enabler issues, improve professional practice, health outcome and close the translational evidence to practice gap (142).

It is further proposed that interventions are designed utilising a step by step process one example is the intervention logic model presented by O'Cathian et al (143) which outlines 11 key actions that intervention developers should consider. A further framework is the Intervention Mapping (IM) protocol (144) which offers a theoretical and practical blueprint for the design, implementation and evaluation of interventions. There are three key initial IM processes 1) assess and understand determinants within the local context, 2) identify theoretically and empirically based techniques that influence the identified context determinants and 3) identify strategies that use the identified technique(s) to address the determinants (145) (146). Whilst (145) intervention mapping processes are predominately aligned to changing health behaviour as opposed to changing HCPs behaviour (147) this approach has been utilised successfully in changing HCPs behaviour (148). It is therefore

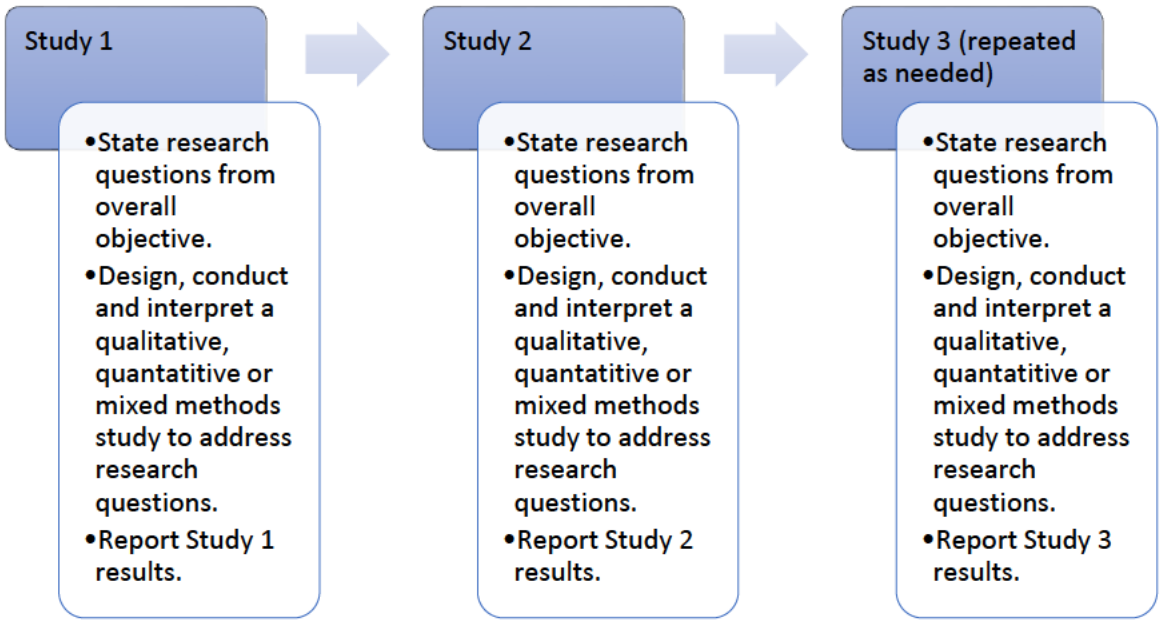
considered to offer potentially useful insight in informing intervention development alongside the MRC framework (132) and O'Cathian's logic model (143).

Therefore in order to get a comprehensive and through understanding of the contextual determinants that influence PR referral behavioural by PHCPs, conducting research via varied paradigm lenses is prudent, therefore the most appropriate design for this thesis is a multiphase mixed method design (149) as shown in figure 4. Multiphase designs are described to

*"occur through an iteration of connected qualitative and quantitative studies that are sequentially… and concurrently aligned, with each new approach building on what was learned previously to address a central program objective'* (149) (pg. 10)

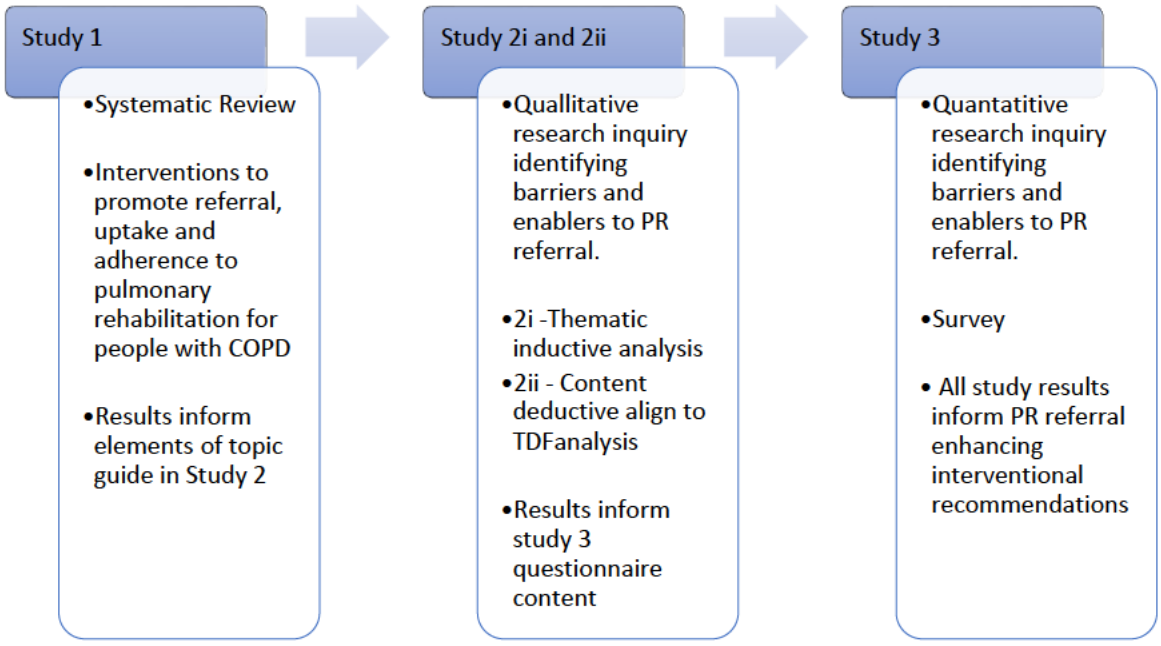
**Figure 4. Basic principles in a multiphase research design**

Adapted from Creswell and Plano Clark (149) and Morse and Niehaus 2009 (150)



The overall goal of adopting a mixed methodological approach is to increase depth and overall knowledge on the phenomena in question (in this case referral to PR by PHCPs) and to improve the validity of those research findings (151). Figure 5 demonstrates the alignment of the multiphase design as applied to this thesis.

**Figure 5. Multiphase design of this thesis**




Study 1 presents a review of collated published empirical evidence relative to PR referral, uptake and adherence. It pools and analyses the data in a predefined systematic manner and uses a number of processes to reduce and consider inherent study bias's (58). Otherwise known as a systematic review this method is considered to offer the highest level of evidence and as such is highly recommended prior to conducting empirical research (132, 152).

Study 2 is the first empirical investigation within this thesis. It is informed by the constructivist paradigm, meaning there are multiple individual perspectives of socially constructed realities which offer insights to that which is being investigated (153). Research informed by a constructivist paradigm are conducted using qualitative methods in order to uncover those individual realities. Data generated from study 2 is therefore expected to offer varied perspectives which will inform understanding and meaning to the PR referral phenomenon from individuals central to its referral process. Using the participant's voice and real life perspectives offers valuable insight into PR referral experiences. It is the collection of these voices that allow data patterns to evolve and therefore offer a broad understanding of the phenomenon (121). Study 2 however will utilise two separate methodological approaches within the same data set. The first will adopt and report a fully inductive approach, whilst the second will adopt and report a fully deductive approach, aligning this to the TDF. Commencing the qualitative approach in the context of implementation development is additionally beneficial as it offers data collection and insights that can guide the development of quantitative measures (154) .

Study 3 as determined by the multiphase mixed method is informed by the findings of study 2ii and takes place sequentially. Study 3 is led by a positivist paradigm, that being that reality can be studied and found and that it exists independently of human observations (155), in direct contrast to the constructivist paradigm.

Positivism therefore guides ordered, statistical approaches to data collection and analysis. Chapter 4 will therefore use quantitative methods to test the findings of study 2ii amongst a

greater number and range of primary care participants. Its value and aim is to identify the national key determinants that influence PHCP PR referral behaviours, utilising the TDF (116). These results are achieved by mixing the findings study 2ii and study 3. Data mixing and triangulation not only increases knowledge, but also increases validity (151).

This mixed methods thesis will identify evidence-based interventional components to increase referral to PR by primary care based HCP's for patients with COPD. In this multiphase design there are several phases; a systematic review, a qualitative study, a quantitative study followed by a mixed method analysis.

The types of data collected across this multiphase design will be interviews and questionnaire data which will be collected sequentially. The reason for using this multiphase design is twofold, it is aligned to the thesis aims and objectives and secondly the contrasting methods reduce the individual qualitative and quantitative methodological weaknesses. In deed this approach can strengthen overall insights which guide effective implementation processes (154). For example qualitative research adds context and detail that quantitative is unable to offer and quantitative research adds breadth and objectivity that qualitative research cannot (149). Combined these layered approaches enable greater understanding of the whole, this is particularly important where interventional design is based on multi-phase study findings.

## 1.23 **Methodological rigour**

Ensuring methodological rigour when conducting research is an important quality assurance process that strengthens the evidence of reported research (156). Yet there are different processes for guiding methodological rigour, dependent on how the research has been conducted (155, 156).

Constructivist informed research, guided by qualitative data methods calls for credibility, transferability, dependability and confirmability (157). Positivist informed research, guided by quantitative data methods calls for rigour specified by predominantly validity and reliability (155, 158), although replicability and generalisability are also considered by some to be important (158).

Methodological rigour in systematic reviews and mixed methods research is somewhat different because of study combination. Systematic reviews offer pre-described steps including pre-specified inclusion and exclusion criteria, primary and secondary outcome measures along with blinded team role division across research processes to reduce possible bias and ensure quality (58). Additionally prospective registration of systematic reviews on platforms such as PROSPERO (159) and/or the publishing of systematic review protocols are further quality assurance steps that promote transparency and reduce bias (160)

Assessing methodological rigour however within mixed methods research (where mixed research has been achieved through the combination of single research studies), is not prescriptively defined by any agreed mixed methods quality criteria (156, 161, 162). This

differs therefore to the earlier presented methodological rigour expected by singular constructivism and positivism led research. For this reason explicit descriptors of integration and the rationale for mixing methods (inferences) are considered key quality measures of mixed methods research (161, 162), as is research transparency reporting and adherence to singular methodological quality criteria (156).

Within this thesis methodological quality is described within each study through the published protocol for the systematic review (chapter 2) in Appendix 3 (163), in the qualitative reporting guidelines (164) for the qualitative study (chapter 3) in Appendix 12 and also the mixed methods reporting guidelines (165), for the mixed methods study (chapter 4) in Appendix 17. Finally each of the studies' methodological quality criteria as specified above, are collated and presented in table format in Chapter 7, pg. 254.

Chapter 2 begins phase 1 of the multiphase study and highlights interventions that have been identified and tested for effectiveness in clinical practice in the context of increasing referral, uptake and adherence to PR for patients with COPD.

# Chapter 2: SYSTEMATIC REVIEW

# INTERVENTIONS TO PROMOTE REFERRAL, UPTAKE AND ADHERANCE TO PULMONARY REHABILIATION FOR PEOPLE WITH COPD

## 2.1 **Chapter objective**

This chapter identifies effective interventions that support referral to, uptake and/or completion of PR for patients with COPD, as aligned to thesis objective 1: "To identify effective previously tested interventions that support referral to, uptake and/or completion of PR for patients with COPD"

This is achieved by conducting and presenting a comprehensive systematic review of studies that examine the effectiveness of interventions tested to increase referral, uptake or adherence to PR for patients with COPD.

## 2.2 **Introduction**

Chapter 1 presented an overview of COPD and highlighted PR effectiveness for patients with COPD. It identified individual characteristic data such as female gender, those living alone, current smokers and individuals with low levels of symptom burden as key barriers to PR referral, uptake and adherence. Whilst those with high burden who are more likely to be referred. PR provider organisational factors such as some providers not accepting current smokers or patients with MRC scores or 5 and/or 2 are also identified barriers (68). Chapter 1 additionally reported patients need to be mentally and physically ready to accept a PR referral, but HCPs are important influencers in that acceptance and need to communicate the benefits of PR in a sensitive and compassionate manner.

This chapter will offer evidence presented by previously published systematic reviews. It will then present the planned methods for this current systematic review, interventions to increase PR referral, uptake and adherence for patient with COPD, as specified in the published systematic review protocol (Appendix 3). It will then present the overall results in terms of PR referral, uptake and adherence separately. It will also undertake methodological quality assessment and present findings for each of the PR referral time points.

Next it will consider the value of the findings to clinical practice, including interventions that may benefit from further research. Strengths and limitations will be considered and discussed followed by the presentation of overall conclusions.

## 2.3 **Abstract**


**Background**

Pulmonary rehabilitation (PR) is an internationally recommended effective treatment for patients with COPD. Yet referral, uptake and adherence to PR is consistently low worldwide.

**Aim**

To determine the effectiveness of interventions to increase referral, uptake, and adherence to pulmonary rehabilitation programmes, for patients with COPD.

**Methods of searching**

Literature searches were conducted across the Cochrane Central Register of Controlled Trials (CENTRAL); MEDLINE (Ovid); Embase (Elsevier); the Cumulative Index to Nursing and Allied Health Literature (CINAHL) (EBSCOhost); Physiotherapy Evidence Database (PEDro) from database inception to May 2020. Conference abstracts and grey literature through the CENTRAL database and the Cochrane Airways Trials Register, as well as three clinical trial registries. Reference lists of relevant systematic reviews for additional studies were also searched. No language restrictions were applied.

**Selection criteria**

We included randomised and non-randomised studies where a co-ordinated set of activities were implemented in order to change or target specific behaviours that aimed to increase referral and/or uptake and/or adherence to PR for patients with COPD.

Primary outcome measures were referral, uptake and/or adherence rates. There were no secondary outcome measures.

**Data collection and analysis**

Reviewers independently screened the titles and abstracts of all identified references for eligibility, followed by full texts of potentially relevant studies. Reviewer's independently assessed included studies for risk of bias (RoB), using Cochrane RoB for randomised studies and ROBINS-I for non-randomised studies, and extracted trial data independently. Behaviour change strategies utilised by included studies were described using content analysis. Disagreements were resolved through consultation with a third reviewer. Outcomes were reported in accordance with the studies' data collection methods, commonly numbers and percentages. Pre-specified study characteristics were described.

**Results**

Seventeen full text papers met study inclusion criteria, of which fifteen full text studies reported outcome measures, enabling data extraction; two cluster RCTs, two RCTs, one quasi-randomised trial and two CCTs. The remaining eight were uncontrolled studies. All studies included patients with only COPD. Researchers tested a variety of interventions

across primary and secondary care health settings. Interventions included education of Health Care Professionals (HCPs) and/or patients, promotional and informative PR material including a video on PR, paper- based prompts for patients to use with staff, such as scorecards, prompts for staff including electronic guided consultations and COPD discharge bundles. Motivational interviewing, CBT, pre-PR session, in-PR electronic diaries and Wii game consoles were also used.

Intervention approaches most frequently used included education, enablement, persuasion and environmental restructuring and behavioural techniques used most frequently were information about health consequences from credible sources, prompts/cues, restructuring the physical environment and empowerment.

Quality of the controlled studies was generally good. In the RCTs and the CCTs risk of bias was low in 3-4 of 7 possible domains. Study heterogeneity meant statistical pooling of studies could not be undertaken. However, there were several effective interventions. In a cluster RCT, nurses trained in respiratory disease management and motivational interviewing delivered personalised care plans to patients in their own home which reported statistically significant uptake rates (OR 5.15; 95% CI 2.4-11.1; p=0.002). A patient scorecard and COPD manual in the CCTs increased referral and uptake rates respectively (p=0.03; p=0.05). For adherence, CBT during and after PR (MD 1.59; 95% CI 0.11-3.07; p=0.03) showed effectiveness.

There were some additional promising interventions from the uncontrolled studies, some of which supported the trial results but others need further testing in comparative studies. These include improving education, prompts and audio-visual material for HCPs and patients to improve referral and uptake, and a pre-PR session as a strategy to improve uptake.

The weight of evidence suggested that interventions that incorporated partnership working between patients and HCPs appeared to increase referral, uptake and adherence rates with greater effectiveness than those that targeted singular population.

**Conclusion**

A small number of studies reported increases in PR referral, uptake and adherence from interventions that target these outcomes. However, concerns about study design and risk of bias impact on conclusions about overall effectiveness and recommendations. Collaborative working, increasing knowledge and empowering HCPs and patients appear to be important strategies.

## 2.4 **Background**

Two previously published systematic reviews that sought to investigate the effectiveness of interventions for increasing engagement with PR have examined differing elements of the PR pathway and/or included differing study designs than the systematic review presented in this chapter (166, 167). The Jones et al review (166) published in 2017 focussed on interventions to increase PR uptake and completion. The review only included RCTs with intervention allocation via individual, group or quasi-randomisation process, only one study was included in the final review (168).

The second systematic review was published in 2018 and focused on interventions to increase PR referral and uptake (167). The review completed its literature search at the end of January 2018. Its inclusion criteria was wider than the previous (166) review as it included all trial designs, surveys, direct observations, action research, interviews, focus groups or questionnaires, systematic reviews, and meta-analyses. The completed systematic review included 14 papers, ten of which reported on referral and five on uptake. They concluded that there were a broad range of tested interventions across primary and secondary care settings, but were unable to draw any clear conclusions oneffective interventions that improved uptake and/or adherence to PR by patients with COPD. The review also highlighted improved understanding across the whole of the PR pathway, referral, uptake and adherence will lead to greater insights in how to improve engagement and therefore enhance patient outcomes and improve service efficiencies.

An additional systematic review was registered with the Cochrane library in 2013 (169). The title indicated its aim was to review interventions that addressed PR adherence for patients with COPD. However, there was no subsequent data or detail other than the title.

Since these reviews, there have been a number of additional relevant studies. This current review brings together the latest literature on interventions for all three PR pathways steps: referral, uptake and adherence. It also includes interventions that aimed to target or influence HCPs, patients and/or partners, caregivers, family or friends across any one of the three outcomes. Similar to the 2018 systematic review (167), we included a wide range of study designs, including abstracts, but excluded systematic reviews. We completed our systematic review protocol 'Interventions to promote referral, uptake and adherence to pulmonary rehabilitation for people with Chronic Obstructive Pulmonary Disease (COPD)' (163) which was published in 2017, please see Appendix 3. The protocol can also be accessed online at: https://www.cochrane.org/CD012813/AIRWAYS_interventions-promote-referral-uptake-and-adherence-pulmonary-rehabilitation-people-chronic

## 2.5 **Aims and objectives**

The overarching aim of the systematic review was to

*'determine the effectiveness of interventions to increase patient referral, uptake, and adherence to pulmonary rehabilitation programmes, for patients with COPD'* (163) (pg. 4).

Specific objectives were to determine effectiveness on:

1. Referral to pulmonary rehabilitation programmes (as measured by referrals sent or received).
2. Attendance at pulmonary rehabilitation programme assessment.
3. Attendance at start of pulmonary rehabilitation programme.
4. Adherence to pulmonary rehabilitation programme (as specified by study reports, but usually percent of sessions attended).

The findings from this systematic review will inform and shape subsequent research questions that aim to improve PR access and engagement for patients with COPD.

## 2.6 **Methods**

The methods section below is taken from the published Cochrane protocol which can be found (Appendix 3) and online at:

https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD012813/full

## 2.7 Criteria for considering studies for this review

### Types of studies

In anticipation of a limited numbers of studies available a broad range of designs were included, which were; RCT (individual or cluster-level) and non-randomised controlled trials, Clinical Controlled Trials (CCT), controlled before-and-after studies and non-controlled, before-and-after studies, as well as quality improvement and feasibility studies. Full text studies and those published as an abstract only were also included. Additionally it was planned to include unpublished data, if found to be relevant.

## 2.8 Types of participants: Inclusion criteria

Interventions to improve referral, uptake, and adherence rates may be applied to healthcare professionals or patients, partners, caregivers, family, or friends of the COPD patient. Therefore, included studies in which the population was either:

1. Healthcare practitioners (of any age) who care for patients with either stable or acute COPD, in all healthcare settings.

Or:

2. Adult participants (at least 18 years of age) who had a primary diagnosis of COPD, defined with or without spirometric confirmation. We included studies in which the participants had any stage of COPD, with either stable disease or post-acute exacerbations, and who might have had singular or multiple co-morbidities. There was no upper age limit.

Or:

3. Partners, caregivers, family, or friends (of any age), of the COPD patient, who may influence referral, uptake, or adherence to pulmonary rehabilitation.

## 2.9 **Exclusion criteria**

Interventions that were designed to target other programmes, such as maintenance pulmonary rehabilitation programmes or studies that aimed to target functional outcomes, such as physical activity within or post PR were excluded. Additionally excluded studies were those that compared different timings of offer of PR, for example immediately post exacerbation and studies where PR was delivered in alternative settings such as the home, where the focus was largely on PR efficacy.

Additional excluded studies where those were the focus of the study was on participants receiving PR with the following primary diagnoses: asthma, bronchiectasis, lung cancer, interstitial lung disease (ILD), and congestive cardiac failure.

## 2.10 **Types of interventions**

Interventions were considered eligible where they were described as a co-ordinated set of activities were implemented in order to change or targeted specific behaviours, (137). Intervention specification was that they aimed to increase referral to, uptake of, or adherence to any type of PR programme.

Comparator arms included usual care, or concurrent control group that was not receiving an intervention that aimed to improve referral, uptake, or adherence to PR. Studies with

alternative intervention(s) that aimed to improve referral/uptake/adherence rates, including historical arms and those with no control were also included.

## 2.11 **Types of outcome measures**

### **Primary outcomes:**

1. Referral to pulmonary rehabilitation programmes (as measured by referral sent or received)
2. Attendance at pulmonary rehabilitation programme assessments
3. Attendance at start of pulmonary rehabilitation programme
4. Adherence to pulmonary rehabilitation programme (as specified by study reports, but usually percent of sessions attended)

Rationale: In order to access and enrol in PR, patients are initially referred by a HCP, or in some circumstances, the patient may self-refer. Attending a PR assessment is the next step, which if successful, is followed by an opportunity to start a PR programme. Adequate attendance at PR programmes is essential in order to gain clinical and psychosocial benefits (47) however, the literature informs us that each of these steps are areas of weakness in PR recruitment and retention (66, 72). Interventions designed to increase uptake and sustainability at each stage are emerging. Identifying those that are effective is a key aim of the systematic review.

## 2.12 Secondary outcomes

There are no secondary outcome measures for this review.

## 2.13 Search methods for identification of studies

### Electronic searches

The search for RCTs in the Cochrane Airways Trials Register, was undertaken by a Cochrane employed information specialist on behalf of the systematic review author group. The Cochrane Airways Trials Register contains studies identified from several sources (see Appendix 3:1 for details). Additional searches were conducted in the following databases, using appropriate search terms to identify both randomised and non-randomised trials and other observational studies:

1. Cochrane Central Register of Controlled Trials through the Cochrane Register of Studies Online (CENTRAL; search date);
2. MEDLINE Ovid (1946 to search date);
3. Embase Ovid (1974 to search date);
4. CINAHL EBSCO (Cumulative Index to Nursing and Allied Health Literature; all years to search date);
5. PEDro (Physiotherapy Evidence Database; search date)

The proposed CENTRAL and MEDLINE search strategies are described in Appendix 3:2.

All databases were searched from their inception to May 2020 present, and there was no restriction on language of publication. We hand searched for relevant conference abstracts and grey literature through the CENTRAL database and the Cochrane Airways Trials Register.

The following trials registries were searched:

1. UK Clinical Trials Gateway (ukctg.nihr.ac.uk)
2. US National Institutes of Health Ongoing Trials Register ClinicalTrials.gov (www.clinicaltrials.gov/)
3. World Health Organization International Clinical Trials Registry Platform (ICTRP; apps.who.int/trial search/)

## 2.14 **Searching other resources**

The reference lists of all primary studies and review articles were checked for additional references. This study search was initially undertaken in September 2019 and then re-run to include papers up to May 2020. However, in light of findings that our initial searches appeared to omit a small number of papers that the 2018 review (167) had included, the author review group agreed that an additional search would be run from Jan 2018 to May 2020 with the removal of the previous study design filters. This unfiltered search was run in MEDLINE, EMBASE and CINAHL given they were the only platforms that supported study designs filtering. An updated search within WHO ICTRP was not possible as the platform was unavailable due to the COVID-19 pandemic. All references were uploaded to Covidence (170) for assessment.

## 2.15 **Data collection and analysis: study selection**

All titles and abstracts were reviewed by myself and one other person (KJ, RG or LG) independently and coded using the Covidence labels; 'yes' 'no' or 'maybe'. The process was repeated for full text papers, where papers were screened for inclusion in accordance with the pre-specified criteria, recording reasons for ineligible studies. Disagreement was resolved by discussion or if needed by one of the review authors who had not undertaken

initial screening. Duplicates were excluded and multiple reports of the same study were collated, meaning each study rather than each report was the unit of interest. Study selection processes are presented in the PRISMA diagram, (figure 6), pg. 61.

## 2.16 **Data extraction and management**

A pre-designed data collection form for the study characteristics and outcome data included;

- Methods: study design, aim of study, total duration of study, details of any 'run-in' period, number of study centres and location, study setting, withdrawals, and date of study. Study inclusion and exclusion criteria.
- COPD patients: N, mean age, age range, gender, severity of condition, diagnostic criteria, baseline lung function, smoking history, medication, prior history of PR.
- Healthcare practitioner: N, mean age, gender, job role, length of time in job role, contracted hours in job role, prior academic experience, knowledge of and experience with PR.
- Interventions: type of behaviour change intervention, duration of intervention and comparator, description of target PR service.
- Outcomes: primary and secondary outcomes specified and collected, and time points reported.
- Notes: any additional information of interest or to note.

Review author JW and one other review authors (KJ, RJ and/or LG) independently extracted outcome data from the included studies through the application of the pre-specified inclusion and exclusion criteria. This was verified by post extraction reviewer discussion and validation of extracted data.

## 2.17 **Intervention assessment overview of methods**

Assessment of the main interventions and behaviour change techniques (BCTs) used within the studies was undertaken using the BCW process (171). Intervention functions seek to described the 'mode' of intervention delivery, whilst BCTs are considered the active intervention component designed to change behaviour (172). These two elements are subsequently aligned and presented in an expert ranked taxonomy (173), known as the BCT taxonomy which is designed to guide inductive intervention design. However it has also been utilised to identify key intervention components deductively (174).

This process was considered important in identifying and describing intervention mode and content used within each study allowing commonality and effectiveness to be assessed and grouped particularly, given there is no pool of effective BCTs. It is suggested a number of factors impede an effective BCT pool, including single BCT effect can be very small and difficult to measure and BCTs may interact with each other to alter the overall effect as will context (175). Therefore identifying effective BCTs relative to a specific field and for a given behavioural outcome using systemic review methods is advocated (175). Identification of the intervention components and alignment to the BCW was undertaken by JW.

## 2.18 **Assessment of risk of bias in included studies**

Review authors (JW, KJ, RJ and LG) independently and then collectively assessed the risk of bias for each study in accordance with the study design. Disagreements were resolved by involving a third review (from those named above). For RCTs the Risk of Bias (RoB) tool as

outlined in the Cochrane Handbook for systematic review of interventions was used to assess risk of bias (176) with bias assessed across 7 separate domains, with each domain judged as high, low or unclear.

1. random sequence generation;
2. allocation concealment;
3. blinding of participants and personnel;
4. blinding of outcome assessment;
5. incomplete outcome data;
6. selective outcome reporting;
7. other bias.

For all other studies the methodological quality used for assessment was the Risk Of Bias In Non-randomised Studies of Interventions (ROBIN-I) tool (177). The methodological quality was assessed across seven domains (outlined in table 4 below) and judged as critical, serious, moderate, low and unclear.

**Table 4: ROBINS-I assessment criteria**

| | |
|---|---|
| Pre-Intervention | 1.Bias due to confounding<br>2.Bias in selection of participants into the study |
| At intervention | 3.Bias in classification of interventions |
| Post-intervention | 4.Bias due to deviations from intended interventions<br>5. Bias due to missing data<br>6. Bias in measurement of outcomes<br>7. Bias in selection of the reported result |

When including non-randomised studies, assessment of potential confounding factors including characteristics of the patients and the healthcare professionals such as age, co-morbidities and prior PR experience was considered and described.

## 2.19 **Assessment of bias in conducting the systematic review**

The review was conducted according the published protocol (163).

## 2.20 **Measures of treatment effect**

The treatment effect was analysed as it was reported, most commonly as the mean difference. We aimed to undertake meta-analyses of RCTs and CCTs only where this was meaningful; that is, if the treatments, participants, outcomes, and the underlying clinical question were similar enough for pooling to make sense. Additionally we stated we would combine RCTs and CCTs if there was minimal clinical and methodological diversity between the controlled studies. Also if large heterogeneity, we would explore reasons for it, including undertaking subgroup analysis of the RCTs and CCTs if possible, using a narrative format. For non-controlled before-and-after studies we describe the results together with caveats about the lack of control group.

## 2.21 **Unit of analysis issues**

We used the patient and/or the healthcare practitioner (where the intervention and/or outcome data is specified) as the unit of analysis.

## 2.22 Dealing with missing data

We contacted investigators or study sponsors to verify key study characteristics and obtain missing numerical outcome data where needed (e.g. when a study was identified as an abstract only). We specified we would contact authors, or use narrative discussion to manage mixed populations, where >80% had COPD, however mixed populations was not a factor in the included studies.

## 2.23 Summary of findings

We created three summary of findings tables with the following outcomes; referral to PR programmes; attendance at PR programme assessment and start of PR programme, and PR programme adherence.

## 2.24 Subgroup analysis

We had planned to undertake subgroup analysis if this was possible of the following groups:

1. Type of referring healthcare practitioner (nurse, doctor, other). Rationale: the type of healthcare practitioner could influence whether patients are referred, and the likelihood of uptake and adherence after referral.
2. Origin of referral (self, community, hospital). Rationale: motivation for adherence and completion may vary according to who made the referral.
3. Pulmonary rehabilitation programme setting (home versus centre-based): Rationale, perceived convenience of attending has been highlighted as a barrier to attendance

in qualitative studies. Therefore, the setting could influence uptake, adherence, or completion.

4. Patient age (up to 65 years, over 65 years). Rationale: patient age and working status are reported to be an influencing characteristic, particularly in adherence. The age cut-off is based on approximate age for retirement.

   COPD severity (as determined by stable disease or post-exacerbation). Rationale: motivation to attend and complete may differ according to whether the patient has had a recent exacerbation.

Where subgroup was not achievable a narrative review was undertaken to address these areas.

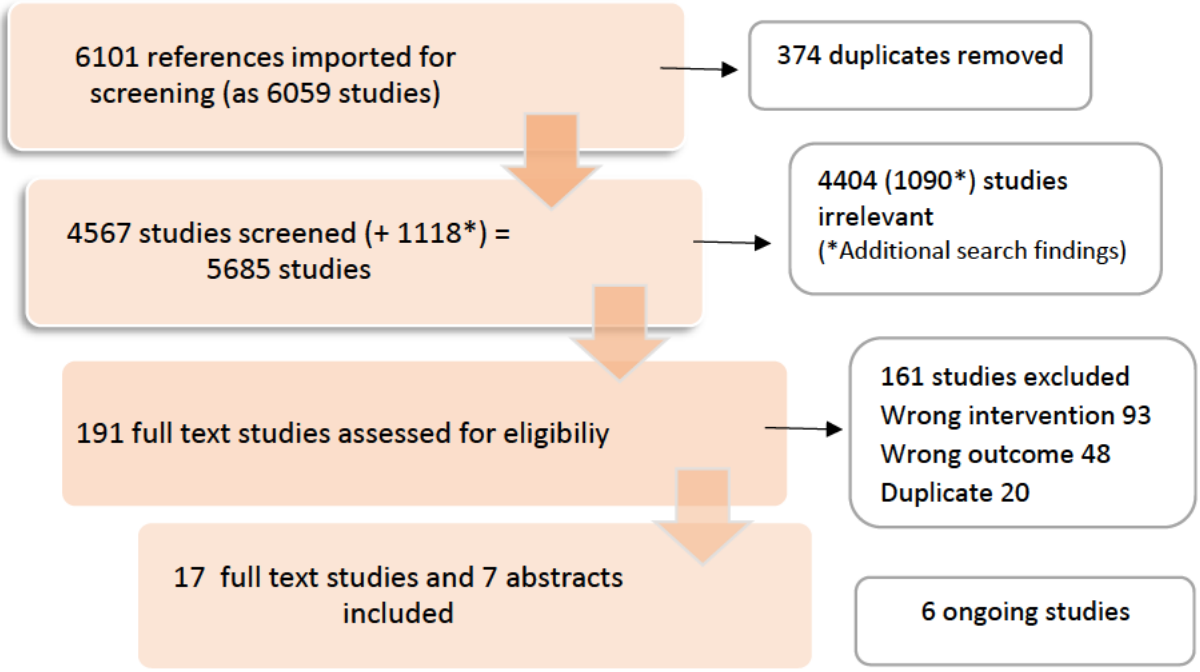
## 2.25 Sensitivity Analysis

We proposed to undertake sensitivity analysis of the meta-analyses, in which we would remove RCTs with high risk of bias in two or more domains. If only non-randomised trials were available, we would remove studies that were at 'serious' or 'critical' risk of bias, according to the ROBINS-I tool (177). We also planned to compare the results using the fixed-effect model and the random-effects model and restrict analyses to those with an active comparator only. However, as meta-analysis was not appropriate, these aspects were not conducted.

## 2.26 **Results**

From the initial 6,101 references and following the processes specified in the methods section, independent and collaborative reviewer screening resulted in 17 final full text studies that were deemed eligible for review inclusion. Please refer to the below PRISMA diagram (figure 6) for a pictorial demonstration of the numerical search and screening results, detailing excluded studies with reasons.

**Figure 6: PRISMA Diagram**




Studies were excluded for a number of reasons, including 'wrong intervention' which related to studies that tested PR effectiveness across differing venues such as home based PR versus community based PR, or those that sought to increase physical activity within or post PR. We also excluded studies which compared different timings of offer of PR. The second most common reason for full text exclusion was 'wrong outcome', where the study evaluated

impact on clinical outcomes after or during PR rather than referral, uptake or adherence to PR.

The characteristics of the final 17 included studies are presented in Table 5, pg. 65. These 17 studies represent a number of different study designs, including: two cluster RCTs (89) (178), three RCTs (179-181), one quasi-randomised controlled trial (168), two controlled clinical trials (CCTs) (182, 183), three intervention studies with historic control (184-186), two quality improvement studies with historic control (122, 187), one service evaluation with historic control (188), two uncontrolled feasibility studies (189, 190) and one uncontrolled service evaluation (191).

Interventions were largely conducted in secondary care settings 10/17 (58.8 %) with 6/17 (35.3%) in primary care and general practice settings and one in a community setting (190). The interventions were targeted predominately at patients, including some interventions that encouraged the patient to prompt HCPs towards referral (182, 183). For HCPs, the intervention focus was education and/or referral prompts. Two studies included interventions that adopted peer support for patients (181, 190). Patient-focused interventions considered the whole of the PR pathway albeit largely in individual parts, whereas HCP focused interventions were orientated towards referral only. Only 3/17 interventions targeted both patients and HCPs (89, 187, 188). One study of peer support highlighted desires to include family members, but no description in relation to the implementation of this was offered (181). The interventions tested were mixed, including education, prompts (electronic and paper), patient self-recording of actions using a tablet or

a manual, a pre-PR taster session and psychological support for patients during the PR programme.

Outcomes measured were largely reported as descriptive statistics; that being number and percentages across individual PR time points, referral, uptake and completion.

**Table 5: Characteristics of all studies meeting study inclusion criteria**

**RCTs**

| Author, setting and country | Study Design | Study Aim | Inclusion/Exclusion | Baseline characteristics | Intervention | Intervention functions and active components (BCTs) | Control | PR pathway | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | Referral | Uptake | Adherence |
| **Zwar 2012**<br><br>General practices<br><br>Sydney Australia | Cluster RCT | To evaluate a partnership model of care for patients with a diagnosis of chronic obstructive pulmonary disease (COPD) by enhancing evidence-based practice | **Inclusion:** GPs using an electronic prescribing system. Patients aged 40-80 yrs., had been prescribed 1 or > SABA,ICS,SAMA,LAMA, oral theophylline & oral corticosteroids, had seen GP in last 12 months.<br><br>**Exclusion**: Non-English speaking. Significant cognitive impairment. | Practice n:44<br>GPs n:56<br>Nurses n:2<br><br>**Intervention**<br>Group n: 234<br>Female: 124 (53%)<br>FEV/FVC <0.7: 146 (62.4%)<br>GOLD 1: 28 (12%)<br>GOLD 2: 70 (29.9%)<br>GOLD 3: 38 (16.2%)<br>GOLD 4: 10 (4.3%)<br>Age: 65.8 (10.3)<br>Current smoker: 74 (31.6%)<br><br>**Control**<br>Group n: 217<br>Female: 111 (51.2%)<br>FEV/FVC <0.7: 111 (51.2%)<br>Gold 1: 20 (9.2%)<br>GOLD 2: 63 (29%)<br>GOLD 3: 19 (8.8%) | **Home visits to eligible patients** by COPD trained nurse who worked with GP and other HCPS.<br><br>Nurse implemented evidence based **individualised patient agreed care plan**.<br><br>(Training included PR in COPD, motivational interviewing and self-management support) | Education<br>Training<br>Persuasion<br><br>**BCT:**<br>Information about health consequence.<br><br>Instruction on how to perform a behaviour.<br><br>Verbal persuasion about capabilities.<br><br>Credible source. | COPD guidelines provided to GPs practices.<br><br>Patients received usual care. | | **X** | |

| Author, setting and country | Study Design | Study Aim | Inclusion/Exclusion | Baseline characteristics | Intervention | Intervention functions and active components (BCTs) | Control | PR pathway | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | Referral | Uptake | Adherence |
| | | | | GOLD 4: 9 (4.1%)<br>Age (range) 64.4 (10.3)<br>Current Smoker: 61 (28.1%) | | | | | | |
| **Zwar 2016**<br><br>General Practices Australia | Cluster RCT | To assess the effectiveness of practice nurse/ GP teams developing and implementing an evidence-based disease management plan for patients newly diagnosed with COPD.<br><br>**Secondary outcome**: PR attendance. | **Inclusion**<br>**Practices:** computer based patient records, Spirometer, employed at least one RN.<br>**Patients:** attended the practice at least twice, with one visit in the preceding 12 months. Risk factors for COPD including documented history of smoking, aged 40-85 years.<br><br>**Exclusion:**<br>**Practices:** NR<br>**Patients**: recorded diagnosis of COPD, unable to understand English. | Practice n:36<br>HCP n:110<br><br>**Intervention**<br>Patient n: 144 (19 practices)<br>Female: 56 (38.9%)<br>Gold 1: 22 (15.3%)<br>Gold 2: 64 (44.4%)<br>Gold 3: 10 (6.9%)<br>Gold 4: 1 (0.7%)<br>Airway obstruction FEV1/FVC < 0.7: 47 (32.6%)<br>Age(mean): 66.5 (10.7)<br>Current Smokers: 41 (28.5%)<br><br>**Control**<br>Patient n: 110 (17 practices)<br>Female: 46 (41.8%)<br>Gold 1: 32 (28.2%)<br>Gold 2: 42 (38.2%)<br>Gold 3: 5 (4.5%) | **Practice staff education** on COPD care & management<br><br>Electronic care planning templates based on national guidelines were provided for HCP use in computerized clinical record system.<br><br>**PLUS same elements as control** | Education<br>Training<br>Environmental restructuring<br><br>**BCTs:**<br>Information about health consequence.<br><br>Instruction on how to perform a behaviour.<br><br>Restructuring the physical environment.<br><br>Prompt/cues | All Practice nurses attended 8 hrs of case finding & spirometry training & interpretation<br><br>Computer based toolkit to help with spirometry interpretation and COPD diagnosis<br><br>Copy of COPD-national guidelines. | | **X** | |

| Author, setting and country | Study Design | Study Aim | Inclusion/Exclusion | Baseline characteristics | Intervention | Intervention functions and active components (BCTs) | Control | PR pathway | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | Referral | Uptake | Adherence |
| | | | Had cognitive impairment | Gold 4: 0 (0)<br>Airway obstruction FEV1/FVC < 0.7: 31 (28.2%)<br>Age (mean): 65.4 (11.0)<br>Current Smokers: 37 (33.6%) | | | | | | |
| **Barker 2020**<br><br>Secondary care, UK | RCT | Determine whether using a patient co-designed education video as an adjunct to usual care could enhance uptake of PR within 28 days of discharge after a hospital admission for AECOPD. | **Inclusion:**<br>>40 years of age, hospitalised with a primary diagnosis of AECOPD or primary diagnosis of pneumonia & secondary diagnosis AECOPD, eligible for PR (able to walk five metres independently, MRC score ≥2), capacity to consent.<br><br>**Exclusion:**<br>Significant cardiovascular co-morbidities. Receiving palliative | **Intervention** n:98<br>Female: 49 (50%)<br>$FEV_1/FVC$: 0.53 (0.16)<br>GOLD stage: NR<br>Age (range mean: 70(11)<br>Current Smokers: 27 (28%)<br>Prior PR: 50 (51%)<br><br>**Control** n:98<br>Female: 52 (53%)<br>$FEV_1/FVC$: 0.53 (0.17)<br>GOLD stage: NR<br>Age (range mean: 68 (11)<br>Current Smokers: 27 (28%)<br>Prior PR: 51 (52%) | COPD discharge bundle **plus patient education video** delivered by a respiratory HCPs including standardised verbal information about PR supplemented by an information leaflet.<br><br>Patient access to the video post discharge. | Education<br>Persuasion<br><br>**BCTs:**<br><br>Information about health consequence<br>Credible source | COPD discharge bundle, delivered by respiratory HCPs including standardised verbal information about PR supplemented by an information leaflet. | **X** | **X** | **X** |

| Author, setting and country | Study Design | Study Aim | Inclusion/Exclusion | Baseline characteristics | Intervention | Intervention functions and active components (BCTs) | Control | PR pathway | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | Referral | Uptake | Adherence |
| | | | care & life expectancy ≤3 months. | | | | | | | |
| **Pumar 2019**<br><br>Secondary care, Australia | RCT | CBT to treat anxiety and depression for patients with COPD attending PR, to improve attendance and participation. (CBT aimed to increase self-management, behavioural activation, unhelpful thinking, improving relaxation, breathing skills promoting coping through problem solving) | **Inclusion**<br>Undertaking PR<br>>18 years of age<br>COPD, ILD, Asthma, Bronchiectasis diagnosed by thoracic physician<br>(Geriatric Depression Scale > 4/15) (Geriatric Anxiety Scale >3/20)<br><br>**Exclusion**<br>Psychotic disorder & undergoing psychological therapy.<br>Unable to give written consent<br><br>Participating in another research project.<br>(MMSE <23/30) | **Intervention** n: 24<br><br>Female: 12 (50%)<br>COPD: 20 (83.3%)<br>Age (range): 69.6 (49-86)<br>GOLD Stage : NR<br><br>**Control** n:41<br>Female: 27 (65.9%)<br>COPD: 29 (70.7%)<br>Age (range): 68.5 (40-85) | 2 x face to face 1 hr **CBT sessions** (just before/or after PR) and **4 x 45 min telephone sessions** within 2 months after face to face session<br><br>Attended 8 weeks of 2 hrly PR x twice weekly and booklet on COPD | Training<br>Persuasion<br>Education<br><br>**BCTs**<br><br>Instruction on how to perform a behaviour<br><br>Verbal persuasion about capabilities<br><br>Credible source<br><br>Information about health consequence | Attended 8 weeks of 2 hrly PR x twice weekly and booklet on COPD<br><br>4 sham (5-10 mins) telephone calls (similar time to intervention group, brief assessment of respiratory symptoms). | | | **X** |

| Author, setting and country | Study Design | Study Aim | Inclusion/Exclusion | Baseline characteristics | Intervention | Intervention functions and active components (BCTs) | Control | PR pathway | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | Referral | Uptake | Adherence |
| **Yao et al 2020**<br><br>Secondary Care, China | RCT | To explore the effect of peer support models on respiratory rehabilitation in patients with COPD. | **Inclusion:** People diagnosed with COPD.<br>Attending PR<br><br>**Exclusion:** Severe liver and kidney dysfunction. Severe immune system diseases. Malignant tumours, extremely weak and unable to perform PR training Cognitive dysfunction or communication impairment. Refused to participate | **Intervention** n:64<br>Female: 27 (42.2%)<br>GOLD: 0.73 (±- 0.21)<br>$FEV_1/FVC$ (%): 44.7 (+- 5.21)<br>Age > 63: 30 (46.9%)<br>Current Smoker: 40 (62.6%)<br><br>**Control** n:64<br>Female: 29 (45.3%)<br>GOLD: 0.72 (+- 0.24)<br>$FEV_1/FVC$ (%): 45.02 (+- 5.32)<br>Age > 63: 31(48.4%)<br>Current smoker: 39 (60.9%)<br>**Peer Supports:** Patients with COPD, who had disease knowledge & deemed better rehabilitation were selected. | **Peer support**<br><br>Patients supported to attend knowledge lectures, community activities once every 2 weeks.<br><br>Peer supports provided telephone/we chat support and undertook PR with patients at least once a day during hospitalisation<br>PR as described in control | Enablement<br><br>**BCT:**<br><br>Social support | Usual care and PR<br><br>PR consists of breathing exercises/although including 5-10 mins walking/jogging | | | **X** |
| **Ringbaek 2016**<br><br>Secondary Care | Quazi-randomised trial | To evaluate the effect of adding a tablet (minicomputer with touch | **Inclusion:** Stable COPD defined by spiro FEV1 <80% pred and FEV1/FVC | **Intervention** n:46<br>Female: 44.6%<br>Smoking history: 14.3%<br>Age (SD): 68.4 (9.1) | **Tablet** with instruction and training (electronic diary given to patients for home and PR use) - in addition to group PR | Enablement<br>Incentivisation<br><br>**BCTs:** | Usual group PR | | | **X** |

| Author, setting and country | Study Design | Study Aim | Inclusion/Exclusion | Baseline characteristics | Intervention | Intervention functions and active components (BCTs) | Control | PR pathway | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | Referral | Uptake | Adherence |
| Demark | | screen) with instructions and training diary to a classic outpatient PR programme on adherence to PR | <70% Motivated for PR<br><br>**Exclusion:** MSK, cardiac and cognitive disorders that limited patients ability to take part in PR | **Control** n: 69<br>Female: 60.9%<br>Smoking history: 17.4%<br>Age (SD): 68.8 (11) | | Self-monitoring of behaviour<br>Feedback on behaviour<br>Feedback on outcomes of behaviour | | | | |

*RCT =Randomised Controlled Trial, $FEV_1/FVC$ <0.7 = Forced Expiratory Volume in 1 second/Forced Vital Capacity ratio, GOLD = International disease classification, BCT = Behaviour Change Techniques CBT = Cognitive Behaviour Therapy, SD = Standard Deviation

**CCTs**

| Author, setting and country | Study Design | Study Aim | Inclusion/Exclusion | Baseline characteristics | Intervention | Intervention functions and active components (BCTs) | Control | PR pathway | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | Referral | Uptake | Adherence |
| **Roberts 2015**<br><br>General Practice England | CCT | Personalised care quality data presented and co-designed by primary care staff with patients would bring about care improvements | **Inclusion**: Practices in Redbridge PCT and in a similar geographical area.<br><br>Patients with COPD<br><br>**Exclusion**: Not explicitly stated | Practices n: 20<br><br>**Intervention**<br>(10 practices)<br>COPD (n,%): 595 (100)<br><br>**Control**<br>(10 practices)<br>COPD (n,%): 755 (100) | **Patient held COPD scorecard** (4 page A4) with 6 quality indicators.<br><br>Advised to discuss scorecard at COPD review | Enablement<br>Training<br>Persuasion<br><br>**BCTs**<br><br>Goal setting<br>Review goals<br>Habit formation | **Usual Care** which included a self-management plan, rescue pack distribution and | **X** | | |

| Author, setting and country | Study Design | Study Aim | Inclusion/Exclusion | Baseline characteristics | Intervention | Intervention functions and active components (BCTs) | Control | PR pathway | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | Referral | Uptake | Adherence |
| | | group of patients with COPD. | | | Helpline for patients to call if they had scorecard queries. | Credible source<br><br>Identification of self as a role model | instruction part of a regional QI intervention. | | | |
| **Harris 2009**<br><br>Hospital setting, Respiratory inpatient & out-patient<br><br>Adelaide Australia | CCT | The aim of this study was to show whether providing summaries of evidence to people who have COPD leads to improved application of that evidence in their medical care including PR. | **Inclusion:** Patients with moderate to severe COPD (GOLD criteria). Inpatient/outpatient COPD clinics.<br><br>**Exclusion**: Lung cancer, dementia, other major unstable illness, patient and/or carer did not have a basic level of understanding of English. | **Intervention**<br>Female (n,%): 56 (44.8)<br>COPD (n,%):125 (100)<br>Mean Age: 73.6<br>Smoker at baseline: n,(%): 23 (18)<br>Prior PR n(%): 19/100 (19)<br>**Control** n:124<br>Female (n,%): 59 (48)<br>COPD (n,%):124 (100)<br>Mean Age : 73.1<br>Smoker at baseline n(%): 29 (23)<br>Prior PR n(%): 3/101 (3) | **Patient held manual** that summarised evidence about COPD and suggested questions to ask Dr accompanied summary.<br><br>Manual plain language and illustrations of people with COPD engaging in activity. | Enablement<br>Training<br>Persuasion<br><br>**BCTs**<br><br>Action planning<br>Habit formation<br>Social comparison<br><br>Credible source<br>Identification of self as a role model | **Patient held information**: simple, single sheet foldout pamphlet containing information about COPD in keeping with usual practice | X | X | |

CCT = Controlled Clinical Trial, BCTs = Behaviour Change Techniques

**Uncontrolled Studies**

| Author, setting and country | Study Design | Study Aim | Inclusion/Exclusion | Baseline characteristics | Intervention | Intervention functions and active components (BCTs) | Control | PR Pathway | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | Referral | Uptake | Adherence |
| **Wardini 2013**<br><br>Secondary care, Quebec Canada | Intervention study with historic control | To assess safety, feasibility and adherence to an in-patient PR programme using Virtual Games System Wii games | **Inclusion:** Patients admitted to 3-4 week PR program referred by physician, community home care service, or transferred from an acute care hospital.<br><br>Patients with moderate to severe COPD<br><br>**Exclusion:** Individuals with severe cardiovascular disease, physical or psychological impairment impeding exercise. limited life expectancy, unable to answer questionnaires, or | **Intervention** n:32<br>Female: 21 (66%)<br>Age(range): 66 (52-85)<br>GOLD: ii- 13%,<br>iii-10%,<br>IV- 77%<br>Smoking pack years: 80 (± 62.7) range 7-250<br><br>**Control** n:NR<br>Female n(%): NR<br>Age (range): NR<br>GOLD: NR<br>Smoking History (pack years) :NR | **Individualised virtual game system Wii** was offered 3 times x week in addition to standard 5 x inpatient PR.<br><br>Participants played at least 2 different types of game per session: 1x lower body & 1x upper body workout.<br>Each type of exercise had different game options and levels.<br>Used for varying lengths & game levels. | Enablement<br>Incentivisation<br><br>**BCTs**<br><br>Self-monitoring of behaviour<br><br>Feedback on behaviour<br><br>Feedback on Outcomes of behaviour | 5 x a week regular inpatient PR | | | **X** |

| Author, setting and country | Study Design | Study Aim | Inclusion/Exclusion | Baseline characteristics | Intervention | Intervention functions and active components (BCTs) | Control | PR Pathway | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | Referral | Uptake | Adherence |
| | | | unwilling to provide written consent. | | | | | | | |
| **Graves 2010**<br><br>Secondary Care, England | Intervention study with historic control | To investigate the effect of a group opt-in session prior to the initial baseline assessment to try to increase appropriate uptake and successful completion of the PR course. | **Inclusion:**<br>Patients referred to PR<br><br>**Exclusion**: NR | **Intervention**<br>Group n: 400<br>Female: 157 (39%)<br><br>**Control**<br>Group n: 200<br>Female n(%): NR | **Pre-PR face to face session:** 90 minutes, 8-12 weeks after referral, attend mandatory session with physio and psychologist to discuss fears, expectations and PR content. | Education<br>Persuasion<br><br>**BCTs**<br>Information about social and environmental consequences<br><br>Feedback on outcomes of behaviour<br><br>Credible source | No pre- PR session (usual care) | | X | X |
| **Ulrik 2010**<br><br>General Practice, Denmark | Intervention study with historic control | To establish whether an educational program could improve adherence to COPD guidelines, including referral to PR (diagnosis, staging and | **Inclusion:** General Practice staff: voluntary participation of GPs.<br>Patients:<br>GP diagnosed COPD based on Age ≥ 35 years, and at least two prescriptions for an inhaled (short- or long- | Total GPs n:124<br>**Survey 1: Before**<br>Patient n:1716<br>$FEV_1/FVC$ - only 45% included relevant data (of which 21% fulfilled diagnostic criteria < 0.7)<br>Age (range):68 (35-95)<br>Male/female (%): 44/56% | **Education program for General Practice staff** based on the GOLD guidelines designed by a group of Danish pulmonologists and GPs with a special interest in COPD. Individual, local, and regional meetings. | Education<br>Enablement<br>Persuasion<br><br>**BCTs**<br>Information about health consequence<br><br>Social support<br><br>Credible source | No control | X | | |

| Author, setting and country | Study Design | Study Aim | Inclusion/Exclusion | Baseline characteristics | Intervention | Intervention functions and active components (BCTs) | Control | PR Pathway | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | Referral | Uptake | Adherence |
| | | treatment of disease). | acting β2 agonist, short- or long-acting anti-cholinergic drug, or, a combination of the two) within the previous year.<br>**Exclusion**:<br>Nil reported for HCP.<br><br>Patients considered to have asthma were excluded. | Smoking pack years: 40 (range 1-110)<br><br>**Survey 2: After**<br>Patient n:1342<br>$FEV_1/FVC$ - (of which 48% fulfilled diagnostic criteria < 0.7)<br>Age (range): 68 (35-97)<br>Male/female (%): 48/52<br>Smoking pack years - 40 (range 3 - 120) | | | | | | |
| **Foster 2016**<br><br>General Practice, UK | QI study with historic control | Project aimed to develop and introduce a range of strategies to influence the behaviour of (GPs & practice nurses) & patients with COPD as a means of increasing PR referrals. | **Inclusion:** Not explicitly specified but Drs and nurses working across primary care in one CCG.<br><br>Practice COPD patients eligible for PR (MRC >3)<br><br>**Exclusion:** Not explicitly stated. | **General practices** n:8<br><br>**Patients** n:126<br>Current smoker: 27<br><br>**HCP:** GPs (n9) & practice nurses (n13) | 6/8 practices had 30 min **in-house training** (for particularly GPs) **run by PR service**.<br><br>Screen prompts at COPD review.<br>Practice protocol re: referrer role & when to refer n:NR<br><br>Memory aids-logo on coasters/mugs n: NR | Education<br>Environmental restructuring<br><br>**BCTs**<br>Information about health consequence<br><br>Adding objects to the physical environment<br><br>Prompt/cues | No control | **X** | | |

| Author, setting and country | Study Design | Study Aim | Inclusion/Exclusion | Baseline characteristics | Intervention | Intervention functions and active components (BCTs) | Control | PR Pathway | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | Referral | Uptake | Adherence |
| | | | | | Pop up alerts for eligible patients (assuming outside of COPD review) n: 2/8 practice | Credible source | | | | |
| **McCarron 2019**<br><br>Secondary care, UK | QI study with historic control | Retrospective analysis of patient reported PR barriers and enablers. This was used to inform QI initiative with the aim of increasing future PR uptake. | **Inclusion:** All people referred for PR in 2016. Questionnaire to randomly selected patients referred to PR who attended, attended and dropped out, did not attend.<br><br>**Exclusion:** NR | **1 year Pre Group** (invited to attend PR) n: 281<br><br>**2 years post Group** (invited to attend PR) n: 323 | **Patient information** (both written and audio-visual (AV) and **education of physicians** on the importance of PR and how to make a referral | Environmental restructuring<br>Education<br>Training<br>Modelling<br><br>**BCTs**<br>Adding objects to the physical environment<br><br>Prompt/cues<br><br>Information about health consequences<br><br>Demonstration of the behaviour | No control | | **X** | **X** |
| **Hopkinson 2012** | Service evaluation | Implementation of a care bundle has the | **Inclusion**: Patients being discharged from | **Intervention:** n:94 Female (n, %): 34 (36%) | **Intervention: Patient Education and support: Implemented** | Environmental restructuring<br>Education | **No control** | **X** | | |

| Author, setting and country | Study Design | Study Aim | Inclusion/Exclusion | Baseline characteristics | Intervention | Intervention functions and active components (BCTs) | Control | PR Pathway | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | Referral | Uptake | Adherence |
| Hospital respiratory ward, London UK | with historic control | potential to produce a dramatic improvement in compliance with optimum COPD health care practice. | respiratory ward following admission to hospital with acute exacerbation of COPD Sept 2009 - August 2010<br><br>**Exclusion:** Not reported | COPD (n,%): 94 (100)<br>Age (Mean/SD): 74.6 (11.2) years<br>Current smokers: 24 (25.5%)<br>Prior PR: NR<br><br>**Pre-comparator** n:22<br>Female (n,%): NR<br>COPD (n,%): NR<br>Age: NR<br>Smokers: NR<br>**Staff:** NR | **via COPD discharge bundle.** Telephone support post discharge<br><br>**Intervention: Staff Education and support:** Directions to notify respiratory nurse specialist, implement discharge bundle* and prize draw incentive. | Incentivisation<br><br>**BCTs**<br>Action planning<br>Prompts/cues<br><br>Information about health consequences<br><br>Material reward | | | | |
| **Angus 2012**<br><br>General Practice, UK | Uncontrolled feasibility study | To determine if the use of a computer-guided consultation that facilitates NICE (COPD) guidance, prompts clinical decision-making and is feasible in primary care. | **Inclusion**: People on the COPD register of general practices due for routine COPD review<br><br>**Exclusion:**<br>None given | **General Practices:** 16<br><br>**Patient** n:293<br>Female (n,%): 130 (44.4)<br>COPD based on spirometry (n,%): 191 (65.1)<br>Age (Mean/SD): 69.7 (10.1)<br>Smoking History: 261/293 (89.1%)<br>**HCP:** 18 nurses, 7 of whom had no previous COPD training. | 45 minute **consultation using computer guided consultation software** based on NICE COPD guidelines and including PR. | Environmental restructuring<br><br>**BCTs**<br><br>Restructuring the physical environment<br><br>Prompt/cues | No Control | **X** | | |

| Author, setting and country | Study Design | Study Aim | Inclusion/Exclusion | Baseline characteristics | Intervention | Intervention functions and active components (BCTs) | Control | PR Pathway | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | Referral | Uptake | Adherence |
| **White 2019**<br><br>Community, London, England | Uncontrolled feasibility study | This study was designed to test the feasibility of conducting a cluster randomized controlled trial of the efficacy of LHWs in improving uptake and completion of PR in COPD. | **Inclusion:** COPD patients newly referred to PR appointment in three PR services in the London Boroughs of Lambeth, Lewisham, and Southwark.<br><br>**Exclusion:** Significant other physical or mental health problems that would interfere with participation | **COPD patients receiving LHW support** n:66<br><br>**LHW** n:40 applied of which n12 supported patients<br><br>Mean time since LHW completed PR months n (range): 4.6 (0–14) | **Peer support (LHW) for COPD patients referred to PR**<br><br>LHW had had 3 days of training, 3 additional phone sessions, 8 mentor meetings | Enablement<br><br>**BCTs**<br><br>Social Support | No control | | **X** | **X** |
| **Sewell 2017**<br><br>Secondary Care, England | Uncontrolled service evaluation | Evaluate COPD bundle on referral rates to PR. | **Inclusion**: Primary reason for hospital admission - suspected AECOPD<br><br>**Exclusion**: Not explicitly stated | **Patient** n:1170<br><br>COPD (n,%): 1170 (100) | **COPD discharge bundle** delivered by specialist respiratory nurses (REDS) to inpatients pre-discharge- 5 quality outcomes plus SM manual & breathe easy contacts. | Environmental restructuring<br><br>**BCTs**<br><br>Action planning<br>Prompts/cues | No control | **X** | | |

| Author, setting and country | Study Design | Study Aim | Inclusion/Exclusion | Baseline characteristics | Intervention | Intervention functions and active components (BCTs) | Control | PR Pathway | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | Referral | Uptake | Adherence |
| | | | | | REDS nurses liaised closely with respiratory ward teams to encourage referral to the COPD discharge care. | | | | | |

*NR = Not reported, LHW = Lay Health Worker, QI = Quality Improvement, MRC = Medical Research Council dyspnoea scale, $FEV_1$=Forced Expiratory Volume in one sec, FVC = Forced Vital Capacity, GOLD = Global Initiative for Chronic Obstructive Lung Disease

## 2.27 **Identified study PR pathways**

Of the 17 identified full text studies only one examined all three components of the PR pathway (179). Three studies focused on two PR pathway elements, uptake and adherence (185, 187, 190). One study however, focused on referral but measured uptake as an outcome measure (183) rather than the referral rates. The remaining 12 implemented interventions by targeting isolated pathway element; six targeted referral (122, 182, 186, 188, 189, 191), two to uptake (89, 178) and the remaining four focused on adherence (168, 180, 181, 184).

Two studies (181, 190) specified study aims to increase uptake and adherence to PR through the use of peer support workers, yet neither reported any outcome measures on Intervention effect, nor offered any written explanation. The omission of this outcome data subsequently impedes the ability to draw conclusions on intervention effectiveness and for that reason both were removed from this review and are excluded from further analysis.

Of the eight controlled studies (cluster RCT, RCT and CCT) only 3/8 targeted referral pathways (179, 182, 183), meaning referral pathway interventions studies were more likely to informed by non-randomised study design (n=5) than randomised.

## 2.28 **Methodological Quality Assessment**

Table 6 below presents the evaluation of the risk of bias (RoB) (176) of the five randomised studies. Whilst there were relatively few elements with high risk of bias across and within

the studies, reporting was unclear in many instances, giving cause for concern as this impacted on abilities to make methodological judgements, thus, affecting the integrity of the overall findings. The main areas of weakness were related to the lack of blinding of the intervention, particularly for HCPs, although given the nature of the interventions this is not surprising. The study judged to have the lowest risk of bias was Barker et al (192), which tested the value of demonstrating PR on a tablet to patients admitted to hospital with an AECOPD in comparison to usual care.

**Table 6: Risk of Bias**

| | **Random Sequence generation** (selection bias) | **Allocation concealment** (selection bias) | **Blinding of participants and personnel** (performance bias) | **Blinding of outcome assessors for all outcomes** (detection bias) | **Incomplete outcome data** (attrition bias) | **Selective outcome reporting** (reporting bias) | **Other sources of bias** |
|---|---|---|---|---|---|---|---|
| **1. Zwar 2012** Cluster RCT | Low | Low | High | Low | High | Low | Unclear |
| **2.Zwar 2016** Cluster RCT | Low | High | High | Low | Low | High | High |
| **3.Barker 2020** RCT | Low | Low | Low | Low | Low | Low | Unclear |
| **4.Pumar 2019** RCT | Low | Low | Unclear | Unclear | Unclear | Low | High |
| **5.Ringbaek 2016** Quazi-randomised | Unclear | Unclear | Low | Low | Low | Unclear | Unclear |

There were 10 studies that were of a non-randomised design and were methodologically assessed by ROBINS-I as recommended by Cochrane (58). This assessment tool has six

assessment domains (see table 7, p 82) (177). The 10 non-randomised studies were particularly varied in design which itself brings a number of methodological concerns. Two studies were CCTs meaning a control group was present, however most of the included studies (n6) utilised historical data for comparison. The two remaining studies had no comparison data. The lack of control group in 8/10 studies is a cause for concern, as any effect observed cannot necessarily be attributed to the intervention (193). There were also potential problems with selection bias, for example the reporting of participants previous PR attendance was omitted in all but one non randomised study (183).

The majority of studies were also not registered with any trial registries meaning there may have been variation in the initial planned study design and outcome measures to that which was finally reported. Similar to the randomised trials, there were many assessment domains rated as 'unclear', limiting the assessment of methodological quality. Where quality could be assessed, the main problems were related to missing data, including baseline patient and HCP characteristics and fundamental outcome measures across all three PR pathways. The key omitted data for patients related to previous PR attendance and HCP characteristic data including number involved in intervention delivery , gender, job role and post registration respiratory education. However, excluding these study designs would have limited insights of real-world practice (177). Including the efforts of researchers trying to overcome the PR referral uptake and adherence barriers, may inform the design of potential interventions that might be tested more rigorously.

**Table 7: ROBINS-I assessment tool**

| | Bias due to confounding | Bias in selection of participants into the trial | Bias in classification of interventions | Bias due to deviations from intended interventions | Bias due to missing data | Bias in measurement of outcomes | Bias in selection of reported result |
|---|---|---|---|---|---|---|---|
| **1. Roberts 2015** | Moderate | Low | Low | Unclear | Low | Low | Unclear |
| **2.Harris 2009** | Serious | Low | Low | Unclear | Serious | Moderate | Unclear |
| **3.Wardini 2013** | Unclear | Serious | Low | Critical | Unclear | Unclear | Unclear |
| **4. Graves 2010** | Unclear | Moderate | Moderate | Unclear | Moderate | Low for attendance<br>Serious for adherence | Unclear |
| **5. Ulrik 2010** | Critical | Serious | low | Serious | Unclear | Critical | Unclear |
| **6.Foster 2016** | Serious | Serious | Moderate | Unclear | Critical | Critical for HCPs<br>Moderate for patients | Unclear |
| **7.McCarron 2019** | Critical | Unclear | Moderate | Low | Low | Moderate | Unclear |
| **8.Hopkinson 2012** | Unclear | Unclear | low | Unclear | Unclear | Unclear | Unclear |
| **9.Angus 2011** | Low | Low | Low | Low | Moderate | Serious | Unclear |
| **10. Sewell 2017** | Unclear | Unclear | Unclear | Unclear | Unclear | Unclear | Unclear |

## 2.29 **Outcome data relative to PR referral**

Intervention outcome data related to increased PR referral are presented in table 8, pg. 83. All but one study (183) opted to report outcomes to PR uptake, rather than referral rates as a measure of intervention effectiveness. This outcome data is presented in table 9, p 88.

**Table 8 Interventions to improve referral to PR: outcomes**

| Author | Study Design | Setting | Intervention | Comparator | Patients referred to PR: N (%) | Notes |
|---|---|---|---|---|---|---|
| **Barker 2020** | RCT | Secondary Care | Educational video to patients | Usual care | **Intervention**<br>70/98 (71%)<br><br>**Control**<br>68/98 (69%)<br>(P-value = 0.754) | Good balance of groups<br><br>High number of previous PR attenders. |
| **Roberts 2015** | CCT | Primary Care | Scorecard | Usual care (included self-management plan & rescue pack) | **Baseline:**<br>**Intervention** n/N: 10/595 (1.7%)<br>**Control** n/N: 15/755 (2.0%)<br>**Referral at 3 months (excluding cluster effects :)**<br>**Intervention** n (%): 51/655 (7.8%)<br>**Control** n (%): 37/804 (4.6%)<br>(no P-value reported)<br>Compliance with 6 x NICE COPD quality indicators, including PR referral<br>(Generalised linear clustered model estimates)<br>**Intervention**: 8.6%<br>**Control**: 2.2%<br>(P-value = 0.03) | Took place alongside a broader COPD QI initiative across 3 boroughs as detailed in control.<br><br>Number in group variation, more at 3 months than baseline |
| **Harris 2009** | CCT | Secondary Care | Patient held manual including suggested questions to ask Dr | Usual care (including single sheet on COPD) | OUTCOME MEASURE IS ATTENDENCE so is reported in uptake (table 10) | Targeted referral but measured uptake |
| **Ulrik 2010** | Intervention study with historic control | Primary Care | HCP attended education programme | Usual care | HCP n124 sampled 20 self-selected patients (expected patient n:2480)<br><br>**Pre (survey 1)** reported n:1716 of which 12% referred to PR | GPs self-selected 20 patients to inform data outcomes, but numbers are lower: large numbers of patients missing (n1138, 45.9%). |

| Author | Study Design | Setting | Intervention | Comparator | Patients referred to PR: N (%) | Notes |
|---|---|---|---|---|---|---|
| | | | | | **Post (survey 2)** reported n:1342 of which 16% referred to PR (NS) | Few had COPD measured FEV1 /FVC ratio in the first survey, this increased in the second (P<0.001)<br><br>17% more smokers in survey 2. |
| **Foster 2016** | Intervention study with historic control | Primary Care | In house training for GPs<br>Screen prompts<br>Memory aids | No control | **Pre** n(%): 16/168 (9.5)<br><br>**Post** n(%): 59/126 (48.8) | 490 questionnaires were distributed to eligible PR patients only 126 returned, so referral numbers maybe lower.<br><br>Of the 126 returned no PR outcomes responses recorded for n45 patients |
| **Hopkinson 2012** | Service Evaluation with historic control | Secondary Care | COPD Discharge Bundle & staff education | No control | **Post** n(%) 64/94 (68)<br><br>**Pre** n(%) 3/22 (13.6) | |
| **Angus 2011** | Uncontrolled feasibility study | Primary Care | Electronic consultation | No control | **Referred** 47/191 (24.6%) | |
| **Sewell 2017** | Uncontrolled Service Evaluation | Secondary Care | COPD Discharge Bundle (+self-management bundle and *Breathe easy* contacts) | No control | **3 months**: n(%):88/228 (38.6)<br>**6 months**: n(%) 157/270 (58.1)<br>**9 months**: n(%) 190/330 (57.6)<br>**12 months**: n(%) 192/342 (56.1)<br>**Total:** 627/1170 (53.6%) | |

*NICE = National Institute of Health and Clinical Excellence, P = P-value, RCT = Randomised Controlled trial, CCT = Controlled Clinical Trial

## 2.30 **Results on interventions to increase referral: narrative description**

There are eight studies presented in table 8 that tested interventions that sought to increase referral to PR by reported referral rates (122, 179, 182, 183, 186, 188, 189, 191). One was an RCT (179), two CCTs (182, 183) and three further non-randomised studies with historical controls (122, 186, 188) and two non-randomised studies without historical controls (189, 191). All eight studies ranged evenly across primary and secondary care settings, spanning a 10 year period. Seven were undertaken in the UK and one conducted in Australia (183).

Of these eight studies, five were targeted towards health care professionals which were predominately focussed on increasing knowledge of COPD through local education training events (122, 186) and/or provision of prompts guided by COPD centred software platforms (189) or paper based platforms such as COPD discharge bundles (188, 191). However, two of the most recent studies targeted both HCPs and patients (179, 187) by combining interventions that aimed to increased PR awareness and education for both patients and HCPs.

The RCT included 198 patients admitted to hospital with an AECOPD (179). All received COPD discharge bundles plus verbal and written information on PR, whilst PR eligible patients (stipulated as $\geq$MRC 2) in the intervention group received a video demonstration of PR on a tablet device. There was no statistical difference in referral rates between the control (69%) and intervention (71%) groups p= 0.754. Incidentally it is possible that this

intervention (along with the COPD discharge bundle) indirectly increased HCPs PR knowledge and awareness, which may have influenced HCP and patient PR conversations.

The two controlled clinical trials sought to empower patients by increasing their COPD knowledge with patient held paper-based COPD educational material (182, 183). Patients were encouraged to share this material at their respiratory healthcare consultations and to ask for evidence-based guideline recommended care by way of prompting HCPs. However only one reported outcomes on referral rates (182), whilst the other Harris et a (183) reported patient uptake rates, which will be included in the uptake discussion presented in table 9, pg 88. Robert's et al (182) score card intervention saw an increase in PR referral from baseline, 1.7% to 7.8%, and an increase of 4.6% when compared to control. Although not randomised Robert et al's controlled trial had the highest methodological rigour after the RCT and reported small, but statistically significant increases in compliance with six NICE COPD quality indicators, including annual reviews, self-management plan, smoking cessation and referral to PR where MRC <3 (p-value 0.03) when compared to control (182).

The remaining five non-randomised studies (122, 186, 188, 189, 191) utilised strategies that largely focused on increasing HCP education and awareness of PR and utilised prompts such as electronic care plans and (secondary care) discharge bundles. All report increases in referral rates ranging from 16-68%, however caution is advised largely because none had concurrent control groups. Additional methodological concerns have been highlighted earlier but also, and as is relevant for all included studies, PR referral recorded as an outcome measure may not always translate to mean a referral has been sent and received.

For example in Foster et al's study (122) outcome data is reported based on 'patient accepted a referral to PR'. Measuring uptake subsequent to interventions that test referral are therefore likely to be a more reliable measure of intervention effectiveness.

## 2.31 Outcome data relative to PR uptake

Uptake data related to interventions that sought to increase PR attendance to initial assessment and/or session one of a PR programme are presented in table 9, pg. 88 and offers a total of six studies. Two studies (179, 187) were continuations of interventions that sought to increase and measure referral rates and four new studies introduced interventions that targeted uptake (89, 178, 185, 187). All studies report patient programme uptake, with only one reporting assessment attendance and commencement of PR programme itself (185).

**Table 9 Interventions to improve uptake to PR (attendance to assessment and/or session 1): Outcomes**

| Author | Study Design | Setting | Intervention | Comparator | Attendance at start of PR: N (%) | Notes |
|---|---|---|---|---|---|---|
| **Zwar 2012** | Cluster RCT | Primary care | Home visit by COPD trained nurse + personalised care plan | Usual care + COPD national guidelines sent to practices | **Intervention** n: 50 (31.1%)<br><br>**Control** n: 16 (9.6%)<br><br>OR 5.16 (95% CI 2.40–11.10)<br>P value=0.002 | |
| **Zwar 2016** | Cluster RCT | Primary Care | Practice staff x3 COPD workshops. Practice nurse – case finding and spirometry training<br><br>Electronic care plans based on guidelines implemented | Practice nurses case findings and spirometry training | **Intervention:** 2 (1.4%)<br><br>**Control** n: 0<br><br>P value n/a | No explanation is offered in relation to the very low attendance rates in either intervention or control. |
| **Barker 2020** | RCT | Secondary Care | Educational video to patients | Usual care | **Intervention n:** 33/98 (34%)<br><br>**Control n:** 40/98 (41%)<br><br>P value = 0.37 | Good balance of groups<br><br>High number of previous PR attenders.<br><br>Outcomes remain similar in these groups. |
| **Harris 2009** | CCT | Secondary Care | Patient held manual including suggested questions to ask Dr | Usual care (including single sheet on COPD) | Stratified by SED (Poisson modelling was used to compare proportions attending PR)<br><br>High SED n22<br>**Intervention:** 22 (18%)<br>**Control**: n72 (0%) (p value= 0.05)<br>**Control**: 0% | Significant differences in SED, Living alone and % previously attending PR (p0.001).<br><br>Analysis adjusted for baseline difference |

| Author | Study Design | Setting | Intervention | Comparator | Attendance at start of PR: N (%) | Notes |
|---|---|---|---|---|---|---|
| | | | | | Low SED n78<br>**Intervention:**12%<br>Low SED n29 (p value= 0.29)<br>**Control**: 7%<br><br>**Overall n (%)**<br>**Intervention:** 30/100 (30%)<br>**Control:** 7/101 (6.93%) | |
| **Graves 2010** | Intervention study with historical control | Secondary Care | Pre-PR opt in session | Usual care – no pre-PR opt in | **Attendance at PR opt in session**<br>**Intervention:** 289/400 (72.3%)<br>**Control**: NA<br><br>**Attendance at PR assessment**<br>**Intervention**: 235/400 (58.7%)<br>**Control**: 150/200 (75%)<br>P value = < 0.001<br><br>**Attendance at start of PR programme**<br>**Intervention**: 207/400 (51.6%)<br>**Control:** 106/200 (53%)<br>p value = ns | Difference in group numbers:<br>Intervention group: n400<br>Control group: n200 |
| **McCarron 2019** | QI with historical control | Primary Care | HCP education and improved written and audio-visual material for patients | Historical control | 1 year pre n: 163/281 (58%)<br>**Attendance at start of PR programme**<br>2017: 101/138 (73%)<br>2018: 165/185 (89%)<br><br>2017+ 2018: 266/323 (82.3%)<br>P value = 0.0001 | P-value reports 12 month pre comparison with 24 months post (2017/18). |

*OR = Odds Ratio, CI = Confidence Interval, SED = Socioeconomic disadvantage level, ns = not significant, NA = Not Applicable, RCT = Randomised Controlled trial, CCT = Controlled Clinical Trial

## 2.32 **Results of interventions to improve PR uptake: narrative description**

There are six studies presented in table 9 that tested interventions that sought to increase uptake to PR by measuring participant attendance at PR assessment and/or to the first PR programme session (89, 178, 179, 183, 185, 187). Two were cluster RCTs (89, 178), one RCT (179), one CCT (183) and two further non-randomised studies with historical controls (185, 187). There was an even split geographically amongst the studies; three were UK based (179, 185, 187) and three Australia (89, 178, 183), spanning an 11 year period. Three were based in primary care and three in secondary care settings.

Three of the six studies were interventions targeted at patients such as pre-PR sessions and education. Similarly, interventions targeted to HCPs included largely education, electronic software embedded prompts and targeted COPD discussions undertaken within home visits. One study McCarron et al, targeted both HCPs and patients by increasing PR awareness using education and improving written sources (187).

The cluster RCT conducted by Zwar et al (89) reports over 20% greater uptake to PR as a result of HCPs visiting patients at home (31.1% v 9.6%; OR, 5.16; 95% CI, 2.40–11.10; P=0.002). The Barker et al RCT of patient targeted PR video demonstration reports no increase in uptake rate between the two groups p = 0.37 (179). Incidentally, despite high levels of initial referral (intervention 71%, control 69%) there is a 37% and 28% respective fall in patient uptake. Meaning commencement rates were 34% for intervention, which as a point estimate is lower than the 41% for control.

Harris et al's CCT (183) of COPD manuals reports intervention effectiveness (30% vs 6.9%), particularly for those in the highest socioeconomic disadvantaged groups, although there are baseline group concerns that impact on methodological quality (see table 7, pg. 82 for ROBINS-I assessment).

The historical controlled studies reported varied results. The pre-PR session did not result in significant increases in rates of PR uptake (207/400; 51.8% vs 106/200; 53%) (185). The HCP and patient intervention study of education and improve audio-visual material (187) reports increases in patient uptake from 58% to 73% and 82%, at one and two years post intervention initiation, which was reported to be statistically significant p value= 0.0001. The three studies conducted in primary care sought to target primarily general practice staff (89, 178, 187), whilst those in secondary care were patient focused (179, 183, 185). It can be concluded that these outcomes highlight a HCP directed intervention has a greater effect on uptake than does patient intervention(s) tested in isolation of the HCP, however it would be expected that the implemented intervention(s) would also have affected referral rates, reporting referral rates would have been valuable as it was for both (179) and (187).

## 2.33 Outcome data- interventions that seek to increase PR adherence

There were seven studies that sought to improve participant adherence to PR as shown in table 10, pg. 92. Whilst three studies were continuations of interventions that sought to increase and measure referral/uptake and/or adherence rates (179, 185, 187), four new studies introduced interventions that targeted the direct engagement of PR participants.

**Table 10 Interventions to improve adherence to PR: Outcomes**

| Author | Study Design | Setting | Intervention | Comparator | Adherence to PR: N (%) | Notes |
|---|---|---|---|---|---|---|
| **Barker 2020** | RCT | Secondary Care | Educational video to patients | Usual care | **Completion**<br>**Intervention** 15/33 (45.5%)<br>**Control** 23/40 (57.5%)<br>P =0.305<br><br>**N (mean) of sessions attended.**<br>**Intervention:**<br>8 (6)/16 sessions<br>**Control:**<br>10 (6)/16 sessions | Outcomes reflect the number that started PR not referral number.<br><br>High loss to follow up.<br><br>Outcomes remain similar in these groups. |
| **Pumar 2019** | RCT | Secondary Care | CBT before/after 8 week course of usual group PR with 4x telephone CBT (during or after PR) | Usual – 8 weeks of PR<br>(4 sham telephone calls after PR) | **N of sessions attended**<br>**Intervention**<br>14 (± 1.7)/16 sessions<br>**Control**<br>12.4 (± 2.6)/16 sessions<br><br>(mean difference reported as 1.59, 95% CI 0.11-3.07 P= 0.03) | 1:1 allocation stated in methods, but considerable imbalance in numbers I:C (24:41) and differences in baseline characteristics: gender, previous anxiety or depression, % with COPD. |
| **Ringbaek 2016** | Quasi-randomised | Secondary care | Tablet for PR participants to use in addition to PR | Usual group PR | **N of individuals completed PR**<br>**Intervention**: 42/46 (91.3%)<br>**Control**: 57/69 (82.6%)<br><br>p=0.19 | n12 (17.4%) drop out in control and n4 (8.7%) drop out in intervention.<br><br>Total sessions either 14 or 20 dependent on venue.<br><br>Session number not reported |

| Author | Study Design | Setting | Intervention | Comparator | Adherence to PR: N (%) | Notes |
|---|---|---|---|---|---|---|
| **Warddini 2013** | Intervention study with historical control | Secondary care | Individualised virtual game system Wii | Usual group PR | **PR adherence (attended 50% of sessions)**<br>**Intervention**: 25/32 (78%)<br>**Control:** NR<br><br>Mean attendance rate measure as sessions attended:<br>**Intervention**<br>64% (+/- 35%)<br>**Control**<br>88% (+/- 13%) | In study adherence reported as 76% but calculated at 78%. |
| **Graves 2010** | Intervention study with historical control | Secondary Care | Pre-PR opt in session | Usual care – no pre-PR opt in | **PR adherence:** (reported as n of attendees who graduated)<br><br>**Intervention:** 182/207 (87.9%)<br>**Control:** 81/106 (76.4%)<br>p=0.05 | Group imbalance<br><br>Session number not reported. |
| **McCarron 2019** | QI with historical control | Primary Care | HCP education and improved written and audio-visual material for patients | No control | **Completed PR Programme**<br>2016 (1 year pre): 125/163 (77%)<br><br>2017 post: 45/101 (57.5%)<br>2018 post: 108/165 (65%) | Outcomes reflect the number that started PR not referral number. |

* CI = Confidence Interval, P = P-value, NR = Not Reported, RCT = Randomised Controlled trial, CCT = Controlled Clinical Trial

## 2.34 Results on interventions to improve PR adherence: narrative discussion

There are six studies presented in table 10 that tested interventions that sought to sustain PR adherence by measuring the rate of patient attendance (168, 179, 180, 184, 185, 187). Two were RCTs (179, 180), one quasi-randomised trial (168) and three non-randomised studies with historical controls (184, 185, 187).Five out of six studies were secondary care based, with worldwide geographical spread including; UK, Canada, Denmark and Australia and span a 10 year period.

An RCT of a CBT intervention to improve attendance and participation (180) reported the intervention as being more effective in enhancing PR adherence than usual care, yet a number of aspects which were not clearly reported made methodological assessment challenging, including reasons behind the group randomisation imbalance (intervention 41; control 24), but 1:1 randomisation was expected as reported in the paper. Ringbaek et al's quasi-randomised controlled trial using an electronic diary to support PR adherence report slightly greater effect than control (168). Adherence was higher in the intervention arm (91.3% vs 82.6%, p=0.14) although not statistically significant, but methodological quality was rated as unclear in 4/7 domains of the RoB (176) (see table 6, p 80).

One of the intervention studies with historic controls reported greater adherence to PR following attendance to a pre-PR session (87.9% vs 76.4%; p 0.05) (185). However, the utilisation of historic controls and large group imbalance (n207 vs n106) weakens conclusions. Similarly adding an individualised video game fitness to a PR programme

reported a 78% adherence rate (measured by attendees who attended 50% of sessions) (184), yet the absence of control attendee numbers, means assessment of the interventions effectiveness cannot be reached.

Barker et al' RCT (179) and McCarron et al's Quality Improvement project (QI) (187) reported no intervention effect on adherence rates. Incidentally these were the only two of six studies where the intervention began at the point of referral and which had a likely impact on both HCP and patient. It is also worthy highlighting that that adherence completion rate was reported in comparison with PR starters, rather than those initially referred. Incidentally McCarron et al (187) presents one year pre data, followed by two years post intervention data, yet in this period it is likely that intervention fidelity will have altered, affecting results but this is not addressed within the study itself.

A further overarching concern in relation to adherence outcome reporting is the variability in the measure of adherence itself. Barker et al (179) reports attendance at 50% of PR sessions (8/16); intervention mean 6/16 (37.5%) vs 10/16 (62.5%) for control. Pumar et al (180) reports session attendance rates > 61.3% and Wardini et al (184) reports PR adherence where > 50% of sessions have been attended. However, the remaining studies do not offer a defining measure for adherence, meaning there is no standard reporting measure of what session percentage equates to adherence.

## 2.35 **Intervention functions and behaviour change techniques**

The characteristics table, table 5, pg. 65 presents the main intervention functions and behaviour change techniques (BCTs) used within each of the studies using the Behaviour Change Wheel (BCW) method (171). Intervention functions are defined as the mode of delivery and BCTs represent the active ingredient of the intervention (171). The most frequently used of nine possible intervention functions were 'education' and 'persuasion' in nine and seven studies (including across study duplication).'Enablement', 'training' and 'environmental restructuring' was utilised in six of 15 studies. The lowest intervention mode used twice was 'incentivisation' and 'modelling'. Meaning the interventions 'coercion' and 'restriction' were not used in any included studies.

In terms of BCT alignment there is sometimes overlap across intervention functions, for example 'credible source' is present in both 'persuasion' and 'enablement' and is utilised across eight studies.

## 2.36 **Sub -Group Analysis**

Implementation of the intervention(s) setting was clearly described across all 15 included full text studies which included six (40%) in general practice and nine (60%) in secondary care. Origin of referral was not explicitly clear in studies, meaning sub group analyses could not be undertaken. No study reported interventions that targeted patient self-referral. PR settings were centred-based, with no interventions targeting uptake and/or adherence to home-based PR in this review. There was insufficient data within the included studies to identify

whether the type of referring HCP influenced patient acceptance and subsequent PR uptake. Indeed HCP demographics were largely omitted across all studies.

It was hoped that patient age (over 65 years), an age cut off for retirement would offer insights into adherence, given working status is reported to be a PR barrier. However, patient age was not consistently reported across the studies, and employment status itself was even less frequently reported.

Three secondary care-based studies (179, 188, 191) included patients who had been hospitalised for an AECOPD and referred for PR post discharge. Referral rates here were high post intervention at between 38.6% and 71%, mean 59.2%.

The remaining six general practice-based referral-focused interventions did not specify whether referral was at the point of COPD stability or post community managed AECOPD (122, 182, 183, 186, 187, 189). Four of the six studies reported post intervention referral rates (122, 182, 186, 189), ranging from 7.8% to 48.8%, mean 24.3%, and a lower rate than those in secondary care. There may be a number of variables that contribute to this variation, meaning clear conclusions cannot be drawn on this sub group analysis.

## 2.37 **Abstracts**

Table 11, p 97 present's seven abstracts that met the review's inclusion and exclusion criteria which have not yet been published as full studies (91, 194-199). They offer a variety

of interventions across both primary and secondary care settings designed to increase predominately PR referral and uptake.

**Table 11: Abstracts of studies meeting inclusion criteria**

| Author Setting and study design | Aim | Demographics Inclusion/ exclusion | Intervention (I)/ Control (C) | Outcomes | Notes |
|---|---|---|---|---|---|
| **Angus 2019**<br><br>Primary Care, UK | To assesses the value of electronic consultation clinical support systems in delivering quality standards | Practices with 'lung health' software implemented: n54 practices<br><br>Completed COPD reviews n:741<br><br>**Exclusion**: NR | **I**: Computer guided consultation standardises review and prompts COPD guideline management.<br><br>**C**: NA | n100 PR eligible patients, 23 had been referred & 12% more were referred.<br><br>n192 (32.5%) were current smokers of which 25(13%) accepted referred for smoking cessation. | It is difficult to untangle true referral numbers<br><br>181/741(24 %) did not have obstruction & should not have been on the register. |
| **Avent 2015**<br><br>Secondary Care, UK<br><br>Compariso n study | Do structured exercise classes for inpatients with COPD increase community (PR) referral and completion rates? | Patients admitted with AECOPD (n50)<br><br>**Exclusion:** NR | **I**: Physio led exercise class 2x week n30 (60%)<br><br>**C**:Usual Care n: 20 (40%) | PR referral **Intervention:** (57%) **Control:** (40%)<br><br>PR completion **Intervention** (18%) **Control:** (13%) | Unclear how long patients were inpatients for. |
| **Cornwallis 2017**<br><br>Primary care x 6 & integrated care<br><br>QI | Secondary care held virtual clinics to primary care (PC) and integrated care (ICT) identify patients who would benefit from PR. | **Total** n161<br>PC n: 94<br>ICT n:67<br><br>Mean age: 63 Years (range 38–96)<br>Male: n67 (42%)<br>Mean% predicted $FEV_1$: 51% (range 11–117).<br><br>**Inclusion:**<br>COPD diagnosis<br>FEV <50%<br>High dose ICS<br>**Exclusion:** NR | Virtual clinic<br><br>Group 1: (PC)<br><br>Group 2: (ICT)<br><br>No control | PR referral recommended:<br><br>PC: n38/94 (40%)<br><br>ICT:n9/67 (13%) | No time frames given<br><br>Unclear on referral completed. |

| Author Setting and study design | Aim | Demographics Inclusion/ exclusion | Intervention (I)/ Control (C) | Outcomes | Notes |
|---|---|---|---|---|---|
| **Cox 2019**<br><br>Hospital setting<br>Before and After<br><br>Pre and post study | Video testimonials may facilitate understanding of and referral to PR in people with chronic respiratory disease | Total: n 29<br>Male: n 10<br>Mean age (SD): 71 (8) years<br><br>**Inclusion:** Individuals with stable (COPD) or interstitial lung disease (ILD)<br>**Exclusion**: NR | Watching a video on PR. | Pre video: n18 (62%) (anticipated PR to be beneficial for them)<br><br>Post: n23 (79%) (expected PR would be beneficial for them)<br><br>n8 (28%) all naive to PR, requested referral | No referral rates recorded.<br><br>Despite interest in attending 45% indicated that getting to PR would be hard or somewhat hard. |
| **Nuguru 2019**<br><br>Outpatient Secondary care<br><br>QI | Improving provider adherence to COPD guidelines improves pulmonary rehab referral. | **Pre:** n60<br>**Post:** n30 | 1. Presentation on the current GOLD guidelines.<br>2. An in-service to describe the implementation of the COPD Action Plan<br>3. GOLD guideline adherence Checklist<br>4. Vaccination Pocket Guide | **Pre:** NR<br><br>**Post:** reported as referral rate improved by 5% | |
| **Tong 2017**<br><br>Respiratory Ward, Secondary Care, Australia<br><br>Pre and post audit | Implementation of a COPD pathway based on national guidelines may adherence to AECOPD management guidelines. | **Pre**<br>2012 –n37<br><br>**Post**<br>2013 –n33<br><br>**Inclusion:**70 inpatients AECOPD<br><br>**Exclusion:** NR | COPD Pathway was a locally-designed, one-page checklist for clinical staff based on key components of AECOPD management from the COPD-X guidelines | **Referred to PR**<br><br>Pre: 24%<br><br>Post:52% | More in pre than post group. |
| **Wexler 2019**<br><br>Secondary Care, USA<br><br>QI | Increase referral to PR | Pre:n21<br>Post:n23<br><br>**Inclusion:** Patients admitted with AECOPD<br><br>COPD Gold B≥ | Flyers in clinical area, educational conferences and faculty reinforcement. | **Referred to PR**<br><br>Pre: n2 (9%)<br><br>Post: n11 (48%) | Dates:<br>**Pre**: 1/9 - 31/10/2018<br><br>**Post**: 1/11 – 31/12 /2018 |

| Author Setting and study design | Aim | Demographics Inclusion/ exclusion | Intervention (I)/ Control (C) | Outcomes | Notes |
|---|---|---|---|---|---|
| | | at least one exacerbation in the past year **Exclusion:** NR | | | |

*$FEV_1$ = Forced Expiratory Volume in 1 second, FVC = Forced Vital Capacity, ICS = Inhaled Corticosteroid. PC = Primary Care, ICT – Integrated Care Team, NR = Not reported, QI = Quality Improvement

None of the findings reported in the seven abstracts offer vastly different approaches to the full text studies that have been included in this review and all include relatively small patient samples. There are interventions that are targeted to HCPs including education, prompts, electronic computer guided consultations and an integrated primary and secondary care virtual clinic. Patient interventions include increasing exposure to PR promotion material and a pre-PR exercise session.

Again it appears that documented referrals are mainly used as the outcome measure for referral, rather than referrals received by the PR provider which may differ. Avent et al, (194) reported referral and adherence rates increased after implementing a structured inpatient exercise class prior to referral to PR. Referrals and adherence rates appeared to be higher in the intervention compared to the control arm, however, given national drives to reduce hospital length of stays, in hospital exercise is unlikely to be a sustainable intervention. The current median length of stay in hospital for an AECOPD admission in the UK is four days (200).

Multi-pronged and multidisciplinary targeted interventions do however appear to offer the most positive outcomes (195, 196, 198). The combined effects of peer support and its

indirect influence on increasing PR awareness, is likely to be beneficial. Indeed the theme of increasing referrers' PR knowledge and awareness through educational strategies in these abstracts is reflective of the most positive outcomes in the full text studies, most notably in relation to PR uptake (89, 187).

## 2.38 **Ongoing Studies**

There were a further six ongoing studies that were identified in the initial searches that aligned with the review's objectives to identify effective interventions that seek to promote referral, uptake and adherence to PR. Aboumatar (201) reports having completed data collection, and two others report study commencement of recruitment (202, 203). However, none had results to report when invited.

The three registered studies that have not yet started included varied PR intervention designs. Acharya (204) seek to build on the care bundles utilised in secondary care organisations. Based in India they aim to conduct a randomized parallel group trial and recruit 110 patients with COPD admitted to hospital with an AECOPD. It is planned to use admission and discharge COPD bundles to assess overall care, in comparison to usual hospital care but include compliance with PR as a secondary outcome. This study was registered in July 2019 and has not as yet commenced recruitment. Early et al's (205) protocol outlines a mixed methods study which seeks to design and implement a toolkit that aims to increase referral and uptake to PR in primary care in patients with COPD, otherwise known as the 'Restore Study'. In the absence of pre-specified study outcomes this

appears to be a feasibility study and as outlined in its mixed research methods it has two separate but sequential phases where the first (phase 1) will inform the data inquiry of the second (phase 2).

The third pending study, Redfern et al (206) is a RCT that combines cardiac and pulmonary rehabilitation. Whilst its primary aim is to assess effectiveness, an included intervention of five times weekly text support messages to enhance adherence and attendance compared to a control of usual care is of interest in the context of this intervention review.

Two of six studies were actively recruiting at the time of writing (202, 203). Sohanpal et al (202) began recruitment to the TANDEM study in April 2017. Its registration portal indicates it will complete in July 2021. This RCT seeks to recruit 430 patients with COPD and mild/moderate anxiety and/or mild/moderate depression. The intervention is made up of multiple components, but includes individualised cognitive behavioural approach (CBA) sessions delivered by trained facilitators before PR commencement, with on-going telephone support for those waiting for PR to commence and during PR itself. Its comparator is usual PR referral processes. PR attendance and completion are named study outcomes.

The trial registry site indicates the second ongoing RCT known as the Comprehensive Health Informatics Engagement Framework for Pulmonary Rehabilitation (CHIEF-PR) commenced in June 2020 (203) . It aims to recruit 120 inpatients within 4 weeks of an AECOPD, and hypothesises that implementation of a number of interventions including computer-

mediated patient counselling, ongoing home-based support of PR by a tele-rehabilitation system that monitors patients' progress, and remote oversight by clinical PR team, will result in higher rates of PR completion compared to a usual care control.

The final study that has completed data collection is Aboumatar (201). This RCT has utilised a peer support model for patients with COPD (n=292) alongside their caregiver (n=50) based in Maryland, America. Drawing on Bandura's principles of social cognitive theory and self-efficacy (207). Its aims are far reaching as it seeks to advance patients understanding of COPD, treatment, self-care and adherence to treatment plan including joining PR. The intervention is described as a communication approach with one arm using HCPs and the other using HCPs plus peer mentors who are defined as patients with COPD or carers of patients with COPD who have become successful in managing COPD. Completed study publication is awaited.

## 2.39 **Discussion: summary of main results**

This systematic review evaluated a variety of studies, including five RCTs, two CCTs, one quasi randomised trial and seven uncontrolled studies that assessed the effectiveness of interventions aiming to increase referral, uptake and adherence to PR. Of the 15 final included full text studies (89, 122, 168, 178-180, 182-189, 191), six targeted PR referral only (122, 182, 186, 188, 189, 191), one targeted referral, but reported uptake (183), two uptake only (89, 178) and three adherence only (168, 180, 184). Of the remaining three, one targeted uptake and adherence (185) and two, referral, uptake and adherence (179, 187).

Owing to such large diversity of the interventions alongside differing settings and target populations they consequently reported differing outcome measures. It is therefore difficult to draw firm conclusions on interventions that are effective in enhancing referral, uptake and/or adherence to PR following this review. However of the controlled studies trials of a patient-held score card and patient held manual respectively, suggested increases in referral, that were statistically significant (182, 183). The cluster RCT of patient visits by respiratory trained specialist nurses working in partnership with other primary HCPs increased uptake to PR (89). For adherence, Ringbaek et al's (168) RCT of electronic instruction and a patient held training diary which allowed personalised recording of achievements above usual PR appeared to increase adherence.

The RCT of a patient education video added to a discharge bundle at hospital discharge had no additional effect on referral, uptake or attendance (179). Also the cluster RCT of HCP training and electronic care templates had little effect (178).

For the uncontrolled studies both education interventions targeted to HCPs, along with prompts appeared to increase referral (122, 186), as did (189) Angus et al's electronic guided consultation and the two secondary care discharge bundle interventions (188, 191). Yet, no difference in reported PR uptake following patient attendance at a pre-PR session, but PR adherence increased (185). McCarron et al's study (187) found increased uptake rates following HCP education and better visual material for potential referrers, although a decrease in adherence rates.

In relation to intervention functions the two patient focused comparative trials that resulted in statistically significant increased referral and uptake rates respectively used similar interventions: a score card (182) and a COPD manual (183). These studies utilised enablement, training and persuasion as intervention functions. In these studies patients were activists in their own COPD healthcare and used these information sources to request evidence-based care from HCPs, including referral to PR.

Whilst for one effective HCP-targeted referral study the range of intervention functions included education, training and persuasion (89). Uncontrolled HCP studies most frequently utilised environmental restructuring (122, 186, 188, 189, 191).

The three effective referral and uptake interventions adopted a dual persuasion and empowerment approach, delivered from patient to HCP and HCP to patient (89, 182, 183). Finally, for adherence, the two patient focused studies that reported increases in adherence included enablement, education and persuasion as functional interventions (180, 185). This review highlights that education *'increasing knowledge or understanding'* and persuasion *'using communication to induce positive or negative feelings of stimulate action'* (171) (pg. 111) are the most frequent modes of intervention that seek to increase PR engagement. In summary effective behaviour change interventions in this review incorporate education, enablement, persuasion and environmental changes. Similarly in a systematic review of behaviour change interventions aimed at HCPs in primary care, collaboration team-based approaches were found to be the most effective, utilising education, training and enablement interventions (208).

Referral rates of 69% vs 71% in both control and intervention arms of Barker et al's RCT (179) were high when compared to the England and Wales national average of 9.3-15.2% (72, 209). This may indicate that COPD discharge bundles act as positive referral prompts and offer a discussion opportunity between HCP and patients. The additional two uncontrolled studies on discharge bundles however had many methodological areas of uncertainty, meaning clear conclusions cannot be drawn on the specific effectiveness of COPD discharge bundles on PR referral (188, 191).

Previously published systematic reviews concluded there was insufficient evidence upon which to draw recommendations on effective interventions to increase referral, uptake and adherence (166, 167). The first published systematic review on PR adherence conducted in 2017 (166) reported only one study, an RCT. This current review demonstrates there has been an expansion of research into PR and patient engagement. The additional 14 studies identified here demonstrated that widening the scope of the study design was valuable as insights on the variety of interventions were gained, providing potential for future testing in comparative studies. In terms of referral an additional three studies were identified compared to the 2018, systematic review (167). For uptake, this was reported as the main outcome in six studies here, thereby offering three additional studies. Finally of the six full text studies that reported adherence outcomes this review added a further five studies to the 2017 systematic review (166). It is interesting that only two of the most recent studies evaluated the PR journey from referral, through to uptake and finally completion (187, 192), neither of which were included in either of the previous reviews.

## 2.40 **Comparison of findings to cardiac rehabilitation**

Cardiac rehabilitation (CR) is a group based combined exercise and educational internationally recommended intervention (210). Similar to pulmonary rehabilitation it has significant clinical benefits (211). CR differs from PR largely only by its chronic disease focus. CR has the same patient engagement challenges as does PR and interventions to test and improve CR engagement have been investigated over many years (212). The most recently published systematic review on interventions to increase CR rehabilitation participation (213) reported positive CR enrolment in studies where interventions to support engagement to CR were delivered face to face by either a nurse or an allied health professional (AHP) when compared to no one (OR 0.73, CI 0.56-0.94, p=0.02). Also non face to face CR programmes had higher adherence rates when compared to those delivered face to face (OR 0.73, CI 0.57-0.93, p=0.01). Yet concerns about PR programme efficacy with remote and telerehabilitation platforms this is an area that needs more research before recommendations on this approach can be made as highlighted previously.

## 2.41 **Strengths and weaknesses of the review**

The review was carried out and reported according to standards expected by the Cochrane Collaboration (58) and that which seeks to minimise any bias of the reviewing process. The search strategy was revised in order to ensure all relevant studies were included. Study design and conduct was highly variable within this review (as demonstrated in the quality assessment tools of table 6 and 7, (pgs. 80 and 82 respectively), thus affecting the internal study validity and thereby the reliability of some reported outcomes. This is a particularly

limiting factor and strengthens the need for robust study design when conducting research. Few studies were truly randomised, many lacked concurrent comparators and the majority lack statistical testing of reported outcomes.

Education and secondary care discharge bundles appear to be the interventions most frequently tested. It is important to note however that discharge bundles offer predominately a tick box exercise in relation to PR referral, meaning it does not necessarily translate to a referral being sent and received by PR providers. Jones et al (214) reported on this phenomena in a published audit examining use of COPD discharge bundles, where of 448 AECOPD admissions, 286 (63.8%) were eligible for PR but only 90 (32%) of referrals were received. This discrepancy may account for the high numbers of loss to follow-up in Barker et al's (179) study as provider PR referral receipt numbers are not stated in the paper. In light of the referral number sent and received omissions in all of the included discharge bundle studies it is difficult to draw firm conclusions on the true effective of discharge bundles in relation to PR referral. Furthermore the discharge bundles are implemented in secondary care settings and given this accounts for a relatively small percentage of the population with COPD, the testing of effective referral interventions in out of hospital settings is important.

We did not include tele-rehabilitation in this review, as the clinical effectiveness of telerehabilitation for those with COPD when compared to traditional group centre based PR is not yet well established, particularly for those experiencing an AECOPD or within 4-6 weeks of an AECOPD (50). It is however of interest that a small number, three of the seven

included recent telerehabilitation systematic review studies that compared telerehabilitation to traditional PR, reported 95% adherence to telerehabilitation (95% CI 90-96) compared to 70% adherence rates of centre based PR attendees (50).

The COVID-19 pandemic has seen an increase in PR being delivered through a variety of telerehabilitation platforms (51, 215). Telerehabilitation may offer some solutions to the reported barriers patients face in terms of access and may also support those wishing to maintain social distancing practices for infection control benefits, although concerns about the dilution of PR programme efficacy are expressed (216).

MRC guidance for complex intervention (132) recommend that theory is used in the development and application of interventions, yet none of the included studies report any theoretical underpinning to their design or application. This may be an important contributing factor to the limited success of tested interventions thus far and as such measuring the effect of theory-based interventions is likely to be valuable, particularly given a cardiac rehabilitation systematic review on patient engagement intervention effectiveness reported 15/26 (57.7%) were theory based (213). However, a systematic review that tested behaviour change interventions for patients with coronary heart disease when based on physiological theory did not demonstrate improvements in mortality rates (217). Additionally neither the number of BCTs used within interventions, or commonly used BCTs such as goal setting or providing feedback were found to statistically reduced mortality (217).

In relation to psychological theory it is noted that the ongoing studies in this review include a variety of theoretical approaches, Sohanpal et al (202) uses a cognitive behavioural approach (CBA), Aboumatar (201) adopting social cognitive theory and Early et al's (205) purports to use Normalisation Process Theory (NPT).

## 2.42 **Strengths and Limitations of the review process**

This review aimed to follow the published protocol (163), although not all steps were achievable. It was not possible to meta-analyse the findings of these studies because of the heterogeneity in populations, settings, interventions and study designs (58), nor was it possible to undertake a sensitivity analysis because of the inconsistency in reported outcome data. Results have therefore been reported narratively and include discussions on lack of control groups in relevant studies. The same approach has been adopted for subgroup analysis.

A strength of our review is that we categorised interventions using a defined intervention descriptor that would affect behaviour change (137) and aligned intervention functions and BCTs in order to overcome difficulties with intervention categorisation and in order to reduce potential subjectivity (171, 218). We included all study designs including abstracts in order to have a full understanding of clinical practice tested interventions as well as larger funded research trials.

Of the 15 included studies there was widespread variation in study design, which has significantly weakened overall findings and under pinning evidence. All included 15 studies appeared to have reasonable male to female ratios, but further characteristic data such as ethnicity and employment status is frequently missing. There was very little mixed disease populations, with most studies targeting patients with COPD only which is seen as a review strength.

Interventions that included or targeted HCPs frequently omitted characteristic data (89, 122, 178, 186-188). Additionally referral from differing healthcare settings has contextual implications which is likely to impact on the ability to make generalised outcomes relative to different settings. Differing setting also represent a likely different target population, with patients in secondary care settings predominately post an AECOPD, as opposed to the more stable populations in the primary care studies.

As highlighted earlier no study utilised or described the inclusion of psychological theories to guide their study design or to support data interpretation. Given the essence of this effectiveness of interventions review, changing behaviour is necessary, this omission therefore felt to be an important limitation. Additionally descriptors of intervention components are weak and the length of intervention application varied in many studies.

Referral, uptake and adherence all represent differing aspects of the PR journey but there is no standardised definition for each that is used across the studies. It is also not clear whether referral translates to referral received by PR providers, there is additionally variation in time between referral and uptake across PR programmes which is likely to have an effect on adherence and other outcomes, but this is not addressed by any included study. In terms of adherence there is in-study different PR programme lengths (168) whilst some included studies do not reported the number of sessions patients attended (184) a greater number do not report programme length or session number (185, 187).

There are a number of limitations as highlighted in this review, including the inclusion of all study designs, however this was important and is considered to be a review strength, allowing greater awareness and insight to research being conducted across the world.

## 2.43 **Discussion**

The context of healthcare is varied worldwide and whilst tested intervention(s) may offer positive outcomes supporting patient engagement with PR, intervention fidelity alters with contextual changes such as that found in different clinical and geographical settings.
It is recommended that trials of single strategy approaches be tested in order to identify interventions 'active ingredients' (213) however, it is recognised as unlikely that a single approach would overcome the multiple barriers that currently impede PR engagement. Therefore, interventions that consider collaborative working are postulated to offer more

success than standalone interventions regardless of clinical context and whilst this might mask the 'key' ingredient to intervention success its highly unlikely there is one key.

The beginning of the PR journey commences with referral; targeting both HCPs and/patients at referral, rather than patients in isolation would be a recommendation. This is not based solely on the finding in this review (which only included two patient focused studies), but considers the international agenda of empowering those with COPD to self-manage and considers the patients requests for HCP support in making PR referral decisions (66). Additionally, PR provider engagement prior to commencing PR is likely to be important to patients and HCPs, yet this is largely omitted in the studies reported here. The absence of this expert resource prior to PR commencement is an interesting finding and as such increasing provider engagement with patients and HCPs before PR is an important area to investigate. This collaboration would also be likely to promote social support and offer feedback opportunities to the referrer and patient, which may influence referral, uptake and adherence rates.

Although this review focused on specific interventions delivered to certain people to improve referral, uptake and adherence, mode of delivery itself might improve these outcomes, such as a hybrid model as recommended as a result of the cardiac rehabilitation uptake and adherence review findings (213). The review reported uptake is improved when an intervention is delivered face to face and adherence greater when completed unsupervised. Meaning a face to face HCP intervention to enhance uptake followed by

unsupervised PR to maintain adherence maybe an intervention consideration. However, for PR the effectiveness of unsupervised rehabilitation would need to be meta-analysed first.

## 2.44 **Implications for practice**

This review suggests educating HCPs and patients on the clinical and function benefits of PR is important, as is patient and/or HCP empowerment. Prompts, whether online or in the format of discharge bundles or COPD manuals are likely to be helpful in supporting initial referral reminders. Including respiratory educated and motivated staff within intervention delivery is also considered valuable as they are likely to influence those around them. There are a number of national drivers advocating for integrated care working across the UK (39) and implementing patient focused PR referral assessment within virtual integrated multi-professional disciplinary teams (MDTs) may offer a simple and practical intervention as was presented in an included abstract by Cornwallis et al (195), testing this intervention in a cluster RCT is recommended. The PR referral, uptake and adherence pathway is complex, in order to accurately measure an interventions effectiveness it is critical that study design standards are improved.

There is a desire and concerted worldwide effort to test and implement interventions that increase referral, uptake and adherence to PR for patients with COPD, but it is important to measure not just referral rates, but to verify their receipt. Combining referral and uptake rates and outcomes in any subsequent research studies is one way to ensure the collection

of this data as well as offering greater assessment on intervention effectiveness, where starting with referral.

In the UK the majority of PR providers are community based (68), with only 13% reported to be acute hospital based (35) it is therefore interesting to find that for adherence, interventions are tested by only secondary care providers, meaning primary and community PR providers need to do more to identify interventions that evaluate and increase PR adherence. Furthermore, of the studies presented here PR providers themselves only appear to be involved in the studies relative to adherence. PR provider engagement at the point of referral is likely to be of considerable value and is highly recommended based on the findings here, but also based on PHCPs requests (76).

## 2.45 **Conclusion**

PR is a highly effective treatment programme for patients with COPD, leading to significant clinical and personal benefits for those that complete it. This systematic review has included 15 full text intervention studies that aimed to improve PR referral, uptake and adherence rates for patients with COPD. It has found that there is no single standardised effective intervention(s) to enhance referral to, uptake of and adherence to PR. Additionally only a few potential referral, uptake and adherence barriers appear to be addressed within a narrow range of intervention functions. Increased practitioner and patient barrier analysis would be advantageous and would support targeted interventions to be tested, a pending

systematic review publication on the factors that influence referral may offer additional insights (219).

Empowering patients and HCPs through education, enablement and persuasion methods appear important and effective PR levers, particularly when undertaken collaboratively. Furthermore, research that explicitly investigates the contribution of PR providers themselves in enhancing referral, uptake and adherence rates early on in the COPD journey is under investigated therefore recommended, Additionally, ensuring trials utilise robust research methods in order to advance understanding and utilisation of effective outcomes are needed. Ongoing research across the PR field will continue to add value and improve knowledge, which is of particular importance and interest to those with and those caring for patients with COPD, as well as for health service providers worldwide.

## 2.46 **Key Chapter Findings**

This chapter has completed thesis objective 1 (Section 1:21, pg 34) and has identified that there is not one single intervention that increases referral and uptake and adherence rates to PR for patients with COPD. There are a small number of interventions that appear to have improved referral only (n6) with the majority being tested in studies that utilise historic controls only. There are also a small number of Interventions that increased referral and uptake (n3), with two of three utilising real time control groups, rather than historical control. For adherence enhancing interventions there were three included studies, two of which utilised historic controls. Study methodical quality of successful interventions was

therefore very mixed. For referral and uptake the interventions that appeared most successful targeted dual populations, patients and HCPs rather than those targeting patients independently. No study included PR referrers as part of any referral or uptake intervention trial, nor did any study draw on psychological theory to guide design.

For referral, the interventions with the highest methodological rigour was a patient held score care (182). For uptake was home visits by respiratory trained nurses utilising motivational interviewing alongside personalised patient planning and collaborative working with GPs and a COPD manual (89, 183). Studies using historical controls and reporting improvements in PR referral and/or uptake rates tended to increase HCP PR awareness and recording of PR referral.

In summary successful interventions tended to include education, enablement, persuasion and environmental restructuring. Whilst the behaviour techniques most frequently included information about health consequences from credible sources, prompts/cues, restructuring the physical environment and empowerment.

## 2.47 **Next Steps**

Testing PHCPs expert views on the likely suitability of these interventions will next be evaluated in the qualitative and quantitative work within this thesis. These findings will further inform intervention design and development in the final chapter, as aligned to objective number 4, section 1.21, pg.34.

# Chapter 3: A QUALITATIVE STUDY

# REFERRAL OF PATIENTS WITH CHRONIC OBSTRUCTIVE DISEASE TO PULMONARY REHABILITATION

## 3.1 **Chapter objectives**

This chapter presents study 2i of the multiphase thesis design (figure 5, p 38) and aligns to the two research questions and objective number 2, as specified in section 1.21 p 34:
"To identify barriers and enablers to PR referral by PHCPs captured through their descriptive experiences and analysed by two separate data analysis approaches; one inductive and the second deductive, through application of behaviour change theory."

Progressing from chapter 2, it seeks to identify PHCPs experiences and to ascertain PHCPs expert views on the viability and practical application of a variety of tested interventions, across differing settings. This chapter utilises the COM-B model (171) to inform its topic guide. COM-B is a combination of psychological theories which seeks to expose behavioural drivers and barriers. These qualitative findings will be important in reaching and informing the thesis' final objective, the design and development of evidenced-based PR referral enhancing interventions.

## 3.2 **Introduction**

This chapter presents a study that was published in The British Journal of General Practice. The citation is as follows: Watson JS, Adab P, Jordan RE, Enocson A, Greenfield S. Referral of patients with chronic obstructive pulmonary disease to pulmonary rehabilitation: a qualitative study of barriers and enablers for primary healthcare practitioners. British Journal of General Practice Online First. 2020 Available online at: DOI: https://doi.org/10.3399/bjgp20X708101

This study gives insight into the PR referral experiences of 19 primary healthcare practitioners based in England. A mixed cohort of PHCPs were interviewed and included seven Advanced Nurse Practitioners (ANPs), six GPs, four practice nurses, one practice manager and one healthcare support worker. PHCPs came from across the Cambridgeshire and Peterborough and the West Midlands regions. Emails were sent initially to regional practice managers to advise of the pending study and financial reimbursement for the practice for their participation (see Appendix 4). Two weeks after this initial notification, potential PHCP COPD/respiratory interested participants were sent direct email invitations (Appendix 5) and again with follow up email invitations sent two weeks after the initial invite (Appendix 6). Additional recruitment strategies were added to supplement the email recruitment strategy which showed initial slow uptake of only six respondents. Strategies included JW attending and presenting the study at local respiratory face to face events and also utilisation of link tracing methods (220), that being PHCPs sharing study information with potentially interested practice-based colleagues.

PHCPs were invited to answer semi-structured questions on their experience(s) when considering or undertaking referral of patients with COPD to PR. The topic guide (Appendix 9) was based on the COM-B model (137). This model seeks to explore factors that influence behaviour and offers a more concise approach than the 14 domained TDF (116). Both behavioural approaches have been presented in greater detail in the introduction chapter Section 1:20, p.30. Participants were also invited to offer strategies that they considered may increase referral to PR.

## 3.3 **Publication number one.**

The publication title is:  Referral of patients with chronic obstructive pulmonary disease to pulmonary rehabilitation: a qualitative study of barriers and enablers for primary healthcare practitioner.

Jane S Watson, Peymane Adab, Rachel E Jordan, Alexandra Enocson and Sheila Greenfield

# Referral of patients with chronic obstructive pulmonary disease to pulmonary rehabilitation:

## a qualitative study of barriers and enablers for primary healthcare practitioners


## Abstract

**Background**
Pulmonary rehabilitation (PR) is a cost-effective, internationally recommended intervention for patients with chronic obstructive pulmonary disease (COPD). Referral is predominately led by primary healthcare practitioners (PHCPs), but referral and patient uptake is poor.

**Aim**
To understand barriers and enablers for PHCPs when considering patient referral to PR, to explore the influence of patient characteristics, and to understand how referral rates may be increased.

**Design and setting**
PHCPs who care for and refer patients with COPD to PR were purposively selected from general practices across Cambridgeshire and Peterborough, and the West Midlands.

**Method**
A qualitative study. Semi-structured interviews were undertaken to theme saturation, exploring PR referral. Images depicting patients with varying COPD severity were used to stimulate memory and associative recall. Interviews were recorded, transcribed verbatim, and analysed using rapid qualitative analysis.

**Results**
A total of 19 PHCPs were interviewed. Barriers to PR referral included limited awareness of the clinical benefits, little knowledge of local PR providers, consultation time constraints, and presumed low patient motivation. While practice nurses had the greatest knowledge, they still described difficulty in promoting PR. PHCPs frequently described assessing patient suitability based on presumed accessibility, social, and disease-specific characteristics rather than the clinical benefits of PR. Referrals were facilitated by financial incentives for the practice and positive feedback from patients and providers.

**Conclusion**
There were more barriers to PR referral than enablers. Providers must engage better with PHCPs, patients with COPD, and carers, and actively promote PR. Increasing PHCPs' awareness of the benefits of PR, financial incentives, and alternative referral pathways should be considered.



**Keywords**
COPD; pulmonary disease, chronic obstructive; pulmonary rehabilitation; referral.


## INTRODUCTION

Chronic obstructive pulmonary disease (COPD) is a chronic debilitating disease, the fifth leading cause of death in the UK.[1] Emergency hospital admissions remain high,[2] and annual general practice COPD consultations have risen from a mean of 6.6 per patient with COPD in 2002 to 12.7 in 2010.[3]

Pulmonary rehabilitation (PR) is a cost-effective, nationally, and internationally recommended intervention for patients with COPD.[1,4–6] It comprises structured multidisciplinary group sessions that combine individualised exercise with disease-related education.[7] Studies consistently demonstrate that PR improves patients' symptoms, in stable disease and post-exacerbation.[8–11] Box 1 summarises the main benefits of PR experienced by patients with COPD.

In the UK, referral is largely undertaken by primary healthcare practitioners (PHCPs),[12] but less than 10%–15% of eligible patients with COPD are being referred, consequently practitioners are being asked to improve PR promotion.[12–14]

Qualitative studies among patients with COPD repeatedly highlight barriers that impede referral acceptance, include fears around exercise and breathlessness, and feelings of guilt. Functional barriers include accessibility of PR, and impacts on family and work.[15–21] Patients also report their referral acceptance is highly influenced by their HCP, citing information about PR, referrer's manner, and professional conviction about PR as important.[15–18,21–23]

To date, only two UK primary care studies[13,24] have sought to understand PHCPs' PR referral experiences. These studies suggest that time constraints, limited knowledge of PR, patient's physicality, and personal culpability for COPD inhibit referral acceptance. Both studies suggest PHCPs' attitudes to PR could be important reasons for low referral numbers.

However, one of the studies,[24] based on five focus groups with 21 HCPs from three general practices in a limited geographical area was conducted over a decade ago when PR availability was limited.[25] The second[13] was based on a pre-post evaluation of multiple interventions to overcome low PR referral, using semi-structured surveys with HCPs. While some potentially useful strategies were identified, the small number of participants (nine out of 22 responded to follow-up), shortcomings in the survey design, and data analysis process limit interpretation of the study findings.

A 2018 systematic scoping review, which included a summary of articles exploring HCPs' perceived barriers and enablers to PR referral,[26] identified nine worldwide studies including two from the UK.[13,24] Poor knowledge of PR was a commonly perceived barrier, with a need for education identified as a potential enabler.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## How this fits in

Referral to pulmonary rehabilitation (PR) is an important activity, yet it is infrequently carried out by primary healthcare staff. It is suggested that increasing healthcare professionals' knowledge and awareness of PR will positively change their referral behaviour; however, this qualitative study highlights many complex intertwined barriers to PR referral and few enablers for primary healthcare staff in England. The findings highlight some of the factors that should be addressed in addition to interventions targeting knowledge and raising awareness, to increase PR referral rates.

However, the included studies were not limited to primary care settings (a setting which is particularly varied worldwide); included surveys that limit exploration of the full range of potential barriers; and were dominated by several studies from the same researchers.[27–29] The design and contextual variations limit interpretation of PHCPs' PR referral experiences relevant to a UK primary care setting. Such understanding is critical for informing interventions to increase referral rates.

This study of PHCPs' perceptions of barriers and enablers for referral of patients with COPD to PR and the influence of patient characteristics on behaviour aims to provide an up-to-date exploration of the referral process, which will inform the development of potential interventions to improve primary care PR referral.

## METHOD

The study was undertaken in general practices in Cambridgeshire and Peterborough, and the West Midlands (NHS Birmingham South Central clinical commissioning group [CCG] and NHS Birmingham CrossCity CCG). It was not the intention to identify differences, but to describe the practices and experiences in two contrasting regions.

The prevalence of COPD across the localities is broadly similar, with rates for 2015–2016 of 1.45%, 1.65%, and 1.67% in NHS Birmingham South Central CCG, NHS Birmingham CrossCity CCG, and NHS Cambridgeshire and Peterborough CCG, respectively.[30] However, spend per 100 000 on COPD emergency admissions in 2014–2015 was higher in the West Midlands.[31] Additionally, Birmingham is one of the most ethnically diverse and deprived regions in the UK,[32,33] which is associated with increased primary care consultations.[34]

There were nine PR programmes available in Cambridgeshire and Peterborough, and seven in the West Midlands, but given the West Midlands' larger population,[35] PR provision per head is less in this location.

### Sampling

Fifty-three practice managers from a total of 272 practices within the two regions were randomly selected and PHCPs interested in respiratory and/or COPD within these practices ($n = 136$) were identified through practice websites and invited by email to participate. Invitations contained participant information sheets and reply slips that collected data on job role, estimated number of COPD patients seen weekly, and referrals to PR. A follow-up email was sent to non-responders.

Adaptive sampling methods were implemented to enhance initial recruitment.[36] This included one author attending three regional respiratory-focused meetings across Birmingham and Cambridgeshire to promote the study verbally. Link-trace sampling approaches were also used,[37] with invited participants suggesting further potential invitees.

Purposive sampling was undertaken to ensure a fair representation of job role in each of the two locations.[38] Practices were remunerated for participant time when interviews took place within working hours.

### Data collection methods

Semi-structured face-to-face[39] or telephone interviews[40] were offered to PHCPs. All interviews were conducted by one author, audiorecorded, transcribed verbatim, checked, and anonymised. Validation of completed individual transcripts was

**Box 1. Benefits of pulmonary rehabilitation in stable disease and post-COPD exacerbation requiring hospital admission[10,11]**

- Health-related quality of life improved (Chronic Respiratory Disease Questionnaire & St George's Respiratory Questionnaire)
- Dyspnoea decreased
- Fatigue decreased
- Emotional function increased
- Mastery increased
- Symptoms reduced
- Disease impact reduced
- Exercise capacity increased
- Hospital readmission likely to decrease (moderate evidence)

*COPD = chronic obstructive pulmonary disease.*

## Box 2. Topic guide

1. Could you tell me in what context do you currently see COPD patients? (for example, planned — annual review/flu jab or unplanned — exacerbation)
2. On average how many COPD patients do you think you see per week?
3. Do you currently refer to pulmonary rehabilitation programmes?
4. What is your understanding/view surrounding pulmonary rehabilitation programmes in general? ... And in relation to your local provider?
5. Do you think pulmonary rehabilitation is beneficial for patients? In what ways? Or why not?
6. How easy or difficult is it for you to refer to your local pulmonary rehabilitation provider? (for example, is it your role to refer? When is it appropriate to refer COPD patients to pulmonary rehabilitation?)
7. What motivates you to refer patients to pulmonary rehabilitation? (for example, do patients/carers ever ask you about pulmonary rehabilitation? Does the post-pulmonary rehabilitation patient summary motivate you? Are you reminded by prompts or other guidance?)
8. What do you think stops you from referring patients to pulmonary rehabilitation? Images* — two images shown to each PHCP, the sequence (A & D) or (B & C) alternated to reflect sex and possible disease severity differences.
9. If this person was your COPD patient, would you consider discussing pulmonary rehabilitation with them? Why?/Why not?
10. Is there anything that you think could improve the primary care discussion surrounding pulmonary rehabilitation and/or encourage you to make referrals to pulmonary rehabilitation?

**The images are available from the authors on request. COPD = chronic obstructive pulmonary disease.*

requested from participants via email to ascertain content accuracy and enhance study reliability.[41]

The topic guide (Box 2) was informed by published literature and encompassed questions around capability, opportunity, and motivation to understand influences on HCP behaviour.[42] This guide was piloted and revised by two authors before study commencement.

Photographic images depicting patients with varying COPD severity were used within each interview to illuminate prior experiences and thoughts around PR referral.[43] The images are available from the authors on request. Data collection continued until theme saturation.[44]

### Data analysis

An iterative whole team two-stage approach to data analysis was undertaken using rapid qualitative inquiry.[45] Rapid qualitative inquiry is helpful for gaining preliminary insight into a complex phenomenon, particularly where little is known and understanding the phenomenon is key.

The transcripts were initially coded to identify themes and patterns within the data. Independent coding by team members occurred following completion of the first five interviews. Emerging themes were then collaboratively discussed and compared to ensure team agreement and the topic guide remained focused. Finally, further independent coding and collaborative team agreement about emergent themes took place again after 14 interviews.

## RESULTS

### Recruitment

A total of 23 participants initially agreed to participate, with 19 PHCPs from 16 practices across three CCGs (seven from Cambridgeshire and Peterborough, and nine from the West Midlands) agreeing to interviews.

Six participants were recruited through email, six through regional respiratory meeting attendance, and seven from link-tracing sampling.[37]

Eighteen face-to-face interviews and one telephone interview were conducted between February and November 2017. Interviews lasted 18–63 minutes (mean = 44.7 minutes). Although all participants indicated that they referred patients with COPD to PR, at interview it emerged that two had no knowledge of PR and had never referred, and a further participant no longer reviewed patients with COPD in practice but considered their respiratory knowledge relevant. All three participants' interview data were included in the analysis as their practice was deemed important to the study. The remainder ($n$ = 16) narratively reported infrequently referring to PR, which differed to what they had documented on the returned self-completed reply slips as detailed in Table 1.

### Themes

Four main themes and eleven subthemes were derived from frequencies and patterns in the interview data.

Figure 1 shows that there is a hierarchical structure to the themes. Awareness and understanding of PR is an important theme because awareness must be present before PHCPs can comment on other aspects. However, where professionals were aware of PR, the characteristics of the PR service, perceptions about patients' ability to attend/benefit, the referral processes, and personal and collective experiences impacted on the perceived value of PR and subsequent referral behaviour.

The themes are discussed in depth below with quotes that reflect the range of views expressed.

### Awareness and understanding about PR

Awareness of the exact nature of PR was variable, with 17 out of 19 reporting some understanding. A small number of PHCPs spoke about PR as a fundamental treatment for patients with COPD:

**Table 1. Participant characteristics (*N* = 19)**

| Variable | | *n* (%) |
|---|---|---|
| Primary health care practitioner role | Practice nurse | 7 (37) |
| | GP | 6 (32) |
| | Advanced nurse practitioner | 4 (21) |
| | Practice manager/nurse | 1 (5) |
| | Healthcare assistant | 1 (5) |
| Sex | Female | 14 (74) |
| | Male | 5 (26) |
| Respiratory qualifications (formal spirometry/COPD/asthma diploma or higher) | Practice manager/nurse | 7 (37) |
| | Advanced nurse practitioner | 2 (11) |
| | GP | 1 (5) |
| Reported number of COPD patient seen weekly | 0–10 per week | 12 (63) |
| | 11–20 per week | 7 (37) |
| Reported number of pulmonary rehabilitation referrals | <1 per month | 8 (42) |
| | <1–2 per week | 10 (53) |
| | >3 per week | 1 (5) |

*'I, 100% feel it is a positive treatment for these patients.'* [practice nurse [PN] 1]

All participants but one [advanced nurse practitioner [ANP]3] reported that they thought PR to be an intervention that incorporated exercise for people with COPD, thereby helping patients to manage their breathlessness:

*'Is all about understanding why they get breathless and how to manage that breathlessness.'* [PN2]

This awareness was gained from many sources including postgraduate respiratory training and respiratory interested/specialist secondary care colleagues.

One GP shared an anecdote, which he described had positively influenced his view of PR and current practice:

*'... [the GP] asked the consultant "which inhaler is best?" The respiratory consultant replied "pulmonary rehabilitation".'* [GP5]

Local CCG interventions such as quality improvement programmes improved awareness of PR:

*'We did it as part of the PDMA, Practice Development and Membership Agreement.'* [GP3]

PNs appeared to be more aware of PR than other PHCPs, yet few were able to fully describe it. Four out of seven PNs and one out of four ANPs described having observed PR, yet one went on to say:

*'I know what pulmonary rehabilitation is, but what is it really?'* [ANP2]

One participant had previously been involved with PR delivery and advocated its benefits, but reported referring few patients:

*'It's beneficial for the right patient; expectations are different to reality.'* [PN1]

This participant conveyed a perception that was echoed by several other PHCPs, suggesting that knowledge of PR could itself impede referral.

Overall, irrespective of level of awareness, most PHCPs underestimated the value of PR in comparison with other interventions:

*'Quite often they're already on triple-inhaled therapy and you're sort of thinking, what else might help and that's when it perhaps comes to mind that maybe pulmonary rehabilitation might be suitable.'* [GP6]

Despite the sample being composed of PHCPs with some interest in COPD, the awareness and appreciation of the relative value of PR among all treatments was relatively poor.

### Characteristics of pulmonary rehabilitation services

Both general features of PR and local PR service providers appeared to influence referral. An important characteristic that PHCPs frequently described as impeding the 'promotion' of PR, is the name itself:

*'Pulmonary rehabilitation, which in itself sounds horrendously frightening.'* [ANP4]

Consequently, PHCPs often pre-empted negative patient responses to PR and used

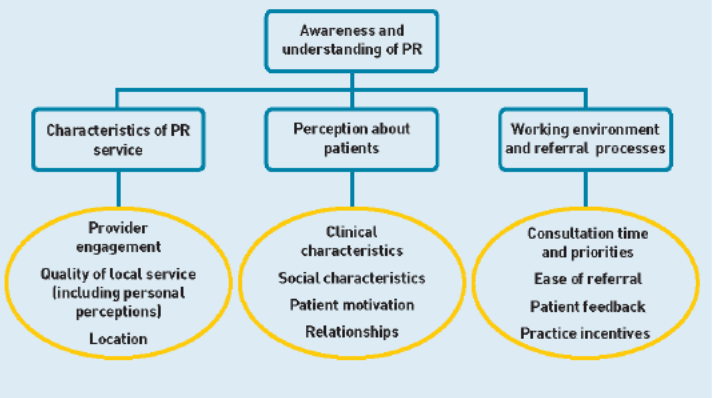


***Figure 1. Main themes and subthemes developed from thematic analysis.***

alternative terms, such as 'exercise' or 'management' when describing PR to patients, while others described avoiding the term 'exercise' completely:

*'I try not to term it as an exercise programme; I tend to explain it as a treatment programme.'* [PN1]

And for some, particularly nurses, greater concern existed about offering PR to patients who they perceived not to benefit:

*'If you raise patients' hopes and say offer it … it could make the depression worse.'* [ANP4]

PHCPs rarely described direct PR benefits, such as improvements in emotional function as highlighted in Box 1.

Where PHCPs knew about PR, they often described articulating it as difficult:

*'I can't always put into words, you know, summarise what the benefits are. You know, sort of in two sentences.'* [PN2]

This was linked to frequent reports of a lack of local practice PR promotional material.

The three subthemes relative to this main theme are now discussed in further detail.

*Provider engagement.* Almost all participants described little engagement from PR providers, mentioning details such as wait time and timing of provision to be frequently unknown:

*'There's a definite lack of understanding about when it runs, how often it runs, who the lead is, what sort of exercises they do.'* [PN1]

Additionally, very few PHCPs knew if, or when, patients who had attended PR could re-attend.

*Quality of local service including personal perceptions.* Wide variations in exercise type offered in PR programmes were described, including tai chi and practice-based chair exercises for general populations. Variation across PR programmes was more prevalent in the West Midlands than in Cambridgeshire and Peterborough; however, differences in content appeared not to influence referral. Instead, factors, such as intervention venue, ease of referral, patient acceptance, and perception of PR providers were considered by PHCP referrers:

*'At the minute I'm probably saying … Because it's local and I think they might buy it. The referral process is really easy, I send an internal message — and it's done.'* [PN7]

*Location.* Participants frequently cited location as a barrier to PR referral yet it is not clear if this was voiced by patients or anticipated by PHCPs:

*'It's two buses from* [name of venue] *and they won't go for two buses.'* [PN4]

However, not all PHCPs knew the venue, or were able to confirm to patients where providers might send them:

*'We can request, but it doesn't always end up being where we say it is, and where we've asked it to be.'* [GP4]

Indeed, the emergence of practice-based group exercises appeared to be a solution to this problem, particularly in the West Midlands.

**Perceptions about patients**

A further important theme that emerged from the data is the PHCPs' perceptions of patients' physical and/or psychological ability to benefit from PR. This theme comprises four subthemes.

*Clinical characteristics.* PHCPs largely described PR as an intervention for patients with defined clinical characteristics, particularly for deteriorating patients, measured by breathless, declining $FEV_1$, or increasing exacerbation frequency. A frequently mentioned PR referral requirement was patients having to meet Medical Research Council (MRC) breathlessness score ≥3.[5]

*'I tend to base it on their MRC scores, so the people who are scoring MRC 3, 4, or 5.'* [GP6]

Nevertheless, assessment of suitability was often subjective, as demonstrated by the photographic images used. Most assumed the patient in image B who was standing upright dressed in a suit did not require referral based on his appearance, and without need for clinical assessment:

*'He's got his walking boots on, I mean he's quite fit.'* [PN7]

On the other hand, there was reluctance about referring patients who used oxygen. This was partly based on preconceptions around potential benefit:

*'I would worry about whether she could physically participate ... or actually benefit.'* [referring to image C of a woman using oxygen] [ANP2]

Others assumed that patients on oxygen would have already been offered PR because of likely contact with secondary care, so they would be less likely to offer PR.

*Social characteristics.* PHCPs frequently described characteristics, such as social isolation and employment as barriers to attendance:

*'I think the majority of patients who say no to me, it's because of that anxiety they've got about going out, I think it's just easier to say no.'* [ANP4]

Yet, paradoxically PHCPs often viewed PR positively in terms of potential social interactions, particularly for those considered socially isolated.

Patients in work were described as being inhibited by PR programme timing; however, PHCPs frequently considered them as being too well to benefit:

*'The biggest thing is when they are still in work and it's going to jeopardise their work situation to take time off to go, and they're not severe yet.'* [ANP1]

A small number of PHCPs also described current smokers as inappropriate for PR:

*'If a patient won't give up smoking almost what's the point in doing it.'* (practice manager [PM]1)

*Motivation.* PHCPs frequently reported that patients are not motivated to attend and described having to 'push' and 'nag' patients:

*'They won't go to PR.'* [PN7]

*'Patients don't want it.'* (PN5)

*'The main hurdle is convincing people to go.'* [GP5]

This described lack of patient motivation can lead to variation in PR introduction approaches:

*'You sort of need to trickle feed it.'* (PN4)

*Relationships.* Relationships between PHCPs and patients were seen as important, but could result in differing patient reactions. Long-term contact with PHCPs resulted in trust for some:

*'I've seen patients for many many years ... they've confidence in you and will say "well, if you think that's its good for me I will go to it".'* (PN3)

In contrast, others found familiarity a barrier:

*'Not again, don't start, not again.'* [PN7]

The relationship also impacted on PHCPs' reactions, with some describing caring for patients with COPD as challenging, captured by the term *'heartsink patients'* (PN2 and GP5).

**Working environment and referral processes**

This final theme included four subthemes. Discussions about PR referral were largely seen as most appropriately undertaken by practice nurses, at COPD annual review:

*'When they're doing the routine review ... that's probably the ideal time.'* (GP5)

GPs largely reported referring infrequently:

*'I can't remember the last time I referred anyone.'* [GP3]

Few PHCPs considered PR discussion appropriate in an acute exacerbation consultation, given clinical priority and consultation time constraints:

*'It doesn't form any part of my acutely unwell consultation.'* (GP4)

However, post-exacerbation review in primary care is an emerging practice, particularly in the West Midlands. This was described as offering an additional referral opportunity:

*'It may get better now we're trying to do these post-exacerbation reviews because then you've got that second opportunity to look and say.'* [GP6]

**Box 3. Suggested enablers and relation to main themes**

| Enablers | Themes |
|---|---|
| Educate PHCP staff on PR | Awareness and understanding of PR |
| Changing the PR name<br>Monthly feedback from PR providers<br>PR closer to practice/in practice<br>Patient self-referral<br>Directly invite eligible patients | Characteristics of PR services |
| PHCP use of motivational interviewing<br>Patient to watch video | Perceptions about patients |
| Post exacerbation follow-up<br>Prompts and/or reminders to staff<br>Additional practice funding/incentive<br>PR posters in practices | Working environment and referral |

*PHCP = primary healthcare practitioner. PR = pulmonary rehabilitation.*

*Consultation time and priorities.* PHCPs often reported that clinical time constraints inhibit PR referral and described rationalising organisational priorities:

*'The biggest barrier to any referral is time ...* [on PR] *it's almost like an optional thing you can consider, not something you have to do.'* (ANP2)

*'There are lots of calls on prioritisation.'* (GP2)

*Ease of referral.* Most PHCPs knew how to refer, describing the process as straightforward, despite some variations. The PR referral on COPD templates was frequently described as a valuable reminder:

*'The template would always prompt.'* (healthcare assistant [HCA]1)

*Patient and provider feedback.* Positive patient feedback motivated PHCPs to discuss PR with subsequent patients with COPD:

*'I have seen patients who ... have been suitable for PR but haven't agreed to be referred in the past ... I would mention ... the experience of other patients ... have found it helpful so that might motivate them to kind of agree.'* (GP1)

However, PR provider feedback was largely described as very poor:

*'I don't know what's happened to my patients that I've referred, whether they've actually gone, what their outcome is.'* (ANP4)

Additionally, where providers had deemed referred patients ineligible for PR, it appeared to be patients rather than providers that fed that information back to the PHCPs. PHCPs described feeling frustrated in these circumstances, demotivating them from future referrals:

*'I was a bit annoyed because I felt quite strongly that he would benefit.'* (PN3)

Public awareness of PR appeared very low, with only two out of 19 participants reporting patients/carers to have asked about PR. PR awareness within some general practices also appeared to be low:

*'It's very rarely talked about, I've never heard it mentioned.'* (ANP3)

*Practice incentives.* Financial incentives appeared to differ between the locations and influence PHCPs' views. In Cambridgeshire and Peterborough there was no financial incentive for PR referral:

*'I'm not saying it should be but if pulmonary COPD was a QOF priority, money attached, we would do it.'* (GP2)

In the West Midlands there were financial incentives, which were deemed as helpful in terms of reminders:

*'Maybe triggers other people's brains ... it's part of a thing you need to do.'* (GP6)

They were also deemed helpful in raising the profile of PR and authorising referrals:

*'It makes it okay.'* (GP6)

### Suggested enablers

All participants were invited to suggest possible enablers to PR referral. Box 3 summarises the 12 suggestions that were proposed and their alignment to the four main themes.

## DISCUSSION

### Summary

This is the first in depth qualitative study to investigate a range of PHCPs' experiences of referring or considering PR referral for patients with COPD in England. It highlights a hierarchical approach to PR discussion and referral by PHCPs that has not previously been reported. This is dominated initially by PHCPs' individual awareness and understanding of PR, which is subsequently strongly influenced by three further factors: characteristics of PR services, perceptions

about patient motivation and characteristics, and the working environment and referral process.

PR referral is a highly complex phenomenon, which was influenced by the PHCPs' knowledge and awareness of the benefits of PR, and contextual factors such as perceived quality of the PR service, engagement with providers, consultation time, referral prompts, ease of referral, PHCP–patient relationship, perceptions of the patient's needs and abilities, and practical considerations, such as PR accessibility. While detailed awareness of the clinical benefits of PR was generally low, it is the combined total of these factors that appeared to greatly inhibit PR referral by PHCPs. As such, increasing PHCPs' knowledge alone will not necessarily translate to increased referral rates; indeed, some PR knowledge appears to impede referral as knowledgeable PHCPs analyse patient assessment and suitability in greater detail.

PHCPs described referral to be considered largely at COPD annual review, yet frequent subjective evaluation of patient characteristics rather than clinical assessment dominated decisions. This subjective assessment led to referral opportunities being considerably narrowed.

PHCPs frequently reported that patients were unmotivated and perceived patient-based difficulties in attending PR as important barriers to referral. In response, a commonly used lever was to offer PR when COPD symptom burden, such as exacerbation rate and dyspnoea is increasing and where pharmacological treatments have been maximised. PR was therefore frequently viewed as an end of the road treatment at a time where patients with COPD often have high symptom burden. PHCPs were aware of this and not always certain how best to support patients, although described introducing PR gradually as one approach.

Relationships with PR providers and environmental factors, such as having the time to refer and practical accessibility of PR service for patients influenced referral behaviours. PHCPs often described a lack of familiarity with their local PR providers contributing to lower referral. Indeed, the most frequent suggested enablers to improve PR referral (Box 3) were related to PR providers.

While it was not intended to make comparisons between the geographical areas, some differences were noted. In some West Midlands practices, PR incentive funding appeared to increase PHCPs' PR awareness and increased reported referral rates; however, higher non-elective COPD emergency admissions in this location[31] may also contribute.

### Strengths and limitations

This study was able to recruit a wide range of general practice-based participants, with knowledge of PR, in all but two out of 19 participants. Gaining insight into PHCPs' real experiences of current PR referral barriers and enablers is important.

Only PHCPs who had an interest in PR and/or COPD may have agreed to take part and had the study been undertaken in different geographical regions, findings may have differed. All practice nurses and one of the GPs interviewed had a post-qualifying respiratory qualification, which may not be reflective of the general practice workforce. Despite this, the awareness and appreciation of the relative value of PR among treatment options for COPD was limited.

One of the authors is an experienced respiratory specialist nurse, whose experiences may have influenced data collection and analysis.[38]

### Comparison with existing literature

PHCPs' knowledge of PR has previously been reported as being low.[23,26] While general HCPs' awareness may have increased since the implementation of secondary care COPD discharge bundles, PR referral and uptake remains low.[46,47]

The current study found that most PHCPs had a general PR awareness, but few had detailed PR knowledge. While knowledge is a key factor to referral, this is highly influenced by additional factors that must be addressed if PR referral rates are to increase and PHCPs are to improve its 'promotion'.

An early qualitative study[24] and a practice-based service evaluation[13] postulated that PHCPs' attitudes may contribute to low PR referral numbers, a factor reported by patients themselves.[19,21] Conversely, the current study found that PHCPs frequently described patients as having little motivation for PR, as has also been reported elsewhere.[24,26] Participants described maximal pharmacological therapy and worsening COPD symptoms as opportunities for motivating patients to accept PR.

This approach has important implications. First, patients with high COPD symptoms live with high levels of fear and panic,[20,48] and have concerns about functional abilities, including beliefs that shortness

of breath is detrimental to lung capacity.[20] These are highly likely to influence patients' referral acceptance and may explain 'low motivation'. Second, many patients with COPD are frequently inappropriately prescribed triple therapy. Referring patients earlier to PR when their symptom burden is less may increase patient acceptance and may reduce prescribing behaviours.

Patients have reported that key factors to referral acceptance are their understanding of the content and benefits of participation in PR programmes.[17] The findings of this study highlight that PHCPs struggle to articulate both content and clinical benefit of PR. HCPs are highly influential in a patient's acceptance of PR referral,[15–18] yet those interviewed had little awareness of this and subsequently no plans to address it.

Financial incentives appeared to facilitate the likelihood of referral in this study and elsewhere.[49] It is likely that the implementation of financial reward for PR referral instilled by the new GP contract changes in England and Wales[50] will yield some positive changes. However, it is important to acknowledge that increased GP PR referral rates do not necessarily translate to greater PR completion, as has been reported by Hogg *et al*.[51] As such, adopting a system-based approach at the point of referral that incorporates the three key parties (PHCP, patient, and PR provider) is likely to be more successful in overcoming the multiple barriers than isolated interventions.

### Implications for research and practice

PR is a nationally and internationally recommended intervention for patients with COPD, yet it remains poorly accessed. Primary care consultations for COPD are increasing, as is the COPD population. Increasing PR referral and likely uptake will reduce patient symptom burden and potentially reduce primary care contacts.

The PR referrer is very important to referral acceptance, uptake, and completion. PHCPs reported large numbers of barriers and very few enablers to PR referral. This appears to indicate that a multipronged approach to enhancing referral is likely to be valuable. This goes beyond education and awareness raising for PHCPs, and includes engagement of PR providers and system-level changes. Identifying the frequency and generalisability of these findings are important next steps. These current findings have been mapped to a national PHCPs survey, for which data has been collected and analysis is underway.


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### Provenance

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### Competing interests

The authors have declared no competing interests.

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## 3.4 **Overview of methodology**

The study was informed by a generic qualitative approach (221-223). This is an approach that is not explicitly aligned to any of the main five qualitative research approaches offered by Creswell (2013) (narrative, phenomenology, grounded theory, case study and ethnography). Generic qualitative research seeks to

*'discover and understand a phenomenon, a process, or the perspectives and worldviews of the people involved'* (223) (p. 11).

In the context of this chapter, the generic qualitative approach has explored and exposed the real-life PR referral experiences by those working within primary healthcare settings through their descriptive accounts. This approach is one that is therefore not looking to be guided or bound by a qualitative philosophical directive, such as building theory in grounded theory, or to explain culture as in ethnography, but one that seeks to present the perspective of PHCPs in action.

A generic qualitative approach is increasingly used by researchers, compared to the main five approaches, as demonstrated in Bradbury el al's (221) review. Reasons for this are likely to be two-fold: one, related to the pragmatism of time and feasibility for researchers to engage in deeply theoretically guided inquiries that are informed by philosophical assumptions and two, where the aim of the inquiry is to represent human experiences (221, 222). It is therefore anticipated that the generic qualitative approach will remain popular across healthcare research.

## 3.5 **Overview and limitations**

This study included only two geographical regions in England which is a potential limitation. Additionally, it is reported that sample sizes of between 15-60 participants are included in qualitative interviews (224), meaning that the sample of 19 PHCPs may be considered small in this study. However, a frequent sampling approach used within qualitative research is purposeful sampling, which is the inclusion of appropriate field contributors who offer depth and reality to the phenomenon in question (225). Appropriate participant selection is consequently integral to uncovering the richly sought phenomena data and offers greater validity than sample size (226). Determining the end point of data collection in qualitative research is often defined by data saturation (that being no new concepts arising) and it is this which determines the sample size (227, 228). As such this is a research design element that cannot be pre-specified (229), which is opposite to the statistical sampling pre-determinants used by quantitative researchers (225). So whilst the sample may be considered small it is in keeping with qualitative research methods as participant selection was purposeful and targeted. A more poignant sample limitation is that it is likely that the interviewed participants had an interest in PR and COPD and are likely to have presented themselves in a positive light, whereas the reality is that referral for PR is woefully inadequate and interviewing a greater number of staff who did not currently refer to PR but who undertook COPD annual reviews would have offered additional and valuable insights to their experiences and challenges. There are therefore some methodological limitations to the study presented.

## 3.6 **Key Chapter Findings**

The key finding of this chapter is that there is a hierarchal pattern present which influences PR referral and one that commences with and is strongly influenced by PHCP PR knowledge and awareness. PR knowledge and awareness is of importance in PR referral, meaning it needs to be present for referral to ensue, but its presence does not directly lead to referral. Indeed the study demonstrated greater PR knowledge often acted as a barrier as a second layer of (often unconscious) additional factors, contributed to PHCP referral assessments and behaviours. These factors included perceptions of patients, characteristics of PR providers, working environment and referral processes (please see figure 1 in the published paper). These are important and novel findings.

Further key findings that acted as barriers and enablers included that it is frequently considered the practice nurse's role to refer, PHCPs would like to refer more patients, a financial incentive appeared to be a positive influencer, relations and feedback from PR providers are poor, local PR program knowledge is poor, patients are described as not wanting PR, meaning PR is offered at a point of increased symptom burden was a strategy adopted. These findings have not previously been reported and therefore further contribute to the originality of this thesis.

This chapter has identified barriers and enablers to PR as experienced by PHCPs, offering answers to the thesis research question 1 and partially answers thesis objectibve 2, as

specified in section 1.21 p 34. This chapter completes Study 2i of the multiphase thesis design (figure 5, p 38).

## 3.7 **Next Steps**

The thesis' overall focus is to understand the barriers and enablers including the intrinsic and extrinsic factors that influence PHCPs PR referral behaviour and then to modify those factors through bespoke evidence-based interventions in order to improve referral rates. Testing the transferability of the experiences reported by the 19 PHCPs presented here by widening the target population is prudent (230).

As highlighted in chapter 1 section 1:20, p. 30, in order to affect behaviour change there is a need to understand current behaviours and the factors which influence them. Analysing behaviour utilising psychological theory is considered effective (117, 132). The TDF is a psychological theory based framework that identifies which HCP behaviours maybe amenable to change (116).

The following chapter, chapter 4 is a mixed methods study that aims to deductively apply the TDF to the key findings of the inductive qualitative data presented here in chapter 3. Meaning the same data was used in the first mixed methods phase as is presented here, but a different deductive approach to data analysis was used. The data derived from the deductive analysis aimed to draw out theoretical behavioural interpretations and inform the design of a bespoke quantitative instrument and guide relevant PHCP PR referral questions

(Appendix 14). This approach expanded the transferability of the inductive qualitative research findings and seeks to identify nationwide key factors that affect PR referral for patients with COPD from primary care settings and additionally uses behaviour change theory to understand why referral remains low. Moreover this approach enabled the development of targeted interventions to improve future PR referral rates as aligned to the thesis overarching research questions and objectives 2 and 3.

# Chapter 4: MIXED METHODS

## INVESTIGATING PRIMARY HEALTH CARE PRACTITIONERS' BARRIERS AND ENABLERS TO REFERRAL OF COPD PATIENTS TO PULMONARY REHABILITATION: AN EXPLORATORY SEQUENTIAL MIXED METHODS STUDY USING THE THEORETICAL DOMAINS FRAMEWORK.

## 4.1 **Chapter objectives**

This chapter has two key objectives; first to deductively transform the previously reported inductive barriers and enablers to PR referral by PHCPs in chapter 3 and align them to the behaviour change theoretical constructs informed by the TDF (231). Second, to test the generalisability of the identified barriers and enablers within a larger PHCP population. These objectives complete study 2ii of the multiphase thesis design (figure 5, p 38), research question 1 and fulfil thesis objectives 2 and 3 (section 1:21, p 34):

- "To identify barriers and enablers to PR referral by PHCPs captured through their descriptive experiences and analysed by two separate data analysis approaches; one inductive and the second deductive, through application of behaviour change theory.
- To identify current practice of PHCP in terms of PR referral and assess generalisability of qualitative findings using a quantitative survey."

These findings will then advance completeness of the final thesis objective, objective 4, development of evidence based theoretical interventions that overcomes PR referral barriers for PHCPs, which will be presented in chapter 6.

This chapter therefore aims to expand the overall knowledge and understanding of barriers and enablers to referring to PR in the UK as experienced by PHCPs in order that evidence-based interventions can be appropriately considered with a view to ultimately increase PR referral rates for patients with COPD.

## 4.2 **Introduction**

This chapter presents a paper that is pending publication in BMJ Open. It is currently available as a pre-print here https://www.researchsquare.com/article/rs-87076/v1. However the included paper presented in this chapter is a revision of the pre-print following responses to BMJ Open peer reviewer comments and is awaiting publication. It is presented in its likely published format. Additional files referred to in the paper can be found in Appendix 2, 13, 15 respectively. The paper presents UK nationwide PHCPs views on and experiences of PR referral for patients with COPD, utilising a two phase sequential mixed methods approach (149) .

Its citation is: Watson J S, Jordan R E, Adab P, Vlaev I, Enocson A & Greenfield S. 2021 Investigating primary health care practitioners' barriers and enablers to referral of patients with COPD to Pulmonary Rehabilitation: an exploratory sequential mixed methods study using the Theoretical Domains Framework.

In this chapter the same narrative descriptions given by the PHCPs in study 2i (chapter 3) have been reanalysed using deductive methods (232) and then aligned to the theoretical constructs that underlie behavioural change theory captured by the TDF (116). Deductively coding data to the TDF domains is the most commonly adopted approach to TDF data analysis (133, 233). The results of this deductive analysis informed the development of one section of an online and paper survey which resulted in n=54 bespoke TDF-based Likert scale questions. This chapter therefore reports on the deductive analytical approach to

qualitative data, survey development, survey distribution and overall findings. It expands upon the key findings of chapter 3, where PHCPs reported a number of factors that influenced their PR referral practice. These included PR service characteristics, relations with providers, perceptions around patient characteristics and patient motivations, referral processes and peer influences.

Testing the transferability of the preliminary qualitative findings amongst a larger cohort of PHCPs allows both professional and geographical spread to increase, consolidates behavioural psychological TDF findings and expands the underlying evidence. Combined these elements seek to inform intervention development, including identification of the important intervention components as recommended both by the MRC framework for complex interventions (132) and the more recent O'Cathain (143) logic model to complex health intervention development.

Title

**Investigating primary health care practitioners' barriers and enablers to referral of patients with COPD to Pulmonary Rehabilitation: a mixed methods study using the Theoretical Domains Framework.**

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Key words

Chronic Obstructive Pulmonary Disease (COPD), Pulmonary Rehabilitation (PR), Primary Care, Theoretical Domains Framework (TDF). Mixed methods research.

List of Abbreviations

PR – Pulmonary Rehabilitation

COPD – Chronic Obstructive Pulmonary Disease

PHCP – Primary Health Care Practitioner

TDF – Theoretical Domains Framework

**Word Count 4,268**

## 4.3 **Abstract**

**Objectives**
Pulmonary rehabilitation is a highly effective, recommended intervention for patients with COPD. Using behavioural theory to understand why referral remains low enables the development of targeted interventions in order to improve future PR referral.

**Methods**
We undertook a multiphase sequential mixed methods study to investigate referral practices of Primary Health Care Practitioners (PHCPs) in the United Kingdom (UK). In phase 1, semi-structured interviews were undertaken. Content analysis was used to map themes to the Theoretical Domains Framework (TDF) and a 54-item TDF-based questionnaire was developed.

In Phase 2 we distributed the questionnaire to a larger PHCP population. We used descriptive analyses to identify barriers and enablers, and key TDF domains. Mixing of data occurred at two points; instrument design and interpretation.

**Results**
19 PHCP took part in interviews and 233 responded to the survey. Integrated results revealed that PHCPs with a post qualifying respiratory qualification (154/241; 63.9%) referred more frequently (91/154; 59.1%) than those without (28/87; 32.2%).

There were more barriers than enablers for referral in all 13 TDF domains. Key barriers included: infrequent engagement from PR provider to referrer, concern around patient's physical ability and access to PR (particularly for those in work), assumed poor patient motivation, no clear practice referrer and few referral opportunities. These mapped to domains: belief about capabilities, social influences, environment, optimism, skills and social and professional role.

Enablers to referral were observed in knowledge, social influences memory and environment domains. Many PHCPs believed in the physical and psychological value of PR. Helpful enablers were out-of-practice support from respiratory interested colleagues, dedicated referral time (annual review) and on-screen referral prompts.

**Conclusions**
Referral to PR is complex. Barriers outweighed enablers. Aligning these findings to behaviour change techniques will identify interventions to overcome barriers and strengthen enablers, thereby increasing referral of COPD patients to PR.

## 4.4 **Strengths and limitations of this study**

1: This is the first mixed methods study to use the Theoretical Domains Framework to identify barriers and enablers to pulmonary rehabilitation referral from a primary health care practitioner perspective.

2: The utilisation and combination of two differing research paradigms in this exploratory sequential approach offers novel and detailed insights through combined research lenses which encompass multiple perspectives.

3: Many geographical regions across the United Kingdom are represented and include a diverse range of primary healthcare practitioners.

4: A combination of participant recruitment approaches have been used to reduce potential sample and selection biases.

5: Generalisability of the overall findings are limited by the inability to calculate distribution and therefore response rates.

## 4.5 **Background**

Pulmonary Rehabilitation (PR) is a low cost, high value, internationally recommended intervention for COPD patients which is effective in improving exercise capacity, reducing the impact of symptoms and improving prognosis (1, 2) . It is a structured multidisciplinary intervention combining individualised exercise with disease-related education (3). Despite the clear evidence of its effectiveness, the proportion of COPD patients receiving PR is

persistently low worldwide (4, 5). Our previously published inductive qualitative paper presented the experiences of primary health care practitioners (PHCPs) as key potential referrers to PR (6). We found that there was a generalised awareness of PR, but little detailed knowledge of either the programme or the clinical benefits. Relationships with PR providers were limited, but considered important. Patient characteristics, rather than clinical need, influenced referral offers and referrers frequently believed patients to be poorly motivated. PR was most commonly offered during times of disease stability (usually at COPD annual review) and ease of the referral process and financial incentives positively influenced referral. In summary, referrers reported many barriers but few enablers, which collectively resulted in infrequent discussions about PR and associated referrals.

However, in order to aid the development of appropriate interventions to improve referral rates it is important to establish the generalisability and relative importance of these findings within a broader population of PHCPs. Furthermore, applying theory to identify the psychological and structural drivers that influence behaviour (7, 8) may offer new insights to shape interventions (9).

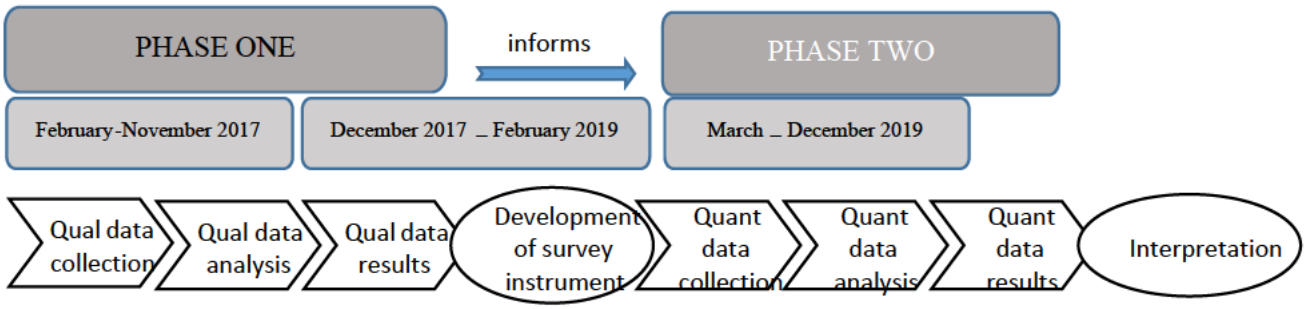
The Theoretical Domains Framework (TDF) is a well-recognised approach which was derived from a synthesis of behaviour change theories (10), and examines the processes that influence behaviour (11). When applied, it offers explanations for behaviours, highlighting reasons that may inhibit or promote (12, 13) implementation of practice-based change (12).

Using mixed methods, and applying the TDF we sought to assess and explain the reasons for low PR referral by primary health care professionals (PHCPs) for patients with COPD. The aim of our multiphase design was to inform the development of theory informed interventions to improve PR referral rates from primary care in future.

## 4.6 **Methods**

We used a multiphase sequential design defined by two separate phases (figure 7). The cognitive and practical experiences of PHCP when considering and undertaking referral for patients with COPD were initially explored using a deductive approach by applying the TDF to data from our previously collected qualitative interviews. These findings informed a second quantitative phase, where we tested themes for generalisability using a nationwide survey of PHCP, to highlight the most relevant factors influencing referral. (14-16).

**Figure 7: Multiphase sequential research design**




Both data sets retained independent value and meaning, but were connected at two time points: 1) where the qualitative data was used to construct the questionnaire and 2) where phase 1 and 2 results were integrated to inform interpretation. The multiphase sequential

mixed methods design therefore achieves both methodological and content integration (15,16).

## 4.7 Patient and Public Involvement

There has been no public and/or patient involvement in this study.

## 4.8 Phase 1 Application of TDF to qualitative interview data.

We re-analysed data from our previously published inductive qualitative study (6) in which 19 PHCPs from two differing geographical regions across Central and East of England were recruited and interviewed to thematic saturation using a pre-designed topic guide. A deductive approach using content analysis (17) was used for re-analysis of the data in order to align the results to the TDF and to offer new insights.

The interview topic guide (Additional file 1) was mapped to the Capability Opportunity Motivation-Behaviour model (COM-B), a model that highlights three critical prerequisites for behaviour change (18). This model was adopted rather than the TDF to guide interviews primarily because of the practical need to reduce interview length without compromising its aim. COM-B is very closely aligned to the TDF and has been utilised as a topic guide and mapped to the TDF in a similar health care professional study (19).

## 4.9 **Analysis**

All interview transcripts were managed using NVivo v12. Barriers and enablers emerging from the interviews via content analysis were mapped to the relevant TDF domain, initially using construct labelling (10, 20) (Additional file 2) (thesis, appendix 2). Utterances were coded once to the key TDF construct which then determined TDF domain alignment. JW undertook the initial coding then 5 transcripts were randomly allocated and distributed throughout the team (RJ, PA, and SG) and independent TDF coding occurred, followed by frequent collaborative team discussion to ensure agreement with the coding. Queries were discussed with a behavioural expert (IV).

## 4.10 **Phase 2 Quantitative Methodology**

### **Study Design – Cross sectional survey.**

PHCPs were recruited via two main methods. Initially an invitation was included in a fortnightly newsletter emailed to members of the Primary Care Respiratory Society (PCRS). The survey was additionally distributed and shared by PCRS via their organisational Twitter and Facebook accounts. Social media distribution of the survey was further increased by individual and other organisational sharing, including the Facebook accounts of Advanced Practice UK and General Practice Nurse UK. A link for questionnaire completion was provided to the platform 'Online Survey' (21). This was open between April and December 2019. To increase participation, responders were invited to opt in to a prize draw to win an I-pad.

Simultaneously, paper versions of the questionnaire were distributed at 6 UK conferences between March and November 2019 to attending PHCPs (predominately by hand by JW, and using 'in-conference bag' distribution at one event). Upon self-completion, questionnaires were placed by participants in a locked ballot box and an optional token of appreciation was offered. Paper questionnaires were manually entered onto 'Online survey' by JW.

As this was exploratory research, no *a priori* sample size calculations were performed. A pragmatic approach to study closure was adopted, this being online availability for a period of 8 months, distribution of the questionnaire at several appropriate PHCP targeted events, and that a reasonable range of PHCP had responded.

## 4.11 **Methodology– Instrument Design**

The cross-sectional survey (Additional file 3) (thesis, appendix 13), collected (1) individual socio-demographic data, (2) current referral experiences, using TDF-based Likert scale questions (n=54) and (3) any new or complementary issues which may not have been previously mentioned, using an optional open question (22).

### Socio-demographic data

These included questions on geographical location of practice, job title, post-qualifying respiratory education and estimated frequency of PR referrals, using questions with pre-specified options.

## 4.12 **Psychometric data**

Barriers and enablers for PR referral identified from the phase 1 qualitative findings were converted into belief statements (20), including some that sought to test direct understanding. All questions were generated and aligned to the TDF by the coder (JW) and validated by other team coders (RJ), including a TDF expert (IV). 54 closed, fully labelled 5point, Likert scale questions/belief statements were included with responses ranging from 'strongly disagree' to 'strongly agree' and a mid-point rating. Some statements were reversed as an opposite belief to that frequently reported in the phase 1 data. These design elements were purposely selected to improve reliability and validity (23).

The final survey mapped the 54 belief statements and open question section to 12 out of 14 theoretical domains ('emotion' and 'behavioural regulation' was excluded, given its low mapping in phase 1 results). Two rounds of survey piloting were undertaken with five practice nurses and the questionnaire refined to ensure question clarity and clearer completion instructions.

## 4.13 **Analysis**

All data were exported into an excel spreadsheet and STATAv16 used to conduct simple descriptive statistics (frequencies and percentages), dichotomising into Agree/Strongly Agree *vs* the remaining options. Free text that directly related to barriers and enablers of referral practice was content-mapped to the TDF and thematic analysis applied (24).

## 4.14 Results: Phase 2 response rates

Paper surveys (>1100) were distributed across 6 UK primary care focused events which were attended by a variety of PHCPs. 154 (~14%) were returned and 134/154 (83%) completed the survey sufficiently and were included. Online, it is unknown how many potential practitioners read the survey invitation, therefore participation rates could not be calculated. 123 participants started the online survey, but only 99 (80.5%) completed it and were included in the analysis. Full details of the paper survey distribution and return rates can be found in additional file 1 (thesis appendix 15).

## 4.15 Description of participants

Table 12 presents the socio-demographic characteristics for participants in the phase 2 quantitative (n=233) studies. Participant's characteristics for phase 1 (qualitative) are available in the previously published paper (6)

In contrast to the qualitative study where 6/19 (32%) were GPs, the survey respondents were predominantly female nurses. Nurse respondents were similarly distributed across both conference and online groups (110/134, 82.1%; and 76/99, 76.9% respectively) and responders from both sources had similar time working in practice. However, respondents recruited through conferences, compared to those who responded online, tended to be younger (28% < 40 years of age), more likely to be practice nurses rather than other types of professionals, but were less likely to have respiratory qualifications, to see COPD patients or to refer them to PR.

**Table 12 Baseline demographics of phase 2 participants**

| | | Phase 2 Survey (n=233) | | |
|---|---|---|---|---|
| | | Conference (n=134) (%) | Online (n=99) (%) | Total (n=233) (%) |
| **Primary Health Care Practitioner Role** | General Practitioner (GP) | 18 (13.4) | 11 (11.1) | 29 (12.5) |
| | Advanced Nurse Practitioner (ANP) | 25 (18.7 ) | 32 (32.3) | 57 (24.5) |
| | Practice Nurse (PN) | 85 (63.4) | 44 (44.5) | 129 (55.4) |
| | Emergency Care Practitioner (ECP) | 1 (0.8) | 1 (1) | 2(0.9) |
| | Pharmacist | - | 4 (4) | 4 (1.7) |
| | Health Care Assistant (HCA) | - | 1 (1) | 1 (0.4) |
| | Other | 5 (3.7) | 6 (6.1) | 11 (4.7)) |
| | **Total responses** | 134/134 (100) | 99/99 (100) | 233/233 (100) |
| **Sex** | Female | 115 (91.3) | 92 (92.9) 7 | 207 (92) |
| | Male | 11 (8.7) | (7.1) | 18 (8) |
| | **Total responses** | 126/134 (94) | | 225/233 (96.6) |
| **Age (years)** | 18-29 | 5 (3.8) | 99/99 (100) | 7 (3.0) |
| | 30-39 | 32 (24) | 2 (2) | 43 (18.5) |
| | 40-49 | 36 (27.1) | 11 (11.1) | 76 (32.8) |
| | 50-59 | 49 (36.8) | 40 (40.4) | 89 (38.4) |
| | 60 + | 11 (8.3) | 40 (40.4) | 17(7.3) |
| | **Total responses** | 133/134 (99.3) | 6 (6.1) 99/99 (100) | 232/233(99.6) |
| **Ethnicity** | White British | 112 (84.2) | 87 (87.9) | 199 (85.7) |
| | White other | 8 (6) | 4 (4.1) | 12 (5.2) |
| | Asian/Asian British | 7 (5.3) | 3 (3) | 10 (4.3) |
| | Mixed Multiple Ethnic Groups | 1 (0.7) | 2 (2) | 3 (1.3) |
| | Black/African/Caribbean/Black British | 2 (1.4) | - 3 | 2 (0.9) |
| | Other ethnic group | 3 (2.4) | (3) | 6 (2.6) |
| | **Total responses** | 133/134 (99.3) | | 232/233(99.6) |
| **Practice Geographical Location** | Scotland | 1 (0.8) | 99/99 (100) | 4 (1.7) |
| | England North East and West | 31 (23.6) | 3 (3) | 46 (20) |
| | Yorkshire and the Humber | 8 (6.1) | 15 (15.1) | 14 (6) |
| | Midlands (East and West) | 20 (15.3) | 6 (6.1) | 36 (15.8) |
| | East of England | 23 (17.5) | 16 (16.1) | 41 (17.8) |
| | Wales | 31 (23.6) | 18 (18.2) | 31 (13.5) |
| | London | 3 (2.4) | - | 9 (3.9) |
| | South (East and West) | 14 (10.7) | 6 (6.1) | 49 (21.3) |
| | **Total responses** | 131/134 (97.8) | 35 (35.4) 99/99 (100) | 230/233(98.7) |
| **Years in General Practice** | < 5 | 39 (29.9) | 23 (23.2) | 62 (27) |
| | 6- 10 | 26 (19.8) | 25 (25.3) | 51 (22.2) |
| | 11-15 | 18 (13.7) | 18 (18.2) | 36 (15.7) |
| | 16-20 | 22 (16.8) | 14 (14.1) | 36 (15.7) |
| | 21 + | 26 (19.8) | 19 (19.2) | 45 (19.4) |
| | **Total responses** | 131/134 (97.8) | | 230/233(98.7) |
| **Currently see COPD patients** | Acute Management | 9 (6.7) | 99/99 (100) | 14 (6) |
| | Chronic Management | 30 (22.6) | 5 (5) | 56 (24) |
| | Acute and Chronic management | 81 (60.9) | 26 (26.3) | 148 (64) |
| | Don't see COPD patients | 13 (9.8) | 67 (67.6) | 14 (6) |
| | **Total responses** | 133/134 (99.3) | 1 (1) 99/99 (100) | 232/233(99.6) |

| | | | | |
|---|---|---|---|---|
| **CPD Respiratory Qualifications*** | None | 62 (46.3) | 19 (19.2) | 81 (34.8) |
| | COPD Diploma | 28 (20.9) | 50 (50.5) | 78 (33.5) |
| | Asthma Diploma | 38 (28.4) | 52 (50.5) | 90 (38.6) |
| | ARTP Spiro | 34 (25.4) | 40 (40.4) | 74 (31.8) |
| | Other | 16 (11.9) | 26 (26.3) | 42 (18) |
| | > one qualification | 32 (23.9) | 51 (51.5) | 83 (35.6) |
| | **Total responses** | 210 | 238 | 448 |
| **Reported PR referral practice** | Yes (frequency not specified) | - | 11 (11.1) | 11 (4.7) |
| | Weekly | 16 (12) | 32 (32.3) | 48 (20.7) |
| | Monthly | 40 (30.1) | 21 (21.2) | 61 (26.3) |
| | < Monthly | 43 (32.3) | 29 (29.3) | 72 (31) |
| | None | 34 (25.6) | 6 (6.1) | 40 (17.3) |
| | **Total** | 133/134 (99.3) | 99/99 (100) | 232/233(99.6) |

## 4.16 Referral **to PR by type of healthcare professional**

Overall, 109 (49.1%) reported being frequent referrers to PR, with GPs being less likely to refer and other professions including emergency care practitioners and nurse practitioners and ANPs more likely to refer. Referral was also higher among those with one or more continuous practice development (CPD) respiratory qualifications. However, this may be partly related to such qualification being higher among ANPs (82.5% (47/57)) and other grouped professions (58.8% (10/17)) than among GPs (17.9% (5/28)). More than 10 years spent in general practice appeared to marginally increase referral frequency (60.7%; 51.8%).

**Table 13 PHCP referral practice***

| | **Frequent Referral n (%) (weekly or monthly) Total n=109** | **Infrequent referral n (%) (>monthly or no referral) Total n=113** |
|---|---|---|
| Staff type | | |
| GP (n=28) | 10 (35.7) | 18 (64.3) |
| PN (n=120) | 57 (47.5) | 63 (52.5) |
| ANP (n=57) | 32 (56.1) | 25 (43.9) |
| Other (ECP/NP/Pharm/HCA) (n=17) | 10 (58.8) | 7 (41.2) |
| CPD Respiratory Qualification | 84 (77.1) | 59 (52.2) |
| Years in Practice > 10 years** | 65/107 (60.7) | 58/112 (51.8) |

*11/99 online PHCPs specified that they referred to PR but did not specify referral frequency and were removed from this analysis. ** 107/109 and 112/113 reported time spent in general practice

40/233 (17.2%) responding PHCPs reported never referring to PR, with the largest group being practice nurses (29/40; 72.5%). 33 of 40 PHCPs offered a variety of reasons for non-referral including; not considering it to be part of their role, not seeing COPD patients or not knowing they could refer (12/33; 36.4%). Others reported it was undertaken by other respiratory specialist/interested health care professionals across primary and secondary care settings (12/33; 36.4%). Further reported reasons were unsure how to and/or a lack of training (5/33; 15.1%), uncertainty about local service provision (3/33; 9.1%) and 1/33 (3.0%) reported belief that patients were not interested.

## 4.17 **Phase 1 Results: TDF analysis of the qualitative interviews**

Table 14 shows the referral behaviour of PHCPs mapped to all 14 TDF domains. The most frequently mapped domain was social and professional role (n=287 times) whilst the least mapped was behavioural regulation (n=4).

**Table 14: Phase 1 Mapping of barriers and enablers for referral to TDF domains**

| TDF Domain (construct mapping frequency) | Content mapping (n) | Key points | Evidence supporting |
|---|---|---|---|
| **1.Social and Professional Role** (A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting) | (n=289) | Referral was considered everyone's role, however it was considered best undertaken by the PHCP during disease stability and at annual review. It was often considered to be the practice nurses' role, but also respiratory-interested others.<br><br>Most PHCPs considered it their duty of care to motivate patients.<br><br>Only 1 of 19 PHCPs described implementing practice leadership | *It is largely the nurses' job to see stable COPD patients at an annual review and that is the most appropriate time to refer to pulmonary rehabilitation, not during an acute exacerbation' –GP5*<br><br>*No, I think it's everybody's role, I mean I'm not sure about my non-respiratory colleagues.* PN2 |

| TDF Domain (construct mapping frequency) | Content mapping (n) | Key points | Evidence supporting |
|---|---|---|---|
| | | to improve PR awareness and/or referral. | *So we've put forward a proper business case for it. (Local PR service).* GP4 |
| **2.Knowledge** (An awareness of the existence of something) | (n=256) | 17 of 19 PHCPs knew of the existence of PR and a generalised understanding of its purpose. PR Knowledge was reported to be gained through post qualification education and networking events.<br><br>Local PR knowledge such as programme timing, waiting list (if any), and availability of patient transport, was often unknown and were described as inhibitors to referral discussions.<br><br>The referral criteria Medical Research Council (MRC) dyspnoea Score ≥3 was frequently cited as a referral prompt, although some PHCPs wanted to refer patients with MRC scores of 2 and felt unable to. | *I think it's a fundamental treatment and I think it's better than drugs.* PN7<br><br>*Do you currently refer to PR? P -I wouldn't know where.* GP2<br><br>*I don't know how to describe pulmonary rehab to a patient.* GP3<br><br>*I just feel that we don't know enough about the program to confidently hand on your heart sell it.* PN1<br><br>*'We've also got the barrier of we can only refer if their MRC is 3 or 4 or 5'* PN5 |
| **3. Environment** (Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence, and adaptive behaviour) | (n=195) | PR referral was often considered inappropriate in non-COPD focused consultations or when a patient was consulting for an acute exacerbation. Clinical time constraints were often described as inhibiting referral, although annual review considered appropriate time because of its clinical focus, template design and longer consultation time.<br><br>PHCPs often stated little PR promotional material was available in practice for patients or staff; there were however mixed views on the potential value of this.<br><br>3 practices had initiated an in-practice 12 weekly, 1 hour generic exercise group, this | *I think in our role when you're treating potentially acutely unwell people in a really limited time span then it's, it is realistically going to be hard to cover everything, really hard.* ANP2<br><br>*On the annual review well I follow the template and when I get to the pulmonary rehab I mention it then and I say, 'Would you like to go?'* PN3<br><br>*It would be useful for our local organisation I think to give us some little leaflets about what they do so we can give that to patients about the local service* ANP4<br><br>*I'm not against a leaflet but have you seen how many* |

| TDF Domain (construct mapping frequency) | Content mapping (n) | Key points | Evidence supporting |
|---|---|---|---|
| | | appeared to be seen as equivalent to PR by 1 PN. | *posters and leaflets we have on our walls?* GP2 |
| **4.Belief about capabilities** (Acceptance of the truth, reality, or validity about an ability, talent, or facility that a person can put to constructive use) | (n=141) | Individual PHCP PR referral confidence varied, with particular uncertainty expressed in how to best 'sell PR' and how to motivate un-motivated patients. Although most were confident in reassuring patients that PR would improve breathlessness.<br><br>PHCPs with positive non-pharmacological and exercise beliefs appeared to have greater confidence in PR benefit and patients' abilities<br><br>A number of PHCPs described COPD patients as uninterested in improving their health and some PHCPs emphasised patients needed to be committed to PR. Whilst some PHCPs described 'knowing' which patients would accept referral, others described undertaking subjective patient assessment and expressed concerns about patients' exercise capability in the presence of breathlessness.<br><br>For patients receiving oxygen therapy there was much uncertainty of the benefit of PR and an assumption that Oxygen/secondary care teams would have previously offered this.<br><br>Most PHCPs considered key environmental factors such as session timing, venue accessibility, patient financial hardship, as barriers for most patients. Patients in work, or those able to take the dog for a walk/wearing walking boots were considered 'too well' for PR. | *I would need to feel confident, before I speak to this patient about it.* ANP4<br><br>*I quite like... Non-medicinal treatment...think if you're excited by it then it's easier for patients to get excited by it as well.* GP4<br><br>*They are also very very clear that there not going to take anyone on their course unless there is 100% commitment at the beginning that they are going to complete the course.* ANP1<br><br>*You look at the ones that you think would more likely go.* ANP4<br><br>*It's really basically where I see a need, where I see they can benefit – ANP1*<br><br>*If the patients already on oxygen therapy, then it's likely that they've already been seen by them.* HCA<br><br>*The main stumbling block is that you come across is " I'm not going every week for x number of weeks, I can't afford it, I haven't got that much time, how do you expect me to get there ....not a huge number of our patients drive.* GP4<br><br>*There's some patients that I would like to refer but they can't go because of work commitments.* PN3<br>*'It's quite surprising that some patients are still working at odd jobs and things like that and keep them very active. So,* |

| TDF Domain (construct mapping frequency) | Content mapping (n) | Key points | Evidence supporting |
|---|---|---|---|
| | | | *for those patients it's not so important.'* PN3 |
| **5.Memory (Inc.: Decision making)** (The ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives) | (n= 118) | Some PHCPs reported forgetting to refer patients to PR, however, embedded system reminders often found in COPD review templates or on-screen prompts were cited as important for most PHCPs.<br><br>Patient behaviour and clinical presentation altered decision making processes for some PHCPs for example not referring current smokers, or remembering PR in light of increasing COPD symptom burden and disease deterioration, whilst earlier concerns for patient capability and commitment became less apparent. | *I do need a reminders because my head's full, so as I say, I don't want to tick boxes but I do need a prompt.'* PN7<br><br>*That's something that we do, so we have a prompt that pops up saying has this patient been referred to pulmonary rehab.* GP5<br><br>*I think I go through phases, I'll do it really well for a while and somebody has motivated me and then I'll forget that and do something else.* PN7<br><br>*Breathlessness and exacerbations, I think, would be the key factors.* GP3 |
| **6.Optimism** (The confidence that things will happen for the best or that desired goals will be attained) | (n=110) | PHCPs frequently reported that patients did not want to attend PR, citing disease stigma and lack of activation as underlying reasons.<br><br>Negative patient responses appeared to dampen PHCPs optimism and reduce subsequent referral offers. Positive patient experience however had the opposite effect.<br><br>Positive and negative perceptions of PR providers were also reported on the basis of service quality and frequency of referral acceptance, this appeared to influence referral behaviour. | *The first thing you think, 'Are they going to do it?* ANP4<br><br>*Patients don't want it.* PN5<br><br>*Even if you then said what the evidence was and how you could improve, it's – I think that group of people are really difficult to engage* .GP3<br><br>*If they're negative anyway everything you suggest they sort of have an answer, 'Oh no that won't work.* PN4<br><br>*The longer the wait time, the less likely they are to turn up. HCA*<br><br>*I don't think it's the greatest service, it does have an impact because I'm not going to tell my patients to go.* PN7 |
| **7.Belief about consequences** | (n=107) | There was a general sense that PR is positive with many health and psychological benefits, but | *I've seen patients that have been… their lives have been* |

| TDF Domain (construct mapping frequency) | Content mapping (n) | Key points | Evidence supporting |
|---|---|---|---|
| (Acceptance of the truth, reality, or validity about outcomes of a behaviour in a given situation) | | beliefs captured in other domains impacted on PHCP belief about consequences of referral offer.<br>A small number of PHCPs expressed concern that PR might worsen patient's depression and/or anxiety, particularly for those socially isolated. | *transformed in the first year.* PN7<br><br>*Might have prevented the exacerbation if they'd gone* PN5<br>*I will say that when I'm talking to patients, say it's better than drugs, but I still get a closed reaction.* PN7<br><br>*If we can improve patient's breathing they're less likely to get anxious, that makes them less likely to dial 999 or likely to do something about it. And perhaps use their rescue packs more appropriately.* ANP4<br><br>*I wouldn't want to mention it if it ended up being that I'm saying there's this really good helpful programme but actually if she's so effected by her disease that she doesn't leave the house then I wouldn't want to have mentioned it and then not for her not to be able to go.* ANP2 |
| **8.Social Influences** (Those interpersonal processes that can cause individuals to change their thoughts, feelings, or behaviours) | (n=84) | Out of practice engagement from PR providers and PR advocates were important in increasing overall awareness and positively influencing referral behaviour.<br><br>Almost all PHCPs described little to no engagement from providers themselves, and described not knowing what had happened to completed referrals.<br><br>PHCPs also reported that positive patient PR experiences positively influenced PHCPs referral behaviour and that family can be influential, yet patients rarely ask for PR.<br><br>PHCPs described a need to increase PR's profile publicly and | *Our referral rate has gone up a lot since the respiratory MDT's because every single one of those patients has subsequently had a referral.* GP4<br><br>*At the moment I wouldn't know how many people we refer, is that referral going up, Nobodies giving us feedback from the rehab team about how we are doing as a surgery.* PN1<br><br>*If patients that have been to it you know express a positive experience that is something you can share with other people that you are trying to refer.* GP1 |

| TDF Domain (construct mapping frequency) | Content mapping (n) | Key points | Evidence supporting |
|---|---|---|---|
| | | for it to be marketed similarly to pharmacological treatments. The name PR itself was considered by some PHCPs to be a negative influence as 'rehab' was deemed to have undesirable connotations. | *I asked him to talk to his wife, because I knew she'd want him to go, because I know her through a different channel, and erm... he's come back and said 'Ooo I'll give it a shot.* PN5 *Nobody has picked up a leaflet and walked in with it and said can you refer me, nobody has.* ANP1 |
| **9.Skills** (An ability or proficiency acquired through practice) | (n=79) | The physical act of referring patients to PR were described as largely straightforward by most PHCPs, although there was no standardised process across the 2 regions.<br><br>Most undertook this action independently, although there were descriptions of practice administrators helping.<br><br>However, frequency of referral to PR when described in interviews, was far lower than that which was documented on the returned research interest form. | *Do you currently refer people to pulmonary rehab? Some, some.* PN7<br><br>*I've been at this practice for nearly three years now and it's sort of something that falls really far down on your list of things that you do on your COPD review, so it's always the last thing that you come to.* GP4<br><br>*It's very easy. It's a form erm it's a just a single sheet.* PN2<br><br>*Quicker, easier referral, much easier referral method* PN7 |
| **10.Reinforcement** (Increasing the probability of a response by arranging a dependent relationship, or contingency, between the response and a given stimulus) | (n=59) | There appeared to be no direct sanctions for non-referral of patients, although practice financial rewards in one region appeared to enhance awareness and referral.<br><br>Outside of these practices there was a suggestion that financial incentives would be advantageous, additionally calculating health cost benefit for PR attendance was suggested as potential enabler.<br><br>Additionally reinforcements such as those offered by social influences and patients were also described to be valuable. | *We've got this thing called A** that we're doing for, you know it was the QOF before, so like A** has taken over that so I think because of the A** the doctor who is the lead A** leader he discusses that a lot because of course you get points, you still get the points for it like QOF. So the more we refer is the more points we get so there's an incentive there for the practice.* PN6<br><br>*Yeah if they did something on the BBC or something they might all be in the next day saying, 'Oh I wanna do that'.* PN4 |

| TDF Domain (construct mapping frequency) | Content mapping (n) | Key points | Evidence supporting |
|---|---|---|---|
| | | | *If you spent 5 minutes with somebody then at the end of that they agreed to go and then they attended, then you would be motivated to do it again.* GP5 |
| **11.Goals** (Mental representations of outcomes or 'end states' that an individual wants to achieve) | (n=47) | Referral to PR was a low-level goal for most PHCPs, but one that varied by consultation type and was not considered during an acute exacerbation review. However, referral appeared to become a goal in the presence of worsening patient symptoms.<br><br>Some PHCPs described wanting to refer more patients and learning strategies to improve patient acceptance, but described frequent discord between PHCP and patient goals which PHCPs found challenging.<br><br>No PHCPs discussed set practice PR referral targets although one GP reported plans to set up a programme geographically closer to practice (captured as leadership in the domain social & professional.) | *As a practice, when we do the acute exacerbation we're pretty much focus on the acute exacerbation.* GP4<br><br>*I refer a few to pulmonary rehab but I don't do as many as I feel I should.* PN7<br><br>*She was more receptive because she'd had a few flares up, not after the first one but because she's had a few. And I think that makes them more receptive to doing that sort of thing.* ANP4<br><br>*One hand I'm wanting them to engage with the disease process so that actually they've got more skills to self-manage and that's going to actually keep them much better for the rest if their whole of their life, on the other hand they don't want to be classified as ill.* ANP1<br><br>*It would help me in trying to find out why she didn't go because I would challenge her on it and try and get her to go again and give it another go and that would help me in.* ANP4 |
| **12.Intentions** (A conscious decision to perform a behaviour or a resolve to act in a certain way) | (n=39) | Some PHCPs have described adopting patient-aimed strategies that included persistence and warnings against overreliance and/or possible reduced effectiveness of pharmacological treatments in an | *I said you know you've used those rescue packs a lot you know if we could get your breathing a bit better, perhaps you wouldn't be so bad...., and she said, alright then I'll see, do the referral.* ANP4 |

| TDF Domain (construct mapping frequency) | Content mapping (n) | Key points | Evidence supporting |
|---|---|---|---|
| | | effort to move patients to a state ready for PR referral.<br><br>There also appeared to be an understanding that acceptance for many patients takes time. | *How would you feel about something that's not medicine based but will probably help you as much as the inhalers that we've put you on, she was suddenly very interested in.* GP4<br><br>*I look for that chink of interest and then I'll try and worm my way in then.* PN7<br><br>*He was very adamant that he didn't want to go, then I gave him the booklet.* PN5 |
| **13.Emotion** (A complex reaction pattern, involving experiential, behavioural, and physiological elements, by which the individual attempts to deal with a personally significant matter or event) | (n=6) | PHCPs emotion was rarely discussed although some said they felt annoyed with providers if a referral had been rejected.<br><br>There were high levels of empathy towards patients particularly amongst nurses; a small number described not wanting to offer the hope of PR to patients and for PR providers to reject referral, this appeared to be a particular concern for patients with high disease burden. | *Most of our patients are reasonably trusting and say well you seem quite excited by it so shall we give it a try.* GP4<br><br>*They're gonna meet all these people they don't know and be told to lift this walk here, do that and they're frightened, its... I'd be terrified.* PN5<br><br>*I just don't want to raise – if you raise patients' hopes and say – and offer it, then it can make them – you know, if they're already depressed because of the COPD, it could just make the depression worse you know, so I don't want to impact on their mental wellbeing. ANP1* |
| **14.Behavioural regulation** (Anything aimed at managing or changing objectively observed or measured actions) | (n=4) | Some PHCPs saw events such as hospital admissions/out-patient appointments as good opportunities for patients to change behaviours but for staff in those settings to instigate referral.<br><br>PHCP personal behavioural regulation was low, many did not know how any they had referred or what, post referral, the patient's journey had become. One participant described the research interview as helpful in | *I don't know how much is done in secondary care, but very often when stuff, when you've been in anywhere near secondary care people really its often quite a sit up moment, gosh this is serious enough for me to have to go to hospital, even if it an outpatient appointment.* ANP1<br><br>*This is one of your treatment choices' and perhaps I need to change, thinking about it, my* |

| TDF Domain (construct mapping frequency) | Content mapping (n) | Key points | Evidence supporting |
|---|---|---|---|
| | | allowing them to consider how to change their referral approach, but most PHCPs did not vocalise intentions to change or modify current or future PR referral behaviours. | *approach in – er, how I word it.* ANP4<br><br>*It's trying to make it a priority.* ANP4 |

## 4.18 **Phase 2. Questionnaire results: Referral practice beliefs.**

Table 15 presents the number and proportion of PHCPs that agreed or strongly agreed with each belief statement by frequency of referral.

**Table 15 Results of TDF belief statements by referral frequency**

| TDF Domain | TDF Questions (n=54) | Frequent referral n=109 (%) (weekly/monthly) | Infrequent referral n=113(%) (>monthly or no referral) | Total n=222(%) |
|---|---|---|---|---|
| 1.Knowledge | I am aware of the content of Pulmonary Rehabilitation (PR) Programmes * | 97/109 (89.0) | 72/113(63.7) | 169/222 (76.1) |
| | I am aware of PR programme objectives. * | 99/109 (90.8) | 75/113 (66.4) | 174/222 (78.4) |
| | I am unsure of the evidence base for PR | 18/109(16.5) | 30/113 (26.5) | 49/222(21.6) |
| | I know where geographically my local PR programme is delivered* | 92/109 (84.4) | 70/113(61.9) | 162/222 (73.0) |
| | I know when it is appropriate to refer a patient with COPD to PR * | 106/109 (97.3) | 74/113 (65.5) | 180/222 (81.1) |
| | I can answer questions patients have about PR* | 88/109 (80.7) | 60/113 (53.1) | 148/222 (66.7) |
| | I know how to contact my local PR provider * | 91/109(83.2) | 68/113 (60.2) | 159/222 (71.6) |
| 2.Skill | It is easy to refer a patient to PR* | 87/109 (80.0) | 48/113 (42.5) | 135/222 (60.8) |
| 3.Social & Professional Role | Referral to PR is the practice nurse role | 63/109 (57.8) | 45/113 (39.8) | 108/222(48.6) |
| | Other General Practice staff in my practice (excluding Practice Nurse) refer patients to PR | 52/109(47.7) | 63/113(55.8) | 115/222 (51.8) |
| | I believe in encouraging patients to attend PR | 109/109 (100) | 104/112 (92.9) | 213/221 (96.4) |
| 4.Environment | Resources about PR i.e. written information) are readily available | 39/109 (35.7) | 25/112 (22.3) | 64/221 (29.0) |
| | There is not enough time in practice to refer | 12/109 (11.0) | 22/113 (19.5) | 34/222(15.3) |
| 5.Social Influences | My local PR providers regularly engage with me | 31/109 (28.4) | 17/113 (15.0) | 48/222 (22.6) |

| TDF Domain | TDF Questions (n=54) | Frequent referral n=109 (%) (weekly/monthly) | Infrequent referral n=113(%) (>monthly or no referral) | Total n=222(%) |
|---|---|---|---|---|
| | PR is something that patients ask for | 3/109 (2.8) | 8/112 (7.1) | 11/221 (5.0) |
| | There are good relationships in practice with PR providers | 44/109 (40.4) | 28/112 (25.0) | 72/221 (32.6) |
| | PR providers are good at communicating outcomes of referrals I have made | 39/109 (35.8) | 25/112 (22.3) | 64/221 (29.0) |
| 6.Optimism (including pessimism) | I am confident my local PR provider offers a good service for my patients.* | 81/109 (74.3) | 52/113 (46.0) | 135/222 (60.8) |
| | I don't believe patients will attend PR after I have referred | 16/109 (14.7) | 16/113(14.2) | 32/222(14.4) |
| | Patients who smoke are not motivated to take part in PR | 7/109 (6.4) | 7/113 (6.2) | 14/222 (6.3) |
| | Patients who live alone won't like to take part in group PR | 5/109 (4.6) | 2/113 (1.8) | 7/222 (3.2) |
| | Patients are motivated to attend PR | 23/109 (21.6) | 30/111 (27.0) | 53/219 (24.2) |
| 7.Belief about Capabilities (self) | I am confident in my ability to encourage patients to attend PR, even when they are not motivated | 91/109(83.5) | 73/113 (67.6) | 164/222 (73.9) |
| | I do not find it easy to discuss PR with patients. | 8/109(7.3) | 25/113 (22.1) | 36/222(16.2) |
| Belief about capabilities (patients) | Patients without their own transport won't be able to get to PR | 40/109(36.7) | 26/113 (23.0) | 66/222 (29.7) |
| | Patients in work are not able to attend PR * | 62/109 (56.9) | 35/113 (31.0) | 97/222 (43.7) |
| | Patients who use home oxygen are unable to take part in PR | 4/109(3.7) | 6/113 (5.3) | 10/222 (4.5) |
| 8.Belief about consequences | If I keep pushing patients to attend PR this will disadvantage my relationship with them. | 10/109 (9.2) | 10/112 (8.9) | 20/221 (9.0) |
| | I believe patients may be harmed by taking part In PR | 1/109 (0.9) | 1/113 (0.9) | 2/222(0.9) |

| TDF Domain | TDF Questions (n=54) | Frequent referral n=109 (%) (weekly/monthly) | Infrequent referral n=113(%) (>monthly or no referral) | Total n=222(%) |
|---|---|---|---|---|
| | I believe most patients will attend and complete PR following my referral | 55/109 (50.4) | 47/112 (42.0) | 102/221 (46.2) |
| | PR is not beneficial to patients who are breathless | 3/109(2.8) | 3/113(2.7) | 6/222 (2.7) |
| | PR is best suited to those patients with worsening breathlessness | 29/109 (26.6) | 29/112 (25.9) | 58/221 (26.2) |
| | PR is **best** suited to those who have frequent exacerbations | 27/109 (24.8) | 28/112 (25.0) | 55/221 (24.9) |
| | PR reduces hospital admissions | 101/109 (92.7) | 97/112 (86.6) | 198/221 (89.6) |
| | PR reduces risk of mortality | 85/109 (78.0) | 82/112 (73.2) | 167/221 (75.6) |
| | If patients attend PR this will reduce their general practice visits | 73/109 (67.0) | 78/112 (69.6) | 151/221 (68.3) |
| | PR reduces exacerbations | 88/109 (80.7) | 84/112 (75.0) | 172/221 (77.8) |
| | PR improves breathlessness | 103/109 (94.5) | 100/112 (89.3) | 203/221 (91.9) |
| | PR reduces a patient's anxiety and/or depression. | 97/108 (89.8) | 96/112 (85.7) | 193/220 (87.7) |
| 9..Goals | Referring patients to PR is something I have been advised to do* | 95/107(88.8) | 57/112(50.9) | 152/219 (69.4) |
| | My practice regularly reviews COPD registers to ensure eligible COPD patients are offered PR | 51/109 (46.8) | 40/113 (35.4) | 91/222 (41.0) |
| | There are set targets within the practice to improve PR referral rates | 23/109 (21.1) | 21/113 (18.6) | 44/222 (19.8) |
| 10. Memory (Inc. Decision Making) | I often forget to refer patients with COPD to PR | 3/109 (2.8) | 23/113 (20.4) | 26/222 (11.7) |
| | Prompts to refer patients to PR within annual review templates are important reminders for me | 72/109 (66.1) | 69/112 (61.6) | 141/221 (63.8) |

| TDF Domain | TDF Questions (n=54) | Frequent referral n=109 (%) (weekly/monthly) | Infrequent referral n=113(%) (>monthly or no referral) | Total n=222(%) |
|---|---|---|---|---|
| | | | | |
| | I only refer patients if they have quit smoking | 1/109 (0.9) | 3/113 (2.7) | 4/222 (1.8) |
| | I only refer patients if they are optimised on their respiratory medication | 17/109 (15.6) | 12/113 (10.6) | 29/222 (13.1) |
| | PR is most suited to COPD patients who have frequent exacerbations | 20/109 (18.3) | 20/113 (17.7) | 40/221 (18.1) |
| | The best time to discuss PR referral with patients is when they are stable. | 32/109 (29.4) | 25/112 (22.3) | 57/221 (25.8) |
| 11.Reinforcement | More health care practitioners will discuss PR with patients because of the QoF incentive. | 75/109 (68.8) | 73/112 (65.2) | 148/221 (67.0) |
| | My practice receives financial incentives for referral to PR (Before April 2019) | 6/108 (5.6) | 5/113 (4. | 11/221 (5.0) |
| | I believe patient attendance to PR will increase because of the QoF Incentive. | 41/109 (37.6) | 58/112 (51.8) | 99/221 (44.8) |
| | I believe the QoF incentive will not increase patients PR attendance * | 29/109 (26.6) | 25/112 (2.3) | 54/221 (24.4) |
| | There will be greater awareness of PR within practices because of the new QoF incentives. | 84/109 (77.1) | 71/112 (63.4) | 155/221 (70.1) |
| 12.Intentions | I will refer more patients to PR now there are practice QoF incentives (from April 2019) | 30/109 (27.5) | 42/112 (37.5) | 72/221 (32.6) |

In general, most PHCPs had some PR knowledge (especially the frequent referrers) and understood the beneficial consequences of PR. However, resources, social influences (such as relationship with PR providers) and pessimism about patient motivations were perceived barriers by a high proportion of PHCPs, irrespective of their referral practice.

There were however, differences in domains between frequent and infrequent PR referrers. The greatest differences were within the 'Knowledge' domain. Frequent referrers most commonly reported agreement with all 7 statements, when compared to the infrequent referrers. For example, 97.3% reported knowing when to refer to PR and 80.7% being able to answer patients' questions versus 65.5% and 53.1% of infrequent referrers.

Further group differences were demonstrated in the 'Skills' domain and 'Beliefs about (PHCP) capabilities', which showed that infrequent referrers were less confident in encouraging unmotivated patients to attend PR (67.6% versus 83.5% of frequent referrers). Reduced confidence amongst infrequent referrers was further reflected within the 'Optimism' domain and belief statement 'I am confident my local provider offers a good service' (46% against 74.3% of frequent referrers). However, over half (56.9%) of frequent referrers felt that patients in work were not able to attend PR, compared to less than a third (31%) of those who referred infrequently.

The remaining belief statements demonstrated greater group similarities than differences. Environment, Social and Professional role: Most respondents felt that there was enough time in practice to refer (84.7%) and believed in encouraging PR attendance (96.4%). Yet

promotional information on PR was rarely available in practices (29%). There was no clearly identified PR referrer; less than half (48.6%) felt it was the practice nurse's role and (51.8%) reported other practice staff refer.

Social influences: Frequent referrers were slightly more likely to agree with 3 of the 4 domain belief statements than infrequent referrers. Although, collectively the groups reported both PR provider engagement and referral outcome reporting as low at only 22.6% and 29% respectively. PHCPs also reported patients rarely request referral to PR (5%).

Belief about consequences and Optimism: Most PHCPs agreed that PR offers physical health benefits, including improving breathlessness and reducing hospital admissions (91.9%, 89.6%) respectively. Yet far fewer PHCPs believed patients would attend and complete PR (46.2%), with fewer still agreeing that patients are PR motivated (24.2%).

Memory (decision-making): Only a small number of PHCPs reported forgetting to refer patients to PR (11.7%). COPD annual review templates were reported as helpful referral reminders (63.8%) and 25.8% reported the best time to discuss referral with patients was during COPD stability. Patient characteristics such as disease stability and smoking status do not appear to impede PHCP referral decisions as 98.2% reported referring smokers.

Goals, Reinforcement and Intention: in-practice review of eligible patients was not commonly reported (41%) and only (19.8%) reported in-practice targets to improve referral

rates. Practice financial reward for referral (pre April 2019) was rarely reported (5%); indeed the implementation of financial reward via national QoF incentives (post April 2019) was considered unlikely to greatly improve referral behaviours, with less than a third (32.6%) stating they would refer more. However, there was general agreement that this incentive would increase practice awareness of PR (70.1%).

## 4.19 Phase 2. Questionnaire: Open question results

A third of PHCPs (33.8%) responded to the open question at the end of the survey including 5/11 PHCPs who reported referral, but did not specify frequency, (answer length 3-167 words, mean 35). Non-frequent referrers reported more open comments (43/113 38.1%) than frequent referrers (33/109 30.3%)

This gave an additional 94 comments that related directly to PR referral. These were content mapped to all 12 relevant TDF domains. The comments predominately cited referral barriers. Belief about capabilities had the highest number of comments 36/94 (38.3%) with many encompassing concerns about PR accessibility, particularly transport challenges for patients. For example, '*Location of PR too far for patients to travel and too much commitment. Patients tend to be older adults on generally low incomes. A number of my patients would attend if it was close by with no expense'.* A small number of PHCPs (3.2%) considered a patient's inability to complete pre-PR spirometry as a referral barrier, and 10.6% of comments related to referral processes, which were reported to be lengthy and as such *'easier simpler'* processes were requested.

## 4.20 **Connected results**

In order to identify the key factors that inhibit and/or enable PHCP PR referral, phase 1 and phase 2 results were merged to allow for data contrast and meta-inference (16) (table 5).

Most PHCPs believed in PR and encouraging patients to attend. Referral is most likely to be considered at annual review (indeed referral is rarely offered to patients outside of this consultation). On-screen prompts are helpful reminders, but in practice material promoting PR is rare. PHCP PR knowledge is largely gained from networking with other respiratory interested health professionals and/or CPD education. PHCPs report patients have little motivation for PR, rarely ask for referral to PR and view that patients in work are unlikely to be able to attend.

Some findings of the qualitative study were not clearly replicated in the survey results. For example, phase one qualitative data highlighted that some GPs and ANPs felt the practice nurse was best placed to undertake PR referral at the time of annual review, yet respiratory interested GPs and those undertaking annual review did not share this view. The phase two survey data supported the latter position, where 29/129 (22.5%) of practice nurses reported never referring. Therefore responsibility of PR referral is not based on profession, but is undertaken by PHCPs who are respiratory interested and/or conducting the patient's annual review.

Qualitative generalisable findings were limited in a number of areas meaning clear conclusion cannot be drawn, these included; time available to undertake referral, ease of referral process, perceptions of quality of PR programme, referral of patients when COPD symptom burden is increasing and non-referral in order to protect patient relationship.

Where generalisability is clear, a summary of the key behavioural barriers and enablers by TDF domain are shown in Table 16, demonstrating a greater number of barriers than enablers to referral. However, it is also important to report that barriers and enablers most commonly co-exist within the same domains.

**Table 16 Matrix of integrated results**

✓Enabler and agreement with Phase 1 data.
✗ Barrier and agreement with Phase 1 data.

| TDF Domain | Phase 1 Qualitative study Main Factors | Phase 2 Survey Main Factors | Barrier - ✗ / Enabler -✓ |
|---|---|---|---|
| Social and Professional Role | It is largely seen as the practice nurse role, or staff undertaking COPD review.<br><br>The best time to refer a patient is when they are stable<br><br>Most PHCPs believe in encouraging patients to attend. | Not clearly PNs role, but PHCP doing annual review is most likely referrer.<br><br>Disagree<br><br>Agree | PHCP undertaking annual review (not necessarily the PN)- ✓<br><br>Not generalizable in quantitative data.<br><br>✓ |
| Knowledge | Generally a good basic knowledge<br><br>Little detailed local programme knowledge<br><br>Knowledge is largely gained from CPD/networking | Agree (Generally higher in frequent referrers)<br><br>Disagree (Higher local knowledge in frequent referrers)<br>Agree | Enabler – but room for improvement<br><br>✓<br><br>✓ |
| Environment | There is a lack of time in practice.<br><br>Referral is only considered during non-acute COPD focused consultations.<br><br>There is a lack of PR promotional material available in practices. | Disagree<br><br>Agreed (some infrequent referrers reported not to see COPD patients)<br><br>Agree | Not generalizable in the quantitative data.<br><br>✗<br><br>✗ |
| Memory | On screen reminders are important<br><br>Referral prompted when patients have symptoms that are worsening | Agree<br><br>Disagree | ✓<br><br>Not generalizable in the quantitative data. |
| Optimism | Patients do not want PR/are not motivated<br><br>PR providers do not offer a good service. | Agree<br><br>Some agreement more so with infrequent referrers | ✗<br><br>✗ |
| Belief about consequences | PR is good for patient's physical and psychological health.<br><br>PR may harm patients (psychologically)<br><br>Pushing PR might harm my relationship. | Agree<br><br>Disagree<br><br>Disagree | ✓<br><br>Not generalizable in the quantitative data.<br><br>Not generalizable in the quantitative data. |

| TDF Domain | Phase 1 Qualitative study Main Factors | Phase 2 Survey Main Factors | Barrier - ✗ / Enabler - ✓ |
|---|---|---|---|
| | Patients will not always attend and complete post referral. | General agreement. | ✗ |
| Belief about capability | Talking to patients about PR is challenging. | Some agreement more so with infrequent referrers. | ✗ |
| | Patients in work are unable to attend PR | Agree | ✗ |
| | Transport is a barrier | Agree (Open question) | ✗ |
| | Not for patients with oxygen | Disagree | Not generalizable in the quantitative data. |
| | Not for patients who smoke | Disagree | Not generalizable in the quantitative data. |
| | Best suited to those who have frequent exacerbations | Disagree | Not generalizable in the quantitative data |
| Social influences | Lack of PR provider engagement and feedback to referrer | Agree | ✗ |
| | Patients do not ask for PR | Agree | ✗ |
| Skills | Referral to PR by PHCP is low | Agree | ✗ |
| | Referral process is relatively easy | Disagreement, particularly by infrequent referrers. | Likely barrier |
| Reinforcement | Financial reward increases referral rates | Most don't think this would change behaviour. | Not generalizable in the quantitative data |
| | Patients decline PR | Not captured explicitly | Likely barrier |
| | Financial reward increases practice awareness | Agree | ✓ |
| Goals | No set in-practice process to improve or review referral rates. | Agree | ✗ |
| Intentions | Referral acceptance takes time | Not captured explicitly | Likely barrier |
| | General desire to refer more patients. | Not captured explicitly | Likely enabler |
| Emotion | PHCPs are fearful on behalf of patients | Concern over access abilities (expressed in free text, may capture PHCP fear) | ✗ |
| | Frustration with PR providers | Not captured explicitly. | ✗ |

| TDF Domain | Phase 1 Qualitative study Main Factors | Phase 2 Survey Main Factors | Barrier - ✗ / Enabler - ✓ |
|---|---|---|---|
| Behavioural Regulation | PHCPs do not know how many patients they have referred.<br><br>PHCPs have no planned intentions to change behaviour | Agree<br><br>Largely agree, although some emerging interventions (free text) | ✗<br><br>Likely barrier |

## 4.21 **Discussion**

This is the first time the Theoretical Domains Framework has been applied to a mixed methods study to understand the key factors that determine referral to PR by PHCPs. Results highlighted multiple intertwined barriers and few enablers across all TDF domains Many (although not all) of the findings from the qualitative study were affirmed by the more generalisable survey and highlight that referral to PR from primary care remains poor, and that PHCPs believed that PR was beneficial for patients and wanted to refer more. They did however, request greater engagement from providers, better knowledge of local programmes and improvements in PR promotion. They also reported that in-practice goals and monitoring of referrals to address the shortfall in patients referred were rare.

However, PHCPs collectively reported low confidence in patients' abilities and motivations to attend PR, a belief likely to be strengthened by reports of few patients requesting referral. Beliefs about low uptake may explain why referral is commonly offered at times of increasing COPD symptoms, thus acting as a lever to referral acceptance. Infrequent referrers reported reduced confidence in encouraging un-motivated patients to attend, with similar findings reported in phase 1 data as PHCPs expressed concerns around the

protection of relationships with patients. Venue accessibility also appears to be a barrier and whilst the direct survey question (question 21) appeared not to overtly agree with this, both phase 1 and the phase 2 open question results highlighted transport as both a practical and financial barrier.

Variability in referral rate by PHCP profession was an unexpected finding and offers insights that (1) few PNs refer and (2) where it is considered to be the 'respiratory nurse' role, referral opportunities may become reduced. The association between referral frequency and respiratory qualification is also a new finding. ANPs were those most likely to refer and to have respiratory qualifications.

## 4.22 **Relation to other studies.**

This mixed methods TDF based study finds agreement with many key referral factors presented in our previous inductive qualitative study using the same data (6) and a TDF-applied systematic review which included patients and HCPs views on PR barriers and enablers (25). However this primary mixed methods study reports additional findings. It disputes that the PN is the main referrer to PR within primary care, and questions the value of practice based financial reward as a referral incentive. It also highlights that the referral process itself is not straightforward and there are no sanctions for non-referral, but that there is time in practice to refer.

Increasing the population sample and geographical reach in this study strengthens current known referral barriers including, poor patient motivation, few in-practice resources,

perceived venue access difficulties and little awareness of local PR provision (26-29). Subjective patient assessments including PHCPs perceptions of patient's capabilities and motivations have been described as influencing PHCP referral decisions here and previously published (6). This is a novel finding in relation to PR referral, yet similar HCP pessimistic attitudes, relating to a patient's capability and motivation to access services and change behaviours to improve health outcomes have been reported in the primary healthcare management of reducing cardiovascular disease risk in people with serious mental illness (30, 31).

Phase one and inductive data analysis (6) suggested that offering PR at COPD symptom increase was common yet this was unconfirmed in the survey results. This may demonstrate further social desirability reporting as previous analyses have demonstrated patients attending PR to have 1.24 hospitalisations per patient-year 95% CI (0.66-2.34) suggesting sicker patients are those most likely to be offered PR (32). However, referral at this time supports both PHCP and patients' concerns about patient's capabilities (6, 25, 33), meaning lower acceptance and adherence to PR is probable, and negative PHCP beliefs about referral outcomes are likely to perpetuate. An alternative approach and one that appears not to be currently undertaken is to refer at the point of an acute exacerbation of COPD, which maybe a referral lever (33).

In our original inductive analysis (6), we reported that financial incentives may be important, yet results in this current study are mixed and PHCPs appear uncertain of their value. It will be interesting to observe the impact of the newly implemented financial rewards for PR

referral in England, but where similar QoF rewards were implemented for referral to diabetes programmes, uptake did not greatly improve (34). Given positive correlations between referral rates and CPD education, efforts to increase the number and education of the primary care workforce by Health Education England (35, 36) is encouraging.

The literature also supports a general consensus that for patients in employment, PR is largely considered inaccessible (6, 28). This was reported as a barrier by the frequent referrers more than the infrequent referrers, which questions whether PR knowledge itself is a potential barrier as previously reported (6) and that PHCP beliefs influence subsequent referral behaviours.

### 4.23 **Strengths and Limitations**

Using the previously published qualitative data to inform the questionnaire offered valuable insights into PHCP referral practices and is a key strength of this research. The range and number of PHCPs included from across the UK were broadly representative of the general practice nursing workforce, whilst less so for others, notably doctors and is a limitation (37). We recognise that predominately respiratory interested participants may have taken part in this study which may skew results, and it is noted that online participants reported higher referral practice and respiratory qualification(s) than their counterparts, which may be a study limitation, suggesting that more emphasis should be placed on the perspective of the infrequent referrers. Adopting additional recruitment strategies such as via general practice-based conferences is seen as a study strength which sought to capture a range of PHCPs

views. Demographic similarities across all 3 recruitment streams highlight study design attempts to reduce participation and sample selection biases. Questionnaire specific biases relating to self-reporting response is a source of potential weakness, specifically where responses maybe perceived to be 'socially acceptable', otherwise known as social desirability (38). This may offer some explanation around the variation observed in the belief about capabilities domain of the integrated results matrix (Table 5). Grouping participants by reported referral frequency is a study strength, particularly as the aim is to understand both what supports and inhibits referral. Another limitation is that we are not sure about exact response rates where distribution was unknown.

Much of the validity of the TDF is gained from its direct application with HCPs, as utilised here. Transcript content mapping to 84 constructs is complex and time consuming as also described by others (39) but was considered the most comprehensive approach in the absence of a gold standard approach to TDF application (39). The TDF offers a functional approach to behavioural data analysis, most likely to be helpful when there is little to no underlying knowledge of the investigating phenomenon. However, the interrelations between referrer, patient and provider have previously been reported to be important factors in the referral journey (6). Yet, the TDF does not offer causal determinants of behaviour (20) and alignment to predetermined domains reduces the ability to consider any phenomena falling outside those domains and the likely connecting relations, meaning the whole picture maybe missed and is a potential limitation.

All authors had different professional backgrounds, one of whom (JW) is an experienced respiratory nurse specialist which may have altered data analysis although transparency and frequent team analysis sought to reduce potential bias.

## 4.24 **Implications for policy and practice**

Whilst this paper highlights multiple barriers in referring patients with COPD to PR, barriers to high quality healthcare for patients with COPD span throughout the disease trajectory and persist across health service provisions worldwide (40-42). It is interesting to note that few participants in our study thought that a financial incentive was important. It is however difficult to assess this given that face to face PR programmes were suspended across the country as a result of the COVID-19 pandemic. However, as previously highlighted QOF incentives for referral to diabetes programmes did not greatly improve uptake. What we need to do now is to design and test an intervention for improving referral to PR which incorporates multi-system level changes. Additional intervention considerations will also need to include post COVID-19 infection control adaptations, as well as managing increases in service demands arising from programme suspension backlogs and new referrals, including COVID-19 survivors (43).

## 4.25 **Conclusions**

This is the first mixed methods research study to examine the factors that inhibit and enable referral to PR for patients with COPD from a primary care perspective. Whilst knowledge

and respiratory qualification appear to be enablers, many barriers persist which must be overcome to increase referral opportunities for all eligible patients. The most important aspects to address are to increase PR provider engagement with referrers, increase PR awareness and support for potential patients and all PHCPs, including those with respiratory qualifications and to increase PHCP internal motivation for PR referral, particularly for those patients in work and those with less symptom burden. Mapping these TDF findings to behaviour change techniques (BCT) are important next steps which will enable clear targeted interventions to be identified and tested in clinical practice, which will ultimately increase referral to PR, thereby improving COPD patients' health outcomes and reducing health service utilization.

## 4.26 **Reference List**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**Ethics approval and consent to participate**

Ethical Approvals: Phase 1 approval granted by Health Research Authority: Project ID: 213367. Phase 2 approval granted by University of Birmingham: ERN_19-0439. All participants in phase 1 and phase 2 studies gave consent.

**Consent for publication**

Not Applicable

**Availability of data and material**

The datasets during and/or analysed during the current study available from the corresponding author on reasonable request.

**Competing interests**

The authors declare that they have no competing interests"

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**Authors' contributions**

JW collected, analysed and interpreted phase 1 and phase 2 data and was a major contributor in writing the manuscript. RJ, PA, SG and AE contributed to study design, data analysis and interpretation of phase 1 and 2 data. RJ, PA and SG all contributed to the writing of the manuscript. IV supported phase 1 topic guide development, phase 1 data alignment to the TDF and the formulation of the phase 2 questionnaire where behavioural expert consensus was sought. All authors read and approved the final manuscript.

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## 4.27 **Summary: Overview of methodology**

This chapter utilised an exploratory sequential mixed methods approach in order to complete objectives 2 and 3 of the thesis as outlined in chapter 1 section 1.21, p 35; conducting a qualitative study with PHCPs to identify barriers and enablers to referral utilising a deductive approach and conducting a nationwide quantitative survey that has been informed by the PHCP qualitative findings in order to identify trends and patterns to PR referral. This also completes Study 2ii and Study 3 of the mixed multiphase thesis described in chapter 1 section 1.22,p 35.

This chapter has provided insight into a variety of current PR referral experiences from a cross section of PHCPs across the UK. Interpretation of these experiences was obtained by re-analysing the data from Study 2i (see chapter 3) using a theoretical behavioural deductive approach; a contrast to a qualitative inductive method (233). Findings from this deductive analysis (study 2ii) informed the question content of the quantitative study, whilst behavioural theory offered the overarching framework. This methodological approach, implemented in two separate phases, commencing with qualitative research and followed by quantitative data collection in order to test the generalisability of the initial qualitative findings through integration, enhances overall value and is otherwise known as an exploratory sequential mixed methods research design (149, 150).

Mixed methods research is only recommended where the research question cannot be answered by a single method (149, 150, 234). Researchers must however be mindful, that mixed methods research is time consuming, not only because of its separate data collection processes but also the volume of data generated and associated data analysis challenges (235).

The mixed methods research design has been valuable within this work for a number of reasons. It has allowed a cross section of perspectives to be presented via differing research lenses, as well as informing the quantitative instrument design, necessary for breadth and validity of initial findings (236). This combined approach has enabled a deeper understanding of the barriers and enablers to PR referral across a wider geographical and multi-professional primary care workforce.

The design to undertake an exploratory sequential approach, rather than an explanatory sequential approach (commencing with quantitative methods, followed by qualitative methods) within this chapter was based on the evidence base at the start of the study. There was little knowledge of the underlying PR referral barriers and enablers for PHCPs. Also, the approach was in line with the desire to align the findings to psychological theory, which is strongly advocated in intervention design, as previously highlighted (132). Furthermore a concurrent investigative approach would not have supported the thesis and chapter objectives as phase one findings were needed to inform the phase two data collection tool.

The initial phase one qualitative data was analysed using content analysis (232) and deductively aligned to the TDF. Emerging patterns found within the qualitative data consequently informed the design of the phase two quantitative data collection. Therefore this sequential design process transforms the qualitative data in order that it can be quantified (150) and is the first 'mixing' of the data, thereby creating mixed methods research (149, 150). The transformation of qualitative findings that subsequently designs a quantitative instrument is a core methodological feature of sequential exploratory mixed methods research (149, 150, 161), described by Creswell and Plano-Clark as 'building' (149).

However, to date, building through data integration is sparsely described by study authors,across a number of differing implementation studies (234, 237, 238). The quality of reporting methodology across mixed methods research studies is often described as sparse , particularly in relation to the data integration process(es) (239-241). Indeed calls for improvement of reporting and better transparency are widespread (242-244). Tools such as the 'Good Reporting of A Mixed Methods Study' 'GRAMMS' (241) have been formulated to guide reporting and thus support methodological quality. For our published mixed methods paper presented in this chapter the 'Guidelines for Conducting and Reporting Mixed Research in the Field of Counseling and Beyond' (165) has been utilised and are presented in Appendix 16. Whilst both are recommended mixed methods reporting guidleines via the Enhancing the QUAlity and Transparency Of health Research (EQUATOR) network (245), Leech and Onwuegbuzi's 'GRAMMA' guideline (165) offers greater depth given its 45 indiviudal reporting steps, in contrast to O'Cathain et al's (241) six steps. Greater step by step methodlogical assessment was considered particulalry helpful for the author as a novice

mixed methods researcher, both in framing the initial research proposal and assessment of the end product.

Our exploratory mixed methods study is qualitatively driven (149). Morse and Niehaus (150) emphasise the importance of ensuring the exploratory approach remains inductive and aligned to the inductive research aims. Yet here, whilst the data is generated inductively, the data has subsequently been deductively aligned to the pre-defined TDF framework, which may conflict with the recommended inductive approach (133, 246). This approach was however discounted in this work because of the large number of TDF domains present and the practical time constraints faced by PHCP participants. For these reasons the associated shorter COM-B was used (137).

In the context of TDF research many researchers conduct and publish barrier and enabler analysis using qualitative inquiry and deductively content map findings to applicable TDF domains without further clear progression (233, 247). The TDF has also been used and applied inductively to research (133, 246, 247). Yet few researchers appear to use exploratory mixed methods research in the context of TDF research. One group of researchers, Dyson et al's TDF informed qualitative study on hand hygiene practices used a Delphi technique approach (248) where content experts agreed on the main modifiable factors relative to hand hygiene, following which a bespoke hand hygiene questionnaire was developed (237). A second TDF based intervention study conducted by McLellan et al (136) included two data collection approaches one qualitative and a second quantitative. However it does not state if the studies were conducted sequentially or concurrently, nor whether the

qualitative study informed the questionnaire. It also offers little insight into how the individual study findings were integrated and supported overall findings. The last identified TDF mixed methods study explores the barriers and enablers to a sepsis intervention tool (247). Data integration at the point of questionnaire development is clearly described, which uses content analysis and team consensus for belief statement agreement. It appears frequency of alignment to belief statements determined overall findings, but there is no clearly described guidance on data comparison, contrast and meta-inference outputs as expected (149). Inferences refer to the researcher's construction of relationships and patterns that the individual research inquiry offers (234). Whilst meta-inference refers to

*'an overall conclusion, explanation, or understanding developed through an integration of the inferences obtained from the qualitative and quantitative strands of a mixed methods study'* (234) p 101.

Otherwise termed 'merging' by Creswell and Plano-Clark (149). In the context of this chapter the individual study inferences and the meta-inferences are presented in table 16, p 161-2.

In keeping with the exploratory methodology within the study presented in this chapter the qualitative study is the core component whilst the quantitative phase seeks to enhance understanding of the phenomenon under investigation (149, 150). It is the consistency between the two sets of findings that is purported to be an indicator of quality (234). Our findings have shown that following merger there is largely consistency with the core qualitative study.

Where findings were inconsistent between two phases, alternative explanations can sometimes be sought by utilising additional evidence. For example, in this study, in terms of the timing of PR referral offer, the qualitative study suggested that the 'best time to refer a patient to PR is when they are stable' and from the survey, that PR 'is best suited to those who have frequent exacerbations'. In this case, service data provide an alternative source and indicates that patients with more advanced COPD are more frequently referred to PR (209) thus providing greater weight towards the quantitative data in this case. For other inconsistent findings post data merger, such as there 'is a lack of time in practice to refer patients', this is perhaps a variable that cannot be truly measured objectively across a diverse professional and geographical population because of multiple confounders.

The greatest inconsistencies between the data were found in the TDF domains 'belief about consequences' of referral and 'belief about capabilities' (the patients). It is questioned whether the quantitative data approaches are able to truly capture PHCP subjective assessments as described in chapter 3, however it is important to present both perspectives and views as suggested by Freshwater (249) and others (234).

The TDF informed exploratory mixed methods methodology presented here offers methodological quality on account of its step by step descriptors and clear approach to mixed methods integration. This research study is novel and further adds to the originality of the thesis, particularly in the context of understanding PR referral barriers and enablers for

PHCPs, which is likely to improve PR offers and therefore referral rates for patients with COPD.

## 4.28 Key Chapter Findings

This research has presented identified and validated the key PR referral barriers and enablers as experienced by PHCPs. These build from chapter 3, which highlighted limited PR knowledge to be an important initial barrier to PR referral, but one that can be overcome by respiratory peer PR advocacy and that PHCPs with respiratory CPD qualifications refer more patients to PR. However, this chapter's utilization of psychological theory has offered greater insight into PHCPs behaviours and the effects on PR referral relative particularly to patient's anticipated or actual behaviours at or preceding referral offers.

The TDF (116) domain 'optimism' was a highlighted barrier as PHCPs described concerns around the likelihood of patient referral acceptance, a concern that overlapped with the domain 'belief about consequences'. Furthermore when a referral offer has been made the patients response often appeared to have consequential (positive and negative) effect on the PHCPs. This further impacts on the PHCPs behaviours of subsequent referral offers. These described anticipatory outcomes, when aligned to the TDF, support the findings reported in chapter 3 and further highlight the role that unconscious processes have upon PHCP referral actions even in the presence of PR knowledge and awareness demonstrated notably as PR is frequently considered inappropriate for patients in employment. Exposure of this unconscious perception on behaviours is an important and novel finding in the

context of PR referral, and one that the TDF has been instrumental in identifying. It is therefore an important finding that must not be overlooked in the design and development of PR referral enhancing interventions.

The merger of study 2ii and 3 highlighted that PHCPs who referred more frequently are more confident in their own and their patient's capabilities. When compared to PHCPs few practice nurses refer to PR and confirmation of previous findings included there are limited PR promotional resources in practices and little engagement with PR providers.

This chapter has identified and confirmed a number of barriers and enablers to PR as experienced by a wide range of PHCPs. This completes thesis question one and thesis objectives 2 and 3, whilst partially answering question 2 (section 1:21, p 34-5).

## 4.29 **Next Steps**

This chapter has highlighted important and original insights that offer explanations for persistent low PR referral rates. Behavioural theory has highlighted that both conscious and unconscious behaviours are important referral influences. PHCP behaviours must therefore be addressed within intervention design. This investigation has also exposed the complexity of the health system and as such a multi-pronged approach is critical in order to manage the many competing PR barriers and enablers in order to affect any possible change.

Chapter 6 builds on from the theoretical diagnostic work presented here and undertakes the process of developing of potential PR referral enhancing interventions. It uses the prescriptive Behaviour Change Wheel (BCW) approach as it sets about identifying the principal Behaviour Change Techniques (BCTs), known as the 'active key ingredients' which are purported to be critical to intervention success (116, 250).

Chapter 5 presents data on UK-based PHCPs views on a number of potential practice based interventions that may increase PR referral rates and moves this work towards achieving its final objective of identifying evidence based interventions that seek to increase PR referral for patients with COPD from primary health care. These were collected within the survey presented here, but not published in the mixed methods paper on account of differing aims and objectives.

# Chapter 5: SURVEY

## INFORMING AN INTERVENTION TO IMPROVE REFERRAL TO PULMONARY REHABILIATION: A SURVEY OF PRIMARY HEALTH CARE PRACTITIONERS.

## 5.1 **Chapter objectives**

The objective of this chapter is aligned to thesis objective 4, as specified in section 1:21, p. 35: “To develop new evidence based, theoretically informed interventions that will increase PR referral for patients with COPD from primary health care.” It aims to identify which are the most feasible practice-based PR referral enhancing interventions as voted by a range of PHCPs themselves. This is achieved by utilising a two-step PHCP voting and ranking process in order to enhance validity of research outcomes.

## 5.2 **Introduction**

This chapter will present further survey data that was collected in addition to that presented in chapter 4. This additional data offers PHCPs views on a number of potential general practice-based interventions to improve referral that emerged as suggestions from the general published literature, the systematic review (chapter 2) and the earlier qualitative study (chapter 3).

## 5.3 **Methods**

PHCPs were recruited as described in chapter 4 and included a cross section of PHCPs, predominately practice nurses (PNs) (n=129), advanced nurse practitioners (ANPs) (n=57) and general practitioners (GPs) (n=29). More detailed PHCP characteristic data is presented in Table 1 (thesis, table 12 p 136) in the paper ‘Investigating primary health care

practitioners' barriers and enablers to referral of patients with COPD to Pulmonary Rehabilitation: a mixed methods study using the Theoretical Domains Framework**'** presented in chapter 4, p 141.

The anonymous survey was open for a total of eight months, between March-December 2019 and used two main data collection methods simultaneously: paper and electronic. Paper versions of the survey were distributed at six UK primary care focused events to attending PHCPs (predominately by hand by JW, although 'in-conference bag' distribution was adopted at one event). Upon self-completion, surveys were placed by participants in a locked ballot box and an optional token of appreciation was offered. To increase online participation participants were invited to opt in to a prize draw to win an I-pad (251).
As reported in chapter 4 this was exploratory research, meaning no *a priori* sample size calculations were performed and pragmatic approaches to study closure were adopted.

## 5.4 **Methodology – Instrument design**

The distributed survey had a total of five sections (Appendix 13). Sections 1, 2 and 5 (open question) are presented in the published paper in the previous chapter and relate specifically to barriers and enablers to referral as experienced by PHCPs.

Sections 3 and 4 are presented here and sought participants' perspectives on 23 potential practice-based interventions that might increase referral rates, generated from both the inductive research (chapter 3 findings) and recent literature on PR referral (including pre-published systematic review data reported in chapter 2). These data were not included in

the final published paper, largely owing to not fitting specifically with the research questions and aims of the paper.

Section 3 asked participants to rate 23 potential interventions on a fully labelled 5-point Likert scale (252), the same scale as used in sections 1 and 2. In section 4 PHCPs were asked to consider the 23 interventions and then identify and rank the top 5 interventions that they considered to be the most effective in enhancing PR referral (1 was considered the most effective and 5 the least).

For consistency, the 11 PHCPs that had not reported referral frequency remained excluded for this analysis, resulting in 88 online participants. There was also an initial online survey design error where question 11 and 12 overlapped into one question, this was amended shortly after survey circulation but meant a further 11/88 online responders were removed from those specific questions. Eventually, for questions 11 and 12 of section 4, 77/99 (77.7%) online responders were included and analysed.

## 5.5 **Analysis**

The survey was analysed largely in the same manner as reported in chapter 4. That being paper questionnaires were manually uploaded to 'Online survey' (253) following which all data were exported into an excel spreadsheet and STATAv16 (254) used to conduct simple descriptive statistics (frequencies and percentages), dichotomising into agree/strongly agree *vs* the remaining options and stratified by frequency of reported referral rates for section 3.

Section 4 results were not dichotomised as participants were only voting for five out of 23 questions.

## 5.6 **Results – Section 3**

A total of 207/222 (93.2%) participants completed at least one question from section 3. This included 119/134 (88.8%) paper PHCP completers and 100% (n=88) of online responders, achieved because of applied software limiters. Attrition was seen in all professions but highest amongst GPs with a loss of 10.7% (n=3). Remaining dropout remained largely comparable across all characteristics for section 3, including those with respiratory qualifications (136/143; 95.1%) and those without (71/79: 89.9%).

Table 17, p 188 presents the proportion of proposed interventions rated agree/ strongly agree (Likert scale 4 and 5) as likely to improve referral to PR, stratified by frequent (n=109) and non-frequent (n=113) referrers. Slightly higher numbers of frequent referrers completed section 3 in comparison 102 (93.6%) to 104 (90.6%) infrequent referrers.

**Table 17 Suggested interventions rated agree/strongly agree as likely to increase referral to PR by survey respondents.**

| Intervention | Frequent referral n=109 (%) | Non-frequent referral n=113 (%) | Total n=222 (%) |
|---|---|---|---|
| 1. Health Care Professional (HCP) referring patients to PR at the time of COPD diagnosis. | 82/103 (79.6) | 81/104 (77.9) | 163/207 (78.4) |
| 2. HCP prescribing PR at the time of COPD acute exacerbation. | 61/101 (60.4) | 65/102 (63.7) | 126/203 (62.1) |
| 3. A standardised summary (i.e.: a 2 sentences) that describes PR succinctly for HCP to recite to eligible patients. | 72/100 (72) | 74/103 (71.8) | 146/203 (71.9) |
| 4. Face to face educational sessions for general practice staff. | 84/102 (82.4)* | 90/104 (86.5)* | 174/206 (84.5) |
| 5. Online educational sessions for general practice staff. | 66/102 (64.7) | 80/102 (78.4) | 146/204 (71.6) |
| 6. Face to face educational sessions for potential patients, carers and family. | 89/103 (86.4)* | 85/103 (82.5) | 174/206 (84.5) |
| 7. Online educational sessions for patients, carers & family. | 65/102 (63.7) | 80/102 (78.4) | 145/204 (71.1) |
| 8. Practice staff loaning DVDs which demonstrate PR to patients. | 54/102 (52.9) | 55/103 (53.4) | 109/205 (53.2) |
| 9. HCP showing patients PR recording within practice or consultation i.e. on a tablet device. | 63/102 (61.8) | 62/102 (61.8) | 125/204 (61.3) |
| 10. Past PR patient attenders directly engage with eligible patients to highlight benefits. | 76/102 (74.5) | 85/101 (84.2) | 161/203 (79.3) |
| 11. PR providers directly contacting eligible practice patients. | 81/102 (79.4) | 90/101 (89.1)* | 171/203 (84.2) |
| 12. PR providers engaging with practice staff by coming into surgeries. | 89/102 (87.3)* | 95/102 (93.1)* | 184/204 (90.2) |
| 13. Personalised letters to eligible patients from general practice advocating PR. | 74/102 (72.5) | 89/102 (87.3)* | 163/204 (79.9) |
| 14. Group consultations with patients, general practice staff and PR provider. | 71/102 (69.6) | 73/103 (70.9) | 144/205 (70.2) |
| 15. Patients being able to refer themselves to PR. | 85/102 (83.3)* | 88/103 (85.4)* | 173/205 (84.4) |
| 16. Patients having their own COPD health care record, similar to a COPD passport, meaning they are prompted to ask for PR. | 79/101 (78.2) | 80/102 (78.4) | 159/203 (78.3) |

| | | | |
|---|---|---|---|
| 17. PR promotional material within patient pharmacy medication packs | 80/102 (78.4) | 85/102 (83.3) | 165/204 (80.9) |
| 18. Greater awareness of PR in practice. i.e. Posters highlighting local PR provider, benefits, etc. | 95/102 (93.1)* | 81/102 (79.4) | 176/204 (86.3) |
| 19. General practice staff being able to refer patients by telephone rather than manually completing referral form. | 60/102 (58.8) | 67/103 (65) | 127/205 (62) |
| 20. If my practice referred more COPD patients this would increase my own referral numbers. | 29/102 (28.4) | 35/102 (34.3) | 64/204 (30.4) |
| 21. Changing the name of PR to something more user friendly. | 51/102 (50) | 44/103 (42.7) | 95/205 (46.3) |
| 22. General practice staff being taught motivational interviewing techniques would improve referral to PR. | 70/103 (68) | 69/102 (67.6) | 139/205 (67.8) |
| 23. Lead practice PR referrer to educate and show PR video to other practice staff at practice meetings, to encourage a whole practice approach. | 72/102 (70.6) | 73/102 (71.6) | 145/204 (71.1) |

*-largest differences between groups
Highlighted test = key/standout findings

Overall, question 12 'PR providers engaging with practice staff by coming into surgeries' was considered to be the most effective intervention of all 23 options offered (184/204; 90.2% rating agree/strongly agree). Increasing practice awareness through PR promotional material, face to face educational sessions for practice staff and potential patients and carers as well as patients being able to self-refer and PR providers directly contacting eligible patients are also interventions that all PHCPS rated highly. It is noteworthy that the highest ranked overall interventions were those that did not directly involve PHCP individual behaviour change, but were interventions related to external factors.

Loaning DVDs, changing the name of PR and referring at a time of an AECOPD were considered less favourable interventions. The intervention that received the lowest number of votes across the whole group was a belief that in-practice peers could influence individual referral behaviour as only 30.4% of participants agreed and/or strongly agreed with question 20, 'if my practice increased PR referral rates, this would increase my own referral numbers'. Some small differences between frequent/non-frequent referrers were found for each of the 23 suggested interventions.

Non-frequent referrers tended to agree or strongly agree with a greater number of interventions compared to frequent referrers (17/23; 74%). The most marked difference was for question 13, 'personalised letter to targeted eligible patients' (89/102; 87.3% for non-frequent, 74/102; 72.5% for frequent), which demonstrated a 14.8% group difference. Additionally question 7, 'online teaching for patients and care-givers' shows a 14.7% difference and 'online educational sessions for practice staff' demonstrated a 13.7% group difference.

Of the six suggested interventions that were rated more highly by frequent referrers compared to infrequent referrers, the largest group difference was question 18, 'greater in-practice awareness, such as PR promotional posters' (95/102; 93.1% for frequent, 81/102; 79.4% for non-frequent). An observational finding appeared to indicate that frequent referrers favour interventions that target largely practice staff, whilst infrequent referrers tended to favour interventions that target patients and carers.

## 5.7 **Results - Section 4**

Section 4 completers included 50/134 (37.3%) paper-based respondents and 100% (n=88) of online respondents. Overall, almost one third less PHCPs (138/222; 62.2%) completed section 4 in comparison to those who had completed section 3 (207/222; 93.4%). There was additionally a marked response rate drop throughout questionnaire progression, for example question 1 has 77 votes and question 23 has 9. Question 1 related to referral to PR at the time of COPD diagnosis received the highest number of votes 77/138 (55.8%). This represented 11 GPs, 33 PNs, 25 ANPs and 3 'others', meaning the largest attrition rate observed here for this question was seen in PNs (n=96) at 74.4%.

**Table 18 suggested top 5 ranked interventions as likely to increase referral to PR by survey respondents.**

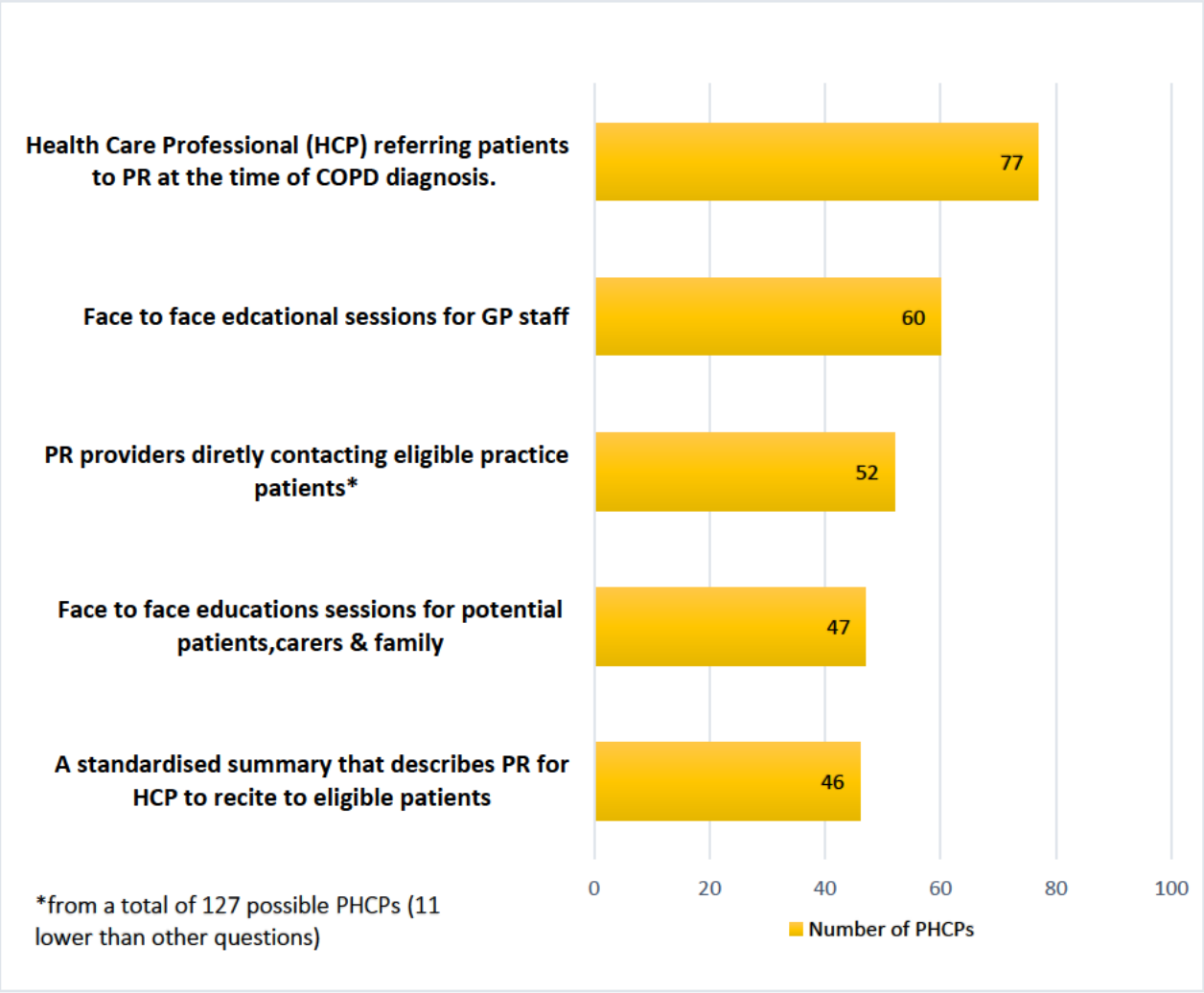
| Intervention | Frequent referral n=109 | Non-frequent referral n=113 | Total n=222 |
|---|---|---|---|
| 1. Health Care Professional (HCP) referring patients to PR at the time of COPD diagnosis. | 40 | 37 | 77 |
| 2. HCP prescribing PR at the time of COPD acute exacerbation. | 22 | 20 | 42 |
| 3. A standardised summary (i.e.: a 2 sentences) that describes PR succinctly for HCP to recite to eligible patients. | 24 | 22 | 46 |
| 4. Face to face educational sessions for general practice staff. | 23 | 37 | 60 |
| 5. Online educational sessions for general practice staff. | 12 | 14 | 26 |
| 6. Face to face educational sessions for potential patients, carers and family. | 26 | 21 | 47 |
| 7. Online educational sessions for patients, carers & family. | 10 | 8 | 18 |
| 8. Practice staff loaning DVDs which demonstrate PR to patients. | 8 | 11 | 19 |
| 9. HCP showing patients PR recording within practice or consultation i.e. on a tablet device. | 10 | 8 | 18 |

| | | | |
|---|---|---|---|
| 10. Past PR patient attenders directly engage with eligible patients to highlight benefits. | 27 | 18 | 45 |
| 11. PR providers directly contacting eligible practice patients. | 25 | 27 | 52 |
| 12. PR providers engaging with practice staff by coming into surgeries. | 18 | 21 | 39 |
| 13. Personalised letters to eligible patients from general practice advocating PR. | 14 | 8 | 22 |
| 14. Group consultations with patients, general practice staff and PR provider. | 14 | 9 | 23 |
| 15. Patients being able to refer themselves to PR. | 19 | 21 | 40 |
| 16. Patients having their own COPD health care record, similar to a COPD passport, meaning they are prompted to ask for PR. | 10 | 8 | 18 |
| 17. PR promotional material within patient pharmacy medication packs | 8 | 12 | 20 |
| 18. Greater awareness of PR in practice. i.e. Posters highlighting local PR provider, benefits, etc. | 15 | 7 | 22 |
| 19. General practice staff being able to refer patients by telephone rather than manually completing referral form. | 15 | 10 | 25 |
| 20. If my practice referred more COPD patients this would increase my own referral numbers. | 2 | 1 | 3 |
| 21. Changing the name of PR to something more user friendly. | 12 | 6 | 18 |
| 22. General practice staff being taught motivational interviewing techniques would improve referral to PR. | 9 | 10 | 19 |
| 23. Lead practice PR referrer to educate and show PR video to other practice staff at practice meetings, to encourage a whole practice approach. | 5 | 4 | 9 |

Highlighted numbers show suggestions with the greatest group difference

The top 5 interventions ranked by respondent's top 5 are shown overleaf in Figure 8. The sixth ranked intervention was excluded by only one vote and related to 'past PR patient's attenders directly engaging with eligible patients to highlight benefits'. In contrast the lowest voted for intervention was 'if my practice referred more COPD patients, this would increase my referral numbers'. Only 3/138 (2.2%) voted for this possible intervention.

**Figure 8: Proportion of each interventions for increasing PR referral ranked in the top 5 by PHCPs**




Comparing the top interventions between sections 3 and 4 as shown in table 5 showed a greater number of similarities than differences in possible effective interventions and include face to face educational sessions for staff, patients and carers and increased contact from PR providers to general practice staff and patients. This resulted in 7 individual possible interventions.

**Table 19: Top 5 voted suggested interventions (ordered high to low)**

| Section 3: Likert exercise (n=203-207) | Section 4: Ranking Exercise (n=127-138) |
|---|---|
| PR providers engaging with practice staff by coming into surgeries.* | Health Care Professional (HCP) referring patients to PR at the time of COPD diagnosis. |
| Greater awareness of PR in practice. i.e. Posters highlighting local PR provider, benefits, etc. | Face to face educational sessions for general practice staff. * |
| Face to face educational sessions for general practice staff. * | Face to face educational sessions for potential patients, carers and family.* |
| Face to face educational sessions for potential patients, carers and family.* | PR providers directly contacting eligible practice patients.* |
| Patients being able to refer themselves to PR. | A standardised summary (i.e.: a 2 sentences) that describes PR succinctly for HCP to recite to eligible patients. |

* Same interventions represented across both exercises

The lowest voted for interventions are presented in table 20, commonalities are seen in 3/6 suggested interventions.

**Table 20: Lowest 6* suggested interventions (ordered low to high)**

| Section 3: Likert exercise (n=203-207) | Section 4: Ranking Exercise (n=127-138) |
|---|---|
| If my practice referred more COPD patients this would increase my own referral numbers. ** | If my practice referred more COPD patients this would increase my own referral numbers. ** |
| Changing the name of PR to something more user friendly **. | Lead practice PR referrer to educate and show PR video to other practice staff at practice meetings, to encourage a whole practice approach. |
| Practice staff loaning DVDs which demonstrate PR to patients. | HCP showing patients PR recording within practice or consultation i.e. on a tablet device.** |
| HCP showing patients PR recording within practice or consultation i.e. on a tablet device. ** | Online educational sessions for patients, carers & family. |

| | |
|---|---|
| General practice staff being able to refer patients by telephone rather than manually completing referral form. | Patients having their own COPD health care record, similar to a COPD passport, meaning they are prompted to ask for PR. |
| HCP prescribing PR at the time of COPD acute exacerbation. | Changing the name of PR to something more user friendly**. |

*4 questions had 18 equal votes, so all were included for transparency
** Same interventions represented across both exercises

## 5.8 **Discussion**

This additional survey data has offered insight into PHCPs views on potential PR referral enhancing interventions utilising two different data collection approaches, the first was PHPCs views on each of the suggested 23 interventions and the second a ranking exercise to identify the top five considered most effective interventions. These data triangulation methods sought to increase reliability of the overall findings and highlighted there are several possible referral enhancing interventions.

The intervention that received the highest number of votes was noted to be the first question on the last section (number 4) and related to referring at the time of COPD diagnosis. However diagnosis of COPD across UK primary care provisions is haphazard with diagnostic inaccuracies commonly reported (90, 255). It was also interesting that whilst it is reported that nurses in primary care are those most likely to refer patients to PR (256) and that COPD diagnostic reliability is increased when undertaken by practice nurses (OR 1.65, 95% CI 1.18 to 2.33) (257). Yet, question 1 that related to referral at the point of diagnosis, saw the highest non-response rate from practice nurses when compared to all other PHCP groups as only 33 from a possible pool of 129 voted representing only 26% of practice nurses

Spirometry techniques are reported to be largely of good quality when undertaken by PHCPs (255), but a 2019 COPD audit (90) found that only 19% of those with a COPD diagnosis had adhered to national and international recommendations where diagnosis had been based on post-bronchodilator spirometry (3, 83). Furthermore, inaccuracies in spirometry interpretation and thus the over-diagnosis of COPD is widely reported (90, 255, 258). Approximately one third of patients with COPD have a prior diagnosis of Asthma (2/3). Which also questions whether offering PR referral at the time of transition to a COPD diagnosis is effective or appropriate. Whilst there is no published literature specifically on timing of respiratory diagnosis and/or the transition from Asthma to COPD and the effects on PR uptake it maybe an area worthy of further investigation.

There is limited published data that reports on PR providers directly engaging with patients and/or potential referrers to directly increase referral and/or uptake. Data from a small online survey of PR providers in the eastern region published as an abstract reported '15/16 provider organisations contained key people who promoted PR' (94). Yet the authors published larger scaled study reports PR provide engagement with PHCPs is challenged by limited number of PR staff and high rates of primary care staff turnover (259).

There is also limited published data on patient self-referral to PR, although national COPD audits demonstrates small increases in self-referral where in 2015 it was reported that 41/7413 (0.6%) (72) patients self-referred which increased to 1.6% (94/6056) in 2020 (260). Anecdotally, in the author's local area patients known to the community respiratory team (also providers of PR) often directly invite patients on their clinical caseload and previously

attended PR participants thereby bypassing PHCPs. It maybe this is the population that is reflected in the audit. There are however to date no published interventions that test PR provider recruitment and/or patient self-referral.

The combined data collection approach within this survey has shown that three out of the five potential interventions (PR providers engaging with practices and face to face education) are consistently rated as important by PHCPs (Table 19). The lowest ranking interventions (that which PHCPs considered to be less effective) had less cross comparison consistency. Only one agreed ineffective intervention (question 20) related to the belief that increased referral behaviour of general practice staff could positively affect that of individual PHCPs. This is particularly interesting as beliefs that humans learn through observing others leads back to the Greek philosophers Plato and Aristotle (261). Psychologist Albert Bandura, has written much about observational learning and its effect on human behaviour. His work led to his theory, 'social cognitive theory', which emphasises that much of the information we gain is derived from our interactions with others (261). Bandura's theory is one of 33 psychological theories, that have been amalgamated to inform the TDF (117). It is interesting then that the mixed methods results of chapter 4 showed TDF mapped 'Social influences' emerged as potential referral enablers. Perhaps the view that the influences of others in general practices as not helpful in this intervention exploration context highlights individuals are not aware or do not want to acknowledge that personal behaviours can be influenced by others.

Further low-rated interventions included changing the name of PR and demonstrating PR visually to patients either in person or by sharing media material for patients to take away. Since the time of survey distribution an RCT that tested the effect of an educational PR video on patients who had been admitted to secondary care with an AECOPD has been published (179), reporting that the intervention had no effect on uptake to PR compared with control (34% compared to 41%; P = 0.037).

Referring patients to PR at the point of a primary care presentation of an AECOPD is also poorly rated in this additional data. Which aligns to that previously reported in the qualitative research of this thesis. However, this is an area that maybe worthy of additional investigation particularly as engagement with PR within 4 weeks of AECOPD has important clinical and functional benefits (61) and as shown in the recent COPD audit this is an emergent population given 250/6056 (4.1%) were referred from primary/community services following treatment for an AECOPD (260). Therefore this is an approach that should remain on the table, even in light of PHCPs ranking it lowly.

## 5.9 **Strengths and Limitations**

Variations in response rates were the most significant limitations to this survey, as participation rates steadily declined throughout the survey. There was a total loss of n=84 participants (37.8%) from the start of the survey (section 1) to the end of the survey. It is postulated that this was related to questionnaire fatigue and cognition overload (262). Particularly in section 4 which asked participants to identify the top 5 from a possible 23 interventions, after individual rating of each intervention (section 3). The Likert rating saw a

mean response rate of 116.3/134 (86.8%), whist section 4 fell to just 50/134 (37.3%), amongst paper participants meaning results in this section should be treated with some caution.

Software limiters strengthened the electronic individual questions to be completed more fully, yet conversely this may have reduced overall online participation rates as 123 participants started the online survey, of which 24 (19.5%) did not complete. Because the survey's distribution methods, response rates could not be calculated. It is therefore not possible to determine that the sample is representative of a normally distributed population and for that reason is a limitation (263).

The strengths however are the collection of PHCPs views on potential interventions, using triangulated data collection approaches and that a reasonable range of PHCPs have contributed. It is interesting also that our findings presented here correlate with the recently published RCT (179) and that demonstrating PR on a digital device is not effective in increasing PR uptake. This finding strengthens calls that practitioners should actively contribute to the design and application of potential practice-based PR referral enhancing interventions (143).

## 5.10 Key **Chapter** Findings

This chapter has presented a number of potential PR referral enhancing interventions as complied initially by published research and then based on PHCP suggestions. A larger number of PHCPs then voted on what they considered to be the most effective interventions

using a ranking and a rating process. This has highlighted there are several areas worthy of further development, including increasing engagement between PR providers and PR referrers, engagement, face to face education for both PHCPs and patients, consideration of referral timing opportunities and increased promotional material. These areas will be the focus of the next chapter and will inform intervention design.

This chapter has supported thesis objective 4 (section 1.21, p 35) and completes study 3 of this multiphase thesis. It has provided insight into the views of a range of staff on possible interventions working in a number of primary health care setting across the UK. This additional survey work has added valuable insight from PHCP to the design and development of potential PR enhancing interventions.

## 5.11 **Next Steps**

The following chapter, chapter 6 progresses this interventional development work further. It will firstly introduce and utilise components of the O'Cathian et al's (143) logic model for intervention development along with the BCW (171). Finally, it will include an analysis of those processes and offer recommendations for evidence-based, theoretically informed PR referral enhancing interventions.

# Chapter 6: INTERVENTION DESIGN AND DEVELOPMENT

## 6.1 **Chapter Objectives**

The objective of this chapter is to draw together all of the research findings presented within the thesis, alongside pertinent published literature, in order to identify and present possible evidence-based theoretical informed primary care based PR referral enhancing interventions. This is aligned to thesis objective 4, as specified in section 1:21, p 35:
"To develop new evidence based, theoretically informed interventions that will increase PR referral for patients with COPD from primary health care."

## 6.2 **Introduction**

This chapter draws on O'Cathain et al's (143) guidance for complex health intervention development. It utilises both behaviour change theory and PHCP expert views and experiences in its aim to present effective evidence-based interventions that seek to increase PR referral for patients with COPD from primary care settings. The findings from the systematic review, qualitative, quantitative and mixed methods research in this thesis will help design interventions, specifically drawing on the identified barriers and enablers to referral and drawing on the small number of effective interventions that this thesis has identified.

This will be undertaken using a step by step approach informed by the Behaviour Change Wheel (BCW) (171) and will complete objective 4 of the thesis 'Making intervention recommendations that will increase PR referral for patients with COPD from primary health care' (Section 1:21, p 35). This chapter will also inform important next steps towards a

possible feasibility study as highlighted in this multiphase thesis (discussed in section 1:22, shown in Figure 5, p 36).

This chapter will be first structured with a brief summary of behaviour change followed by an overview of how patients living with chronic illness process information and how information processing affects the implementation of behaviour change. The chapter then centres on the factors that influence PHCPs behaviour and the effect this has on the patients they care for. It will introduce interventions that seek to change practice through behaviour change, including psychological theory. This will be presented as a three part process; part one will follow the prescriptive BCW methods (including TDF and COM-B) to intervention development using the empirical barrier to PR referral findings from chapters 3 and 4. Part two will draw on the effective interventions identified in the systematic review and part three will identify the key functional and behavioural elements from the ranked PHCP interventions in chapter 5. All parts will then be combined to identify possible data alignments. This approach embraces published evidence as well as empirical data and stakeholder views to formulate possible PR referral enhancing interventions. Following these steps, the methods and results will be discussed, strengths and limitations highlighted and conclusions offered.

## 6.3 **Abstract**

**Background**

PR is a national and internationally recommended treatment for patients with COPD, yet referral rates are persistently low and there is a paucity of rigorously tested evidence-based interventions that improve referral rates.

The BCW is a psychological behaviour change theory. It highlights key intervention components deemed necessary for behaviour change and does this inductively, usually through barrier and enabler data analysis or deductively following effective trial intervention review. It achieves this by identifying the 'mode of intervention delivery' and 'content', the granular active intervention component(s), referred to as Behaviour Change Techniques (BCTs).

**Aim**

To design and develop interventions that will increase PR referral from patients with COPD from primary care, using empirical evidence alongside behaviour change theory, including the BCW both inductively and deductively.

**Methods**

Using a three part strategy; one inductively aligns the empirical barrier and enabler findings from chapters 3 and 4 to the prescriptive Behaviour Change Wheel (BCW); two, deductively applies the BCW to the effective interventions of chapter 2's systematic review and three deductively applies the BCW to the top ranking PHCPs suggested interventions from chapter 5. These individual findings are then combined to offer evidence based suggestions.

**Results**

PR referral is a singular event that occurs within a complex process and one that is influenced by a number of populations and factors before, during and after the physical act of referral itself. Findings from part one highlighted significant gaps in service provision and that PR service support for PHCPs was scarce.

The combined results of parts one, two and three highlighted three key (of a possible nine) intervention functions; 'Education', 'Persuasion' and 'Enablement'. Main intervention BCTs included; receiving information from credible source, verbal persuasion, social support, prompts/cues, action planning, goal setting and feedback.

In an effort to address PR pathway complexity, interventions to address the individual time points, pre-referral, at referral and post-referral are offered. These include education for referrers and patients, alongside a patient held scorecard, recommendations on increasing referral opportunities such as offering PR at an AECOPD and for PHCPs to vocalise a standardised PR script. Post referral actions centre on PR provider and PHCP engagement which embrace feedback and action planning opportunities, whilst also seeking to sustain behaviour change.

**Conclusion**

Efforts to overcome the overarching lack of support for PR referral in primary care is important. It is for this reason that whilst a number of individual interventions have been suggested at key time points, for success it is considered these not be individually extrapolated, but delivered in a combined approach allowing for the critical inclusion of patients, PHCPs and PR providers. Partnership working is considered vital in enhancing PR referral from primary care. Stakeholder views are advocated and important next steps and which must be sought prior to any pilot testing.

## 6.4 **Behaviours**

Evidence-based behavioural medicine seeks to ensure that approaches to behaviour change have proven effectiveness (264). Intervention targeting behaviour change are defined as '*a coordinated set of activities designed to change specified behaviour patterns'* (137) (p 1). In a healthcare context changing behavioural outcomes can be aimed at patients and/or HCPs (175).

The passive transfer of information on COPD to patients with COPD does not result in changes to individual health and lifestyle behaviours (265). Importantly, when diagnosed with an illness patients develop patterns of beliefs to make sense of the diagnosis and the symptoms they associate with their condition (266). It is these Illness perceptions that affect behaviours including adherence to treatments and those holding generally negative beliefs are more likely to have increased long term disability (266). It is important therefore for HCPs to recognise the role that patients' personal beliefs and emotions have on their actions (265). Meaning in order to support patients to embrace self–management through behaviour change HCPs need to adopt holistic interactive patient centred approaches and move away from commonly used passive didactic approaches (126, 265, 267).

## 6.5 **Healthcare systems and intervention development frameworks**

Healthcare based human interactions occur within complex interacting systems. Central therefore to supporting behaviour change is ensuring that the systems within which

behaviours operate are acknowledged and understood (137, 250, 268), meaning interventions that focus on improving health must not be isolated from patients, HCPs and/or healthcare systems. On account of the number of elements involved and associated behaviours (current and emerging) proposed PR referral enhancing intervention(s) are considered complex (132, 143).

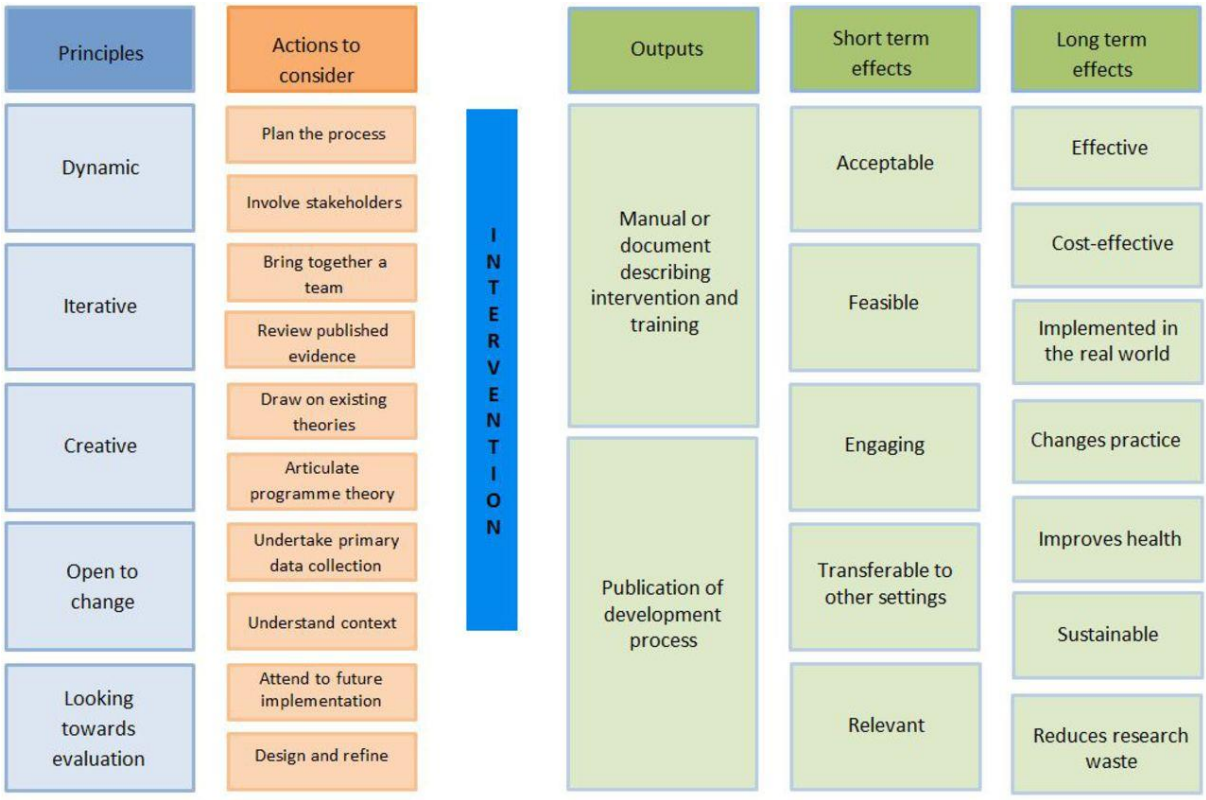
Intervention researchers outline a number of essential intervention steps which when summarised offer two overarching key elements to intervention development (264). The first is 'mode' of delivery which includes 'who delivers the intervention, to whom, for how long, in what format and in what context'. The second is the intervention 'content' which describes the active ingredient to bring about behaviour change. 'Mode' of intervention delivery is frequently the central feature of multiple intervention development frameworks (269), such as 'Reach, Effectiveness, Adoption, Implementation Maintenance' (RE_AIM) (270) and 'Six essential steps for quality intervention development' (6SQuiD) (271). Both frameworks adopt slightly different approaches to intervention implementation, for example RE_AIM focuses on primarily intervention uptake and evaluation, rather than intervention design and development (269). The second framework 6SQuiD adopts a systematic six stepped approach. It commences with analysis of the problem, the context and then considers the system approaches necessary to bring about change and enable implementation. However, neither offer detail on 'the key ingredients' necessary to change behaviour or intervention content, their focus is largely on the process, the 'mode'. Interventions that omit key content ingredients of 'how' are therefore more difficult to define and replicate (264). In response to these individual framework weaknesses, some

researchers opt to combine approaches and indeed a combined approach is reported to sustain behaviour change with greater effectiveness (154, 267).

## 6.6 **Behavioural theory in intervention development frameworks**

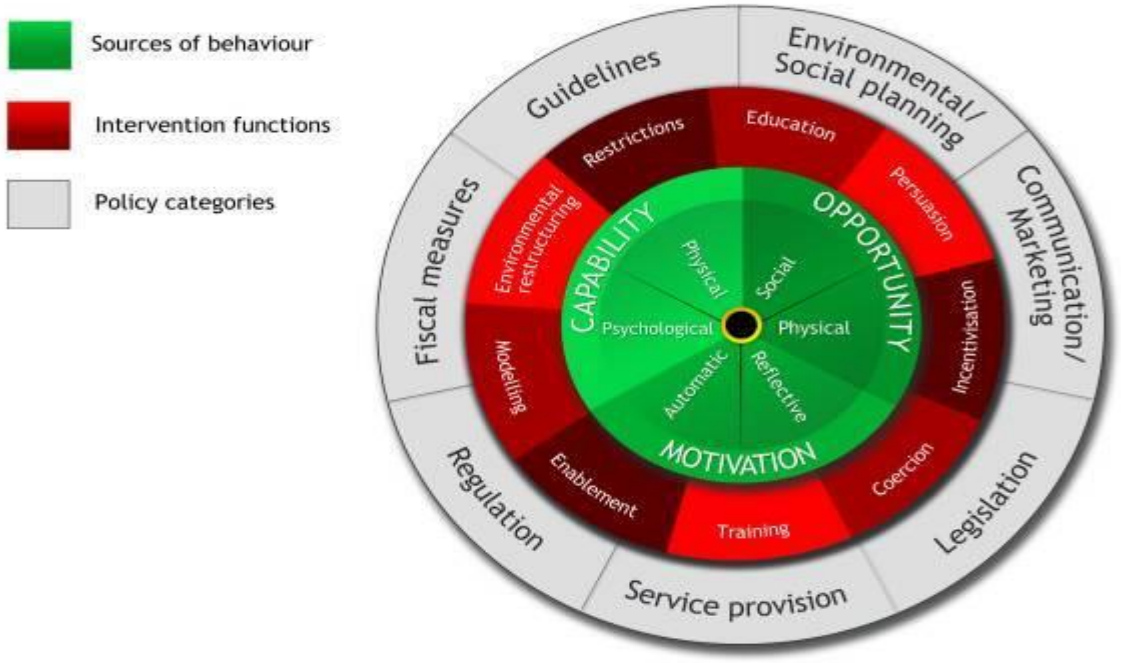
The use of behavioural theory as a basis to guide the design and evaluation of effective behaviour change interventions is strongly advocated (132, 267). Yet, others dispute the effectiveness of interventions built on theory (272). There are a limited number of implementation frameworks that inherently include theory including RE-AIM and 6SQuiD presented above (269). The MRC framework advocates for the use of both theory and evidence in the design of complex healthcare interventions (132). However, the MRC is a broad framework and offers little to no detail on the key intervention components. O'Cathain et al's (143) process framework for intervention development advocates also for theory and presents designers with a number of key prescriptive actions, whilst recognising and advocating for intervention development to be iterative (as shown in figure 9).

**Figure 9: Logical model for intervention development** (reproduced from O'Cathian et al (143)




One theoretical based behaviour change tool is the Behaviour Change Wheel (BCW) designed for intervention development (137) (see figure 3, p 34). The BCW was developed specifically as an aid to transition theoretical behavioural constructs to practical behaviour change techniques (BCTs). BCTs are described as the minimally active ingredient to activate change and but one that is replicable, observable, specified by an active verb and includes enough detail that it achieves agreement by experts (172). For example 'information about health consequences 'is a BCT. The BCW addresses both 'mode' and 'content' and at its core is a model named COM-B, which was briefly presented in chapter 1 (Section 1:11), along with the linked TDF.

**Figure 3: Behaviour Change Wheel** (reproduced from Michie et al (171)



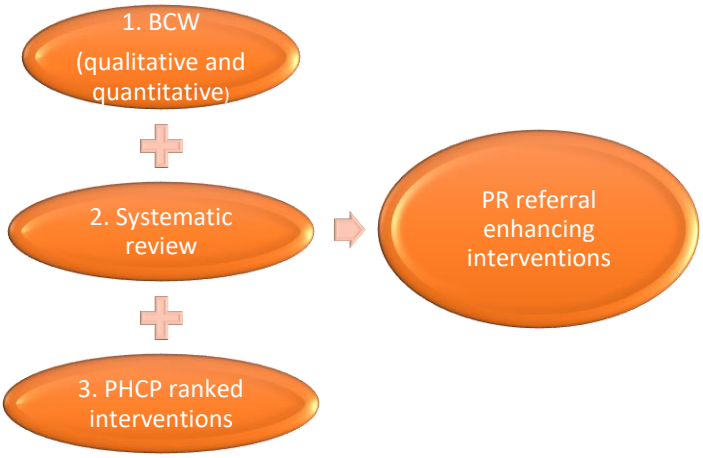

A key stage of intervention design is analysis of current behaviours, which allows diagnosis of what and why certain behaviours occur, thus supporting the systematic identification of 'what' needs to change (273). It is proposed that the COM-B model (affiliated with the behaviour change wheel) offers a simple model to understand behavioural determinants (274), whilst the TDF (a further theoretical behavioural based framework) characterises the determinants of health behaviour (116). Both the TDF and COM-B approaches are extensively advocated theoretical intervention models that report successful HCP behaviour change across the literature (116, 137, 173, 174, 275, 276). However there is little direction on the TDF application to intervention development and it is for that reason the BCW is a suggested, yet associated alternative (174). Widespread advocacy of the BCW, along with

the TDF informed data (from chapter 3) and the extensive utilisation of COM-B in HCP focused behaviour change research rationalises the BCW as the model of choice and will be used in conjunction with the logic model presented in figure 9, p 20 to develop interventions within this chapter. The aims therefore of this thesis' penultimate chapter is to bring all findings together which will inform the design and development of PR referral enhancing interventions.

## 6.7 **Methods**

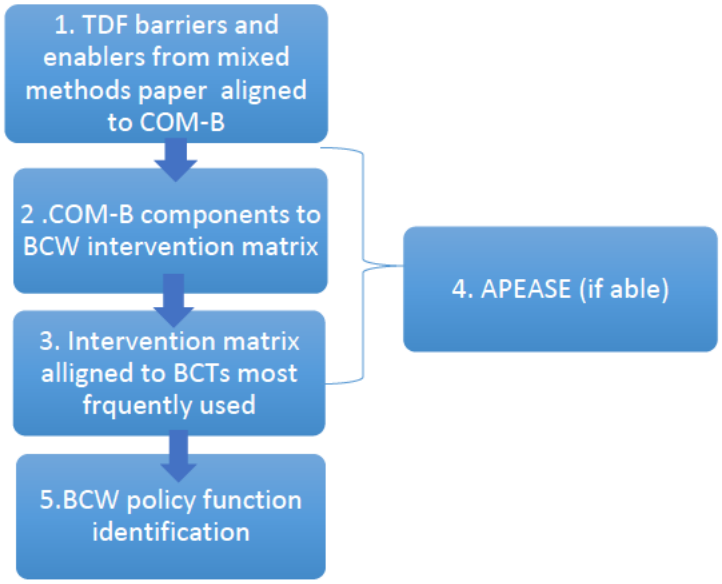
This chapter will combine three research parts to formulate potential interventions as shown in figure 10 and in keeping with the thesis' multiphase methodology. This is a process referred to in mixed methods research as 'embedding' (149), where data collection and analysis are linked at many time points, generally occurring at the point of intervention design (161).

**Figure 10: Intervention formulation**



Part one will utilise the qualitative and mixed methods findings and then inductively follow the prescribed BCW process, to which there are several steps, as demonstrated below in figure 11. Part two and three will deductively identify the key effective behavioural elements identified in the interventions tested and presented in chapter 2's systematic review and the PHCP suggested interventions suggested in chapter 5. The effective behavioural elements will be determined by the BCW intervention functions and the corresponding BCTs.

**Figure 11: Part one: Behaviour change intervention generation using BCW methodology**

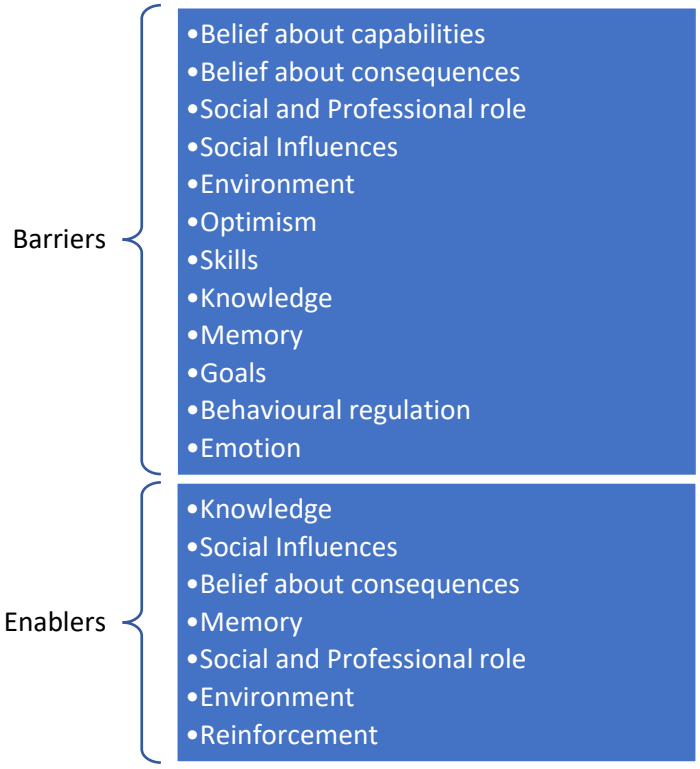



## 6.8 Part 1: BCW methods inductive

### Step 1: TDF barriers and enablers to COM-B

The key TDF aligned barriers and enablers identified in the primary research studies chapter 4 (informed also by the results in chapter 3) are shown in figure 12.

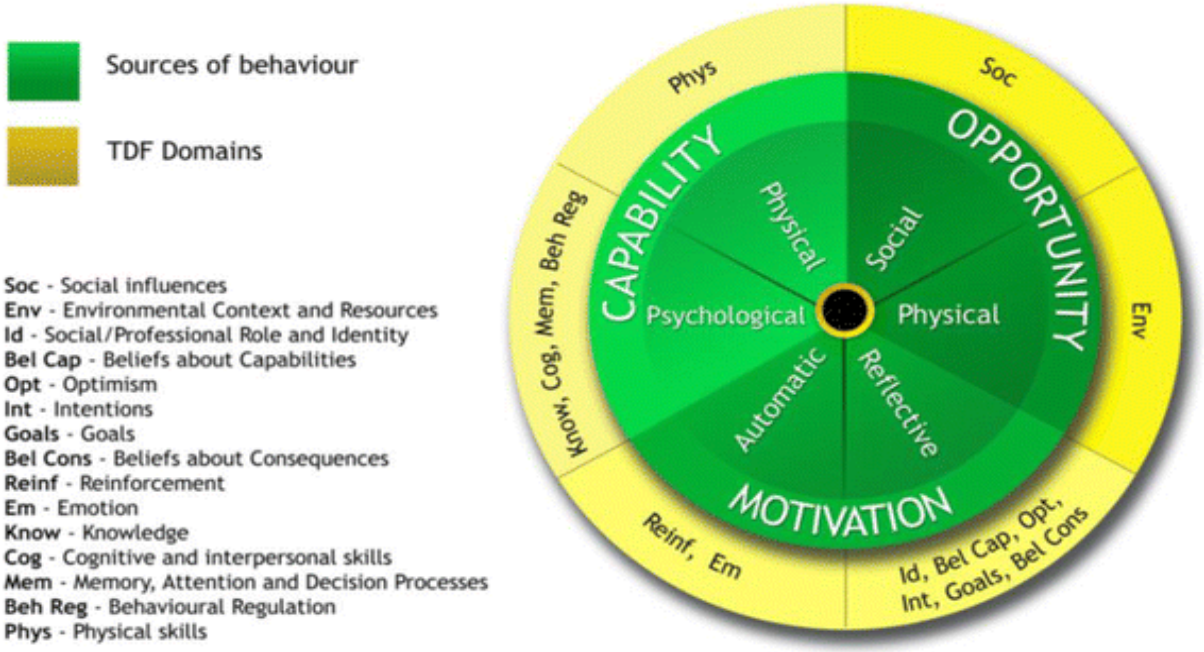
**Figure 12: Key barriers and enablers by TDF domain arising from the sequential mixed methods PR research (chapter 4)**




The TDF and COM-B model are closely aligned as demonstrated in figure 13 (173, 277). Of note the TDF to COM-B alignment in figure 13, p 215 shows COM-B (171) offers 15 TDF domains, whereas the original TDF framework presents only 14 domains (278). This has arisen as the authors of COM-B have divided the TDF 'Skills' domain into two, 'Physical skills' and 'Cognition and interpersonal skills', each of which align to Capability (physically and psychologically) within differing components of COM-B. 'Physical skills' is not a TDF domain and data has therefore not been aligned to this additional domain across the research thus far and has subsequently been omitted from any further analysis.

The TDF domain derived barriers and enablers are now mapped to the five components of the COM-B, Capability – psychological, Opportunity – social and physical, Motivation – automatic and reflection model having omitted physical skills, as outlined by the BCW below.

**Figure 13 TDF domains linked to COM-B components** (reproduced from Michie et al (171)




## Step 2: Methods: Aligning COM-B barrier to the intervention matrix

Following TDF to COM-B component alignment given it is the barriers that are desired to be modified it is the barrier alignment that will progress through the BCW. Mapped COM-B components are then aligned to intervention functions. An intervention function is defined by Michie et al as *' broad categories of means by which an intervention can change behaviour'* (171) p109. However the alignment in the BCW wheel in figure 3 does not demonstrate direct affiliation, this is demonstrated by the intervention functions matrix (137) shown in figure 14. All highlighted cells are reported to affect change, so for example

where physical opportunity has indicated a barrier, implementing 'training' would be a modifier.

**Figure 14: Master matrix of links between COM-B and intervention function links**
(reproduced Michie et al (171)

| | Intervention Functions | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| **COM-B Components** | Education | Persuasion | Incentivisation | Coercion | Training | Restriction | Environmental Restructuring | Modelling | Enablement |
| **Physical Capability** | | | | | ■ | | | | ■ |
| **Psychological Capability** | ■ | | | | ■ | | | | ■ |
| **Physical opportunity** | | | | | ■ | ■ | ■ | | ■ |
| **Social opportunity** | | | | | | ■ | ■ | ■ | ■ |
| **Automatic motivation** | | ■ | ■ | ■ | ■ | | ■ | ■ | ■ |
| **Reflective motivation** | ■ | ■ | ■ | ■ | | | | | |

*Orange cells indicate correlation between intervention functions and COM-B components

### Step 3: Methods: Intervention matrix to BCT taxonomy

Post intervention function alignment is the next directive BCW step is to align identified intervention functions to BCTs from the BCT Taxonomy v1 (BCCT1), of which there are n149 (137). In recognition of this unpractical number of BCTs, behavioural theory experts have since collated a smaller most frequently used BCTs list (277). This frequent BCT list derived from an expert assessed frequently used BCT analysis across 40 intervention studies, 22

isolated BCTs were identified in 16/40 (40%) of studies and achieved good inter-reliability assessment across the coders. These 22 BCTs therefore formulated the frequently used list (218). As a result of this work, BCTs intervention designers are advised to consider using the most frequently used BCTs, as opposed to those less frequent as detailed in the BCW supporting literature (171).

### Step 4: Methods-APEASE

To support intervention function(s) and/or BCT(s) selection, the BCW advises adoption of the APEASE criteria (Affordability, Practicality, Effectiveness and cost-effectiveness, Acceptability, side-effects/safety and Equity). This approach encourages developers to consider each of the APEASE factors in the context of individual interventions (171).

### Step 5: Methods- BCW policy function identification

The final step in the COM-B to BCW process is to identify policy categories. These are represented in the outer ring of the BCW as shown in Figure 3 p 34 and 210, highlight seven separate categories. Policy categories place greater emphasis on external influences (137). Similar to the intervention to COM-B matrix there is a policy to intervention matrix (shown in figure 15, p 218), again the highlighted orange cells indicate a correlation between category and function.

**Figure 15: Master matrix of links between intervention functions and policy categories**
(reproduced from Michie et al (171))

| | Intervention Functions | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| **Policy Categories** | Education | Persuasion | Incentivisation | Coercion | Training | Restriction | Environmental Restructuring | Modelling | Enablement |
| **Communication/ marketing** | | | | | | | | | |
| **Guidelines** | | | | | | | | | |
| **Fiscal measures** | | | | | | | | | |
| **Regulation** | | | | | | | | | |
| **Legislation** | | | | | | | | | |
| **Environmental/ social planning** | | | | | | | | | |
| **Service provision** | | | | | | | | | |

*Orange cells indicate correlation between intervention functions and COM-B components

This concludes the BCW prescriptive steps that the inductive qualitative and mixed methods data align to the COM-B and BCW. Next steps are then to deductively apply the BCW to part two, findings from PHCP intervention ranking exercise and part three effective tested interventions. This supports the developed process to incorporate context, further pertinent evidence as well as ensuring stakeholder and expert views are included (143, 279).

## 6.9 **Part 1: Results**

### Step 1:1: Aligning COM-B barrier results to the intervention matrix

Tables 21 and 22 demonstrate the TDF barrier and enabler findings to COM-B components.

**Table 21: Mapping TDF 'barriers' to BCW**

| TDF Domains | COM-B Components |
|---|---|
| Belief about capabilities, Belief about consequences, Optimism, Goals, Social, Professional Role and Identity | Reflective Motivation |
| Emotion | Automatic Motivation |
| Knowledge, Behavioural regulation, Memory, Skills (Cognitive and interpersonal skills) | Psychological Capability |
| Social Influences | Social Opportunity |
| Environment | Physical Opportunity |

**Table 22: Mapping TDF 'enablers' to BCW**

| TDF Domains | COM-B Components |
|---|---|
| Social Professional Role and Identity, Belief about consequences | Reflective Motivation |
| Reinforcement | Automatic Motivation |
| Knowledge, Memory | Psychological Capability |
| Social Influences | Social Opportunity |
| Environment | Physical Opportunity |

The results highlight that for both barriers and enablers five out of six COM-B components are represented with physical capability omitted across both, as a result of the physical skills domain being removed.

### Step 1:2: Aligning COM-B barrier results to the intervention matrix: results

Despite removing the COM-B component physical capability, the mapped COM-B PR referral barrier results to the intervention functions highlight all nine intervention functions remain active, demonstrated by the green correlating cells in figure 16.

**Figure 16: Matrix of links between COM-B and intervention function – results** (reproduced Michie et al (171))

| | Intervention Functions | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| **COM-B Components** | Education | Persuasion | Incentivisation | Coercion | Training | Restriction | Environmental Restructuring | Modelling | Enablement |
| **Psychological Capability** | | | | | | | | | |
| **Physical opportunity** | | | | | | | | | |
| **Social opportunity** | | | | | | | | | |
| **Automatic motivation** | | | | | | | | | |
| **Reflective motivation** | | | | | | | | | |

*green highlights PR barrier results overlaid on master matrix

The matrix alignment results demonstrate the intervention function "enablement", defined as *'using communication to induce positive or negative feelings or stimulate action'* (171) (p 111) has the highest possible number of alignments, four out of five when compared to other intervention functions. Additional intervention behavioural correlations include 'environmental restructuring' with all three available components aligned and for 'training'

three out of four alignments. Whilst the remaining six interventions all received two out of two matrix correlations.

Yet in the context of intervention design it was important to start to narrow the focus and as such a pragmatic approach to intervention function was adopted. Intervention function exclusion was easier than inclusion at this stage and was based upon the researcher's general practice experience working as a respiratory nurse specialist. Two intervention functions 'Coercion' defined as '*creating expectations of punishment or cost*' and 'Restriction' defined as '*using rules to increase the target behaviour by reducing the opportunity to engage in competing behaviours'* (171) (p 111) were removed on the basis that these would be impractical and probably unethical to implement in general practice settings. The resulting seven key interventions remained; education, persuasion, incentivisation, training, enablement, environmental restructuring and modelling.

### Step 1:3: Results - Intervention matrix to BCTs

Following this approach the seven intervention functions now identified 37/42 most frequently used BCTs from the BCTT1 (277), of which 10 were duplicated across several intervention functions. For example: feedback on the behaviour is identified as a frequent BCT in four of the seven important intervention functions. Therefore, with duplicates counted only once there were 22 frequently used BCTs identified and listed in table 23.

**Table 23: PR barrier BCW data generated BCTs**

| Intervention Functions | BCW generated BCTS (most frequently used) |
|---|---|
| 1.Education<br>2.Persuasion<br>3.Incentivisation<br>4.Training<br>5.Enablement<br>6.Environmental restructuring<br>7.Modelling | -Adding objectives to the environment*<br>-Self-monitoring of behaviour*<br>-Restructuring the physical environment*<br>-Demonstration of the behaviour*<br>-Feedback on outcome(s) of behaviour*<br>-Information about social and environmental consequences*<br>-Information about health consequences*<br>-Feedback on behaviour*<br>-Prompts/cues*<br>-Monitoring of behaviour by others without evidence of feedback*<br>-Social support (unspecified)<br>-Social support (practical)<br>-Goal setting (behaviour)<br>-Goal setting (outcome)<br>-Problem solving<br>-Action planning<br>-Review behaviour goal(s)<br>-Review outcome goal(s)<br>-Instruction on how to perform a behaviour<br>-Behavioural practice/rehearsal<br>-Monitoring outcome of behaviour by others without evidence of feedback<br>-Credible source |

*BCTs represented more than once across intervention functions

Having completed this process the results still appear to offer no clear PR referral enhancing interventions and progress appears stunted by the number of possible intervention functions and BCTs, which additionally only offers 'frequently used' rather than effective BCTs.

### Step 1:4 Results - APEASE

As yet, the data has not generated tangible interventions therefore at this stage APEASE cannot be applied. However, it will be applied and demonstrated further on in this chapter.

### Step 1:5 Results - BCW policy function identification

Progression to the final step 5 section policy categories was undertaken, see figure 17.

**Figure 17: Matrix of links between intervention functions and policy categories-results**
(reproduced from Michie et al (171)

| Policy Categories | Education | Persuasion | Incentivisation | Training | Environmental Restructuring | Modelling | Enablement |
|---|---|---|---|---|---|---|---|
| Communication/ marketing | | | | | | | |
| Guidelines | | | | | | | |
| Fiscal measures | | | | | | | |
| Regulation | | | | | | | |
| Legislation | | | | | | | |
| Environmental/ social planning | | | | | | | |
| Service provision | | | | | | | |

*green highlights PR barrier results overlaid on master matrix

As previously demonstrated in the intervention matrix, highlighted cells indicate a relationship with the corresponding cells. Those coloured green are indicated as likely to be

modifiable in a PR referral context, meaning all seven are likely to be influencers even after the removal of coercion and restriction. In order to identify the most appropriate policy categories as before, contextual application is helpful here.

There are three policy categories that currently seek to address PR referral in England; 'guidelines', 'fiscal measures and regulation'. National and international COPD guidelines have recommended PR referral for eligible patients for many years (3, 42, 280) but referral rates have remained relatively stagnant at less than 10% of eligible UK patients in 2010 (281) rising to just 15.2% in England and Wales in 2015 (64). Practice fiscal rewards have been reported to have a positive effect on PHCP PR referral behaviour (76) and since April 2019 national fiscal reward to general practices for referral have been awarded via the general medical services contract (282), meaning this policy category 'fiscal' is currently addressed. Financial behavioural reward also loosely addresses the policy category 'regulation', largely as practices consider the completion of QoF points acquisition as a must do rather than something that is optional. However since March 2020, national PR programmes have been suspended due to the COVID-19 pandemic, in view of backlogs and social distancing restrictions it is likely this is going to be slow to recover and will therefore affect all policy functions for some time yet (216).

The four remaining potential policy categories are therefore; 'communication/marketing', 'legislation', 'environmental/social planning' and 'service provision'. Legislation for PR referral would be impractical, yet the remaining three policy functions appear prudent. This

BCW process has now resulted in the following identifiers shown in table 24 as based on PHCP reported barriers presented in this thesis.

**Table 24: BCW originated elements**

| Key Policy Categories | Key Intervention functions | BCTs (most frequently used) |
|---|---|---|
| Communication/ Marketing | Education<br>Persuasion<br>Incentivisation<br>Modelling | Adding objectives to the environment*<br>Self-monitoring of behaviour*<br>Restructuring the physical environment*<br>Demonstration of the behaviour*<br>Feedback on outcome(s) of behaviour*<br>Information about social and environmental consequences*<br>Information about health consequences*<br>Feedback on behaviour*<br>Prompts/cues*<br>Monitoring of behaviour by others without evidence of feedback*<br>Social support (unspecified)<br>Social support (practical)<br>Goal setting (behaviour)<br>Goal setting (outcome)<br>Problem solving<br>Action planning<br>Review behaviour goal(s)<br>Review outcome goal(s)<br>Instruction on how to perform a behaviour<br>Behavioural practice/rehearsal<br>Monitoring outcome of behaviour by others without evidence of feedback<br>Credible source |
| Environmental/social planning | Environmental restructuring<br>Enablement | |
| Service Provision | Education<br>Enablement<br>Training<br>Persuasion<br>Incentivisation<br>Modelling | |

*BCTs represented more than once across intervention functions

Whilst the data in table 24 is helpful, this process has yet to identify clear tangible interventions to overcome the barriers PHCPs face when considering or undertaking referral to PR. It is for this reason further empirical evidence is drawn upon using deductive methods.

## 6.10 **Part 2: Results – PHCP ranked interventions deductive**

Table 25 shows the top seven suggestions from the surveyed PHCPs as presented in chapter 5. The author has used a BCW deductive approach to the COM-B component and subsequent intervention function alignment.

**Table 25: PHCP ranks and rated intervention top suggestions combined and aligned to COM-B and BCW**

| Likert and Ranking intervention exercise | COM-B components | BCW – Intervention functions | BCT |
|---|---|---|---|
| 1. Face to face educational sessions for general practice staff.<br><br>2. Face to face educational sessions for potential patients, carers and family.<br><br>3.A standardised summary (i.e.: two sentences) that describes PR succinctly for HCP to recite to eligible patients. | Psychological Capability | Education<br><br>Training<br><br>Enablement | Information on health consequences<br><br>Feedback on behaviour<br><br>Prompts/cues<br><br>Credible source<br><br>Habit formation |
| 4. PR providers engaging with practice staff by coming into surgeries. | Social opportunity | Restriction<br><br>Environmental restructuring<br><br>Modelling<br><br>Enablement | Social support<br><br>Credible source<br><br>Instruction on how to perform the behaviour<br><br>Exposure |
| 5. Greater awareness of PR in practice. I.e. Posters highlighting local PR | Physical Opportunity | Training<br><br>Restriction | Restructuring the physical environment |

| Likert and Ranking intervention exercise | COM-B components | BCW – Intervention functions | BCT |
|---|---|---|---|
| provider, benefits, etc.<br><br>6. Patients being able to refer themselves to PR. | | Environmental restructuring<br><br>Enablement | Adding objects to the environment<br><br>Prompts/cues<br><br>Exposure |
| 7. Health Care Professional (HCP) referring patients to PR at the time of COPD diagnosis. | Reflective Motivation | Education<br><br>Persuasion<br><br>Incentivisation<br><br>Coercion | Prompts/cues<br><br>Action planning<br><br>Credible source<br><br>Identification of self as role model<br><br>Habit formation |

This deductive exercise was a simpler less complex process than the earlier inductive one. The results highlight that the COM-B component automatic motivation did not receive COM-B alignment the relevance of which will be discussed further on in the chapter. However, all nine intervention functions remain. For BCTs there are twelve singular aligned options, of which nine are frequent.

Having considered top PHCP ranked interventions against BCW components, the next section, part 3 will now identify key BCW intervention modes and active ingredients (BCTs) from tested interventions presented first in the systematic review.

## 6.11 **Part 3: Results systematic review intervention findings-deductive**

The first empirical research presented in this thesis was that generated from the systematic review findings, presented in chapter 2. Yet, for referral specifically there were three controlled studies in the systematic review that positively increased PR referral and uptake (89, 182, 183). Table 26 gives the intervention detail and BCW alignment of the three effective controlled studies. Of note all three studies included patients and referring HCPs, or vice versa, rather than just one single population.

Remaining studies that reported improvements in referral and/or uptake rates utilised strategies that largely focused on increasing HCP education and awareness of PR by using PR promotional material and utilised prompts such as electronic care plans and secondary care discharge bundles (122, 186-189, 191). These studies aligned primarily to the intervention functions education and environmental restructuring, but given their uncontrolled design this evidence is of low quality and needs to be treated with caution.

Two of the three controlled studies activated patients to ask PHCPs for referral by using COPD scorecards and manuals (182, 183). The third study, an RCT included patient home visits and personalised patient care plan generation undertaken by a respiratory trained nurse, who additionally adopted motivational interviewing techniques (89).

**Table 26: Intervention function and BCTs identified in effective studies of systematic review**

| Study, design and intervention | Intervention delivery | Key BCW Intervention functions | Key BCTs |
|---|---|---|---|
| Zwar 2012<br>RCT<br>(home visits/motivational interviewing and patient personal care plans) | HCP to patient | Education<br>Training<br>Persuasion | Information about health consequences<br>Instruction on how to perform a behaviour<br>Credible source<br>Verbal persuasion |
| Roberts 2015<br>CCT<br>(COPD scorecards) | Patient to HCP | Enablement<br>Training<br>Persuasion | Goal setting<br>Review goals<br>Habit formation<br>Credible source<br>Identification of self as role model |
| Harris 2008<br>CCT<br>(COPD manuals) | Patient to HCP | Enablement<br>Training<br>Persuasion | Action planning<br>Habit formation<br>Social comparison<br>Credible source<br>Identification of self as role model |

Effective intervention functions identified in these three studies included education, persuasion, training and enablement, which when aligned to identify BCTs, using the BCTTv1 (277) finds n92 BCTs of which n28 are frequent. Yet this is still a high number and identification of interventions challenging. Subsequently, the author identified ten likely important BCTs that correlated across all three studies (see table 26). Seven of which were in the two patient-focused referral enhancing controlled studies (182, 183); 'credible source' (n2), 'identification of self as a role model' (n2), 'habit formation' (n2), 'social comparison', 'goal setting', 'action planning' and 'review goals'. The remaining three in the controlled HCP focused study (89), 'information about health consequences', 'instructions on how to perform a behaviour' and 'verbal persuasion'. Next steps are now to bring all BCW findings from the three parts together in order to identify effective interventions.

## 6.12 **Alignment of all results**

The results of parts one, two and three have been combined and are presented in table 27. The table presents the key BCW policy categories, intervention functions and BCTs as derived by following the cyclic process of mapping evidence, contextual insights and stakeholder views to PR referral using both inductive and deductive methods as described (171).

**Table 27: BCW informed intervention design to increase PR referral from general practice**

| Key Policy Categories | Key Intervention functions | BCTs (most frequently used/considered important to include) |
|---|---|---|
| Communication/ Marketing<br>Environmental/ social planning<br>Service Provision | Education<br>Persuasion<br>Enablement<br>Training<br>Modelling<br>Environmental restructuring | Information about health consequences<br>Instruction on how to perform a behaviour<br>Credible source<br>Goal setting (behaviour)<br>Goal setting (outcome)<br>Action planning<br>Review behaviour goal(s)<br>Review outcome goal(s)<br>Habit formation<br>Verbal persuasion<br>Identification of self as a role model<br>Social support (practical)<br>Restructuring the physical environment<br>Prompts/cues<br>Feedback on behaviour |

The three identified policy categories emerged from the initial BCW barrier work and were first presented in table 24, p 225. Whilst all three are considered important, service provision described as delivering and establishing support services in workplaces (171), alongside the inclusion of improved communications and planning process are likely to be key.

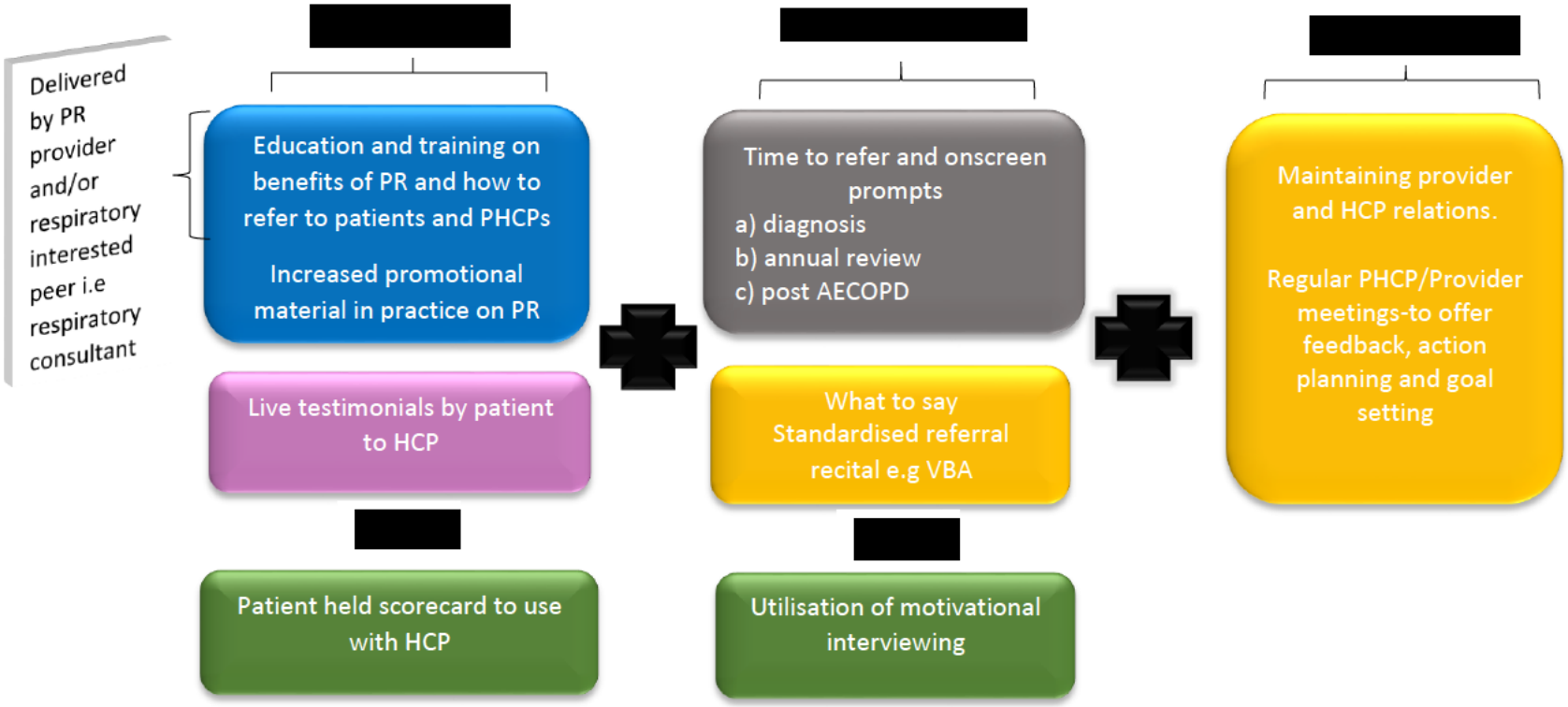
The six intervention functions arose from the initial barrier mapping exercise after the removal of incentivisation. The systematic review identified four of the six intervention functions had been used in studies with PR referral intervention effectiveness (see table 26,p228). The correlated BCW, PHCP ranked interventions from chapter 5 reintroduced intervention functions; restriction, incentivisation and coercion in line with the COM-B component to intervention function master matrix (figure 16,p 219). However earlier justifications for the removal of those three intervention functions remained, as based on the same rationalisation. Of note each of the seven PHCP ranked suggestion had three or four intervention functions aligned, removal of the three restriction, incentivisation and coercion retained all of the top rated and ranked PHCP interventions (see table 25, p 225).

Of the final six intervention functions presented in table 27, p 229 there were a possible n104 aligned BCTs (n32 frequent). Given this unmanageable number the final BCT list included 15 possible options. These 15 were derived from the effective referral studies presented in the systematic review and includes the PHCP top ranked suggestions such as increasing awareness in the practice by 'restructuring the physical environment', qualitatively reported PHCP requests for feedback and drew upon reported referral enablers such as annual review prompt/cues and social support.

## 6.13 **Recommended interventions**

Combined, all BCW elements presented in table 27 offer a number of elements that could be tested across the PR journey. These elements have been subsequently been converted (and or added) to previously tested interventions to a number of suggested referral enhancing interventions, across the PR journey including pre referral, referral and post referral and are presented in figure 18, p 232.

**Figure 18: Suggested interventions to increase referral from primary care for patients with COPD**




Key: Blue- Uncontrolled Systematic Review (SR) studies and primary PHCP studies (chapter 2, 3, 4 & 5)
Grey- PHCP primary studies (chapter 3, 4 & 5)
Lilac- Building on empowerment of patients on HCPs shown in scorecard and checklist studies in SR and BCTs verbal persuasion, credible source and feedback (chapter 2, 3 &4)
Yellow- Building on patient reported research, PHCP inductive and psychological theory findings, summarising PR succinctly, overcoming unconscious bias' and BCT use i.e. habit formation, credible source, verbal persuasion, social support, feedback, action planning (chapter 1, 3, 4 & 5)
Green- Controlled studies, within SR (chapter 2)

Figure 18 seeks to offer an overview of the complete PR referral journey and includes individual time points and key population processes. This is important because in order to increase PR referral, one needs to understand its entire process and the system within which it operates. Changing only one part of the pathway is unlikely to result in change because of its interconnections with so many other elements, but increasing awareness through education at the outset is important.

All recommended interventions seek to change behaviour in order to activate referral or thoughts of as well as included interventions that seek to maintain increases in referral behaviour.

## 6.14 **Pre-Referral**

Education on the benefits of PR are reported to increase PR referral and uptake rates (122, 178, 182, 183, 188). Additionally PHCPs with respiratory qualifications report referring more patients to PR than those without as presented in chapter 4. PHCPs have expressed a wish to increase their PR knowledge and understanding with some citing respiratory HCP peers as influential in this process (76).

Training in how to refer a patient to PR is considered sensible, particularly given there is no national standardised referral form or process. Referral processes are determined by local providers which offers a further level of complexity for PHCPs, especially those who maybe working across multiple practices. Promotional material within general practice and information to give to patients has also been requested by HCPs and used with some success

in some uncontrolled studies (182, 183). Utilising patients to activate PHCPs is also an intervention with proven effectiveness (182, 183). This approach additionally draws on the behaviour change theory of the BCW utilising 'information about health consequences', 'verbal persuasion' and 'goal setting' behaviour change techniques.

## 6.15 **Referral**

Referral itself identifies the PHCP as the key individual, it recommends referral prompts and for there to be clear time points for referral. Whilst annual review is widely cited as a clear and defined time for referral, referring post AECOPD has also been described as helpful (76). Additionally PR post exacerbation is known to be effective (55) and referral at diagnosis was a PHCP ranked intervention. Increasing referral opportunities is likely to increase awareness and build on the BCTs, 'habit formation' and 'credible source'.

The qualitative analysis on PHCP referral behaviour found some PHCPs expressed concerns about having PR discussions with patients (76) and several barriers linked to automatic motivation were highlighted although, not identified by PHCPs themselves. Strategies to overcome this are therefore important. Both motivational interviewing and Very Brief Advice (VBA) have been adopted successfully in primary care (89, 283) and are advocated here, as both strategies draws on the BCTs 'goal setting', 'credible source' 'verbal persuasion' and 'habit formation'. VBA and its evidence base is discussed in more detail within the discussion section of this chapter.

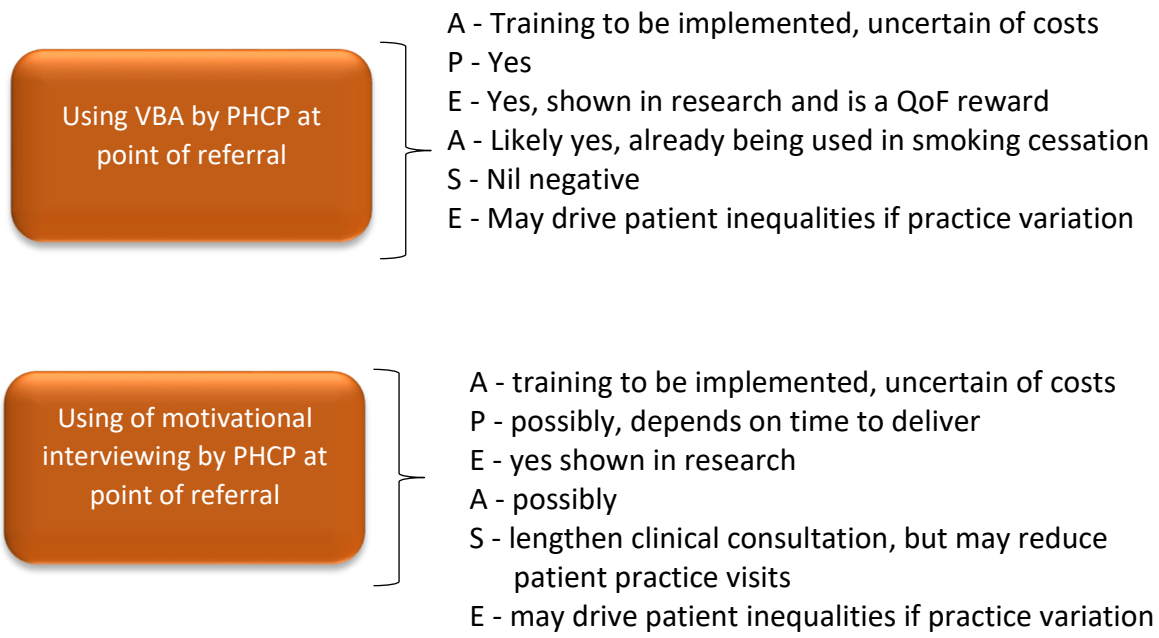
## 6.16 **Post-Referral**

Finally feedback and peer support between referrers and providers is likely to become a helpful PR reinforce and can be achieved by increased engagement. Whilst no studies in the field of PR has tested the effect of PR provider and PHCP engagement on referral or uptake rates, it has been reported as a PR enabler (76). Furthermore, it is requested by PHCPs and supports a number of BCTs including 'social support', 'credible source', 'action planning' and 'identification of self as a role model'. This is therefore strongly advocated, not only in post-referral stages, but also at pre-referral as presented in figure 18, p 232.

## 6.17 **APEASE**

Figure 18 has offered a number of interventions and the author has stressed the importance of addressing the referral process as a series of events and advises against the implementation of only one intervention in the pathway. However there are a number of differing interventions offered. Introduced earlier in the BCW process was a concept named APEASE, a tool designed to assess the suitability and appropriateness of generated interventions based on affordability, practicality, effectiveness & cost-effectiveness, acceptability, side-effects and safety and equity (171). As an example, the APEASE criteria (see figure 19) has been applied to the interventions VBA (implemented with success in primary care smoking cessation discussions) and motivational interviewing which allows contextual consideration to be applied, see figure 19, overleaf.

**Figure 19: Application of APEASE: Example**




*APEASE = Affordability, practicality, effectiveness & cost-effectiveness, acceptability, side-effects and safety and equity.

On balance this exercise appears to indicate VBA maybe a more appropriate intervention over motivational interviewing, however this brief analysis has only been undertaken by one person, the author, meaning only one perspective has been considered.

## 6.18 **Discussion**

This chapter set out to design and develop novel theoretical based interventions to support the offer of PR referral by PHCPs to patients with COPD. It utilised two models to support this development and design process; a logical model for intervention development (143) and the BCW (171). Combined these models highlight changes to current service provision is key to improving referral rates to PR. It further recommends that service level change be

supported by a number of interventions considered important not only increasing initial PR referral rates, but also offers interventions to ensure the sustainability of this behaviour.

Interventions presented were derived from both historic and emergent evidence and applied psychological theory. Utilisation of the BCW was particularly challenging because of the number of steps and BCTs that arose. This led to searches for 'effective BCTs', however a pool of such data has been discounted by behaviour change experts (175) who report challenges around identification of activate components, effect of interacting BCTs and contextual variation impede definitive 'effective BCT' lists. It is subsequently recommended that researchers identify key effective BCTs through pooling research from similar fields such as systematic reviews (175), which this work has sought to do.

Whilst the BCW was a lengthy and challenging process, the utilisation of theory in this work highlighted not only the presence of automatic motivation but its role as a barrier to PR referral. Yet BCW strategies to overcome this appear limited, particularly as the removal of automatic motivation did not affect any intervention functions as all nine functions remained (shown in figure 14, p 219). Automatic motivation encapsulates a well-known concept 'Implicit bias' described as unconscious automatic associations between assessment of individuals with a certain characteristics and following which follows negative evaluation(s) arise (284). Impact bias and its negative effect on particularly HCPs behaviours of HCPs affecting subsequent patient interactions is well reported across differing disease spectrums. (284-286). Therefore, for intervention developers, recognising the significance of implicit bias at the outset of intervention design is important, particularly as HCPs are largely

unaware and therefore unlikely to consider addressing this in intervention design. This has been demonstrated by the PHCPs in this thesis, where implicit bias was unconsciously present captured largely in the PHCP ranking exercise. However, implicit bias appeared to be addressed through the use of persuasion methods in the effective studies of the systematic review (89, 182, 183). Notably however, none of the systematic review three controlled studies included psychological theory in intervention design, nor did they offer explanations on intervention mode or content choice.

The qualitative analysis of PHCP referral behaviour found some PHCPs expressed concerns about PR discussions with patients, citing a desire to protect patient relationships and reduce hostility. These are barriers discussed also in smoking cessation and weight management studies where GPs avoided discussions based on anticipated patient alienation (287, 288), yet in a weight management study n1530 (81%) of patients considered the conversation appropriate. Standardising health promotion scripts in healthcare based consultations is a strategy to support this phenomena and one approach used is Very Brief Advice (VBA), using the Ask Advise, Act model (83). This has however not been tried and tested in relation to PR referral discussions. The VBA standardised approach to smoking cessation conversations between HCPs and patients is embedded across primary care practice as part of the General Medical Services NHS contract (282). Its origins are based upon the PRIME theory of motivation (283) meaning it seeks to overrule internal processes that alter behaviour. Given the findings in this thesis that unconscious PHCP assessments of patients occur and subsequently influence PHCP referral behaviour, adopting VBA for PR conversations are postulated to be a potential intervention that may overrule these internal

assessments in the same way it has for smoking cessation introductions and discussions by HCPs (283). HCP pre-patient selection for health promoting conversations is an important issue, Aveyard et al reported in the VBA for smokers research which found VBA to be more effective when delivered to all smokers rather than to just those who show motivation for quitting (283).

A similar important consideration is practitioner professional apathy, reported and compounded when patients themselves are poorly motivated (presented in chapters 3 and 4). The BCW does not clearly address this topic, yet high PHCP staff burnout and persistent staff vacancies are a national concern (289) and likely to impact further on professional apathy. Patient published data frequently reports the need to be reassured by HCPs prior to their accepting of a PR referral (102, 115), whilst in contrast over-reassurance by HCPs has the opposite effect (290). HCPs influencing patients' referral decisions is likely to be an important ongoing factor and one that must not be overlooked in future PR referral enhancing interventions.

The TDF/BCW approach used in this thesis has helped to identify the significance of implicit bias on PHCPs actions which has been exposed through the use of psychological theory in the inductive qualitative work, but the lengthy BCW process did not in this iteration offer tangible interventions to overcome this bias. The deductive work was however advantageous, it supported the exposure of effective and practical BCTs, which helped to demonstrate clarity on 'the what' is needed in intervention design. In the context of PR referral, specifying direct activities such as ensuring measurable feedback is given to

referrers and action planning whether individually, or across practice networks were not reported in published studies, but they are requested from PHCPs and is subsequently included in the interventions recommended post-referral (figure 18, p 232). This level of intervention detail, otherwise known as intervention fidelity offers intervention transparency, which supports the supporting adaption and replication for further potential intervention adopters, moreover it is considered good practice and is specified in intervention reporting guidelines (291).

## 6.19 **Application of the TDF by others**

There are a number of TDF/COM-B studies that have used the BCW to identify barrier and enabler factors (268, 276, 292, 293), but there is no 'gold standard' on how to directly apply the TDF to intervention design and development (174). A review of published TDF/COM-B studies sought to identify intervention descriptors, but found intervention mode and content are frequently omitted with researchers describing intervention design agreed at local levels, for example 'mode of delivery was based on feasibility and relevance locally' (268) and 'BCTs were practically considered and agreed within the study intervention group, which included expert researchers and practitioners' (292). This demonstrates ongoing TDF and BCW application ambiguity and subjectivity, which further questions intervention fidelity, impacting on further adopters (133, 143).

## 6.20 **TDF – BCW: critique of the methodology**

The TDF/COM-B initial step (step 1) whilst straightforward in principle raised queries relative to the weight of each TDF domain to COM-B component alignment, for example in 'reflective motivation' there were six TDF domains aligned and for 'social opportunity' only one, as shown in figure 13, p 214.

Imbalance is further shown in the intervention function to COM-B alignment (figure 14 p 217). Physical capability for example has only two intervention functions aligned whilst automatic motivation has seven, the significance of this is not clear within the literature. A possible explanation maybe automatic motivation behaviours are more difficult to change given earlier discussions, or overlapping maybe a way to utilise resources efficiently, rather than this being a methodological design. The same overlapping and imbalance phenomena are present for both BCT to intervention function and intervention function to policy categorisation, but no rationale or explanation is offered by BCW authors (171). Furthermore it is not clear whether a greater number of barriers in one COM-B component is important or not.

A further BCT limitation that originated throughout its application to this chapter relates to the differing approaches in which they can be used and with whom. For example the BCTs 'restructuring the physical environment', 'biofeedback' and 'health consequences' can be delivered in various ways, positive (rewarding) or negative (health scaring/threatening). Where the desire is to change behaviour these subtle BCT differences are likely to be

important, but decision making here is challenging for the non-behaviour change expert and it maybe a balance of the two messages is most effective. Additionally, modes of delivery can also vary for example generic email, personalised email, postal letter are examples of different modes of communications, understanding which is most effective in differing contexts would be helpful.

There is also the potential risk that a BCT has a positive effect in one domain, but a negative effect in another. For example adoption of 'verbal persuasion to increase self-efficacy' in an intervention conducted by PHCPs to patients, may conflict with the PHCPs belief about patient PR capabilities meaning referral opportunities maybe reduced as a result of pre-patient selection based on practitioner assessments, as discussed earlier. However motivational interviewing has been shown to be effective (89) and further patient motivational work is currently being undertaken in an RCT by Sohanpal et al (202). It may however also be PR barriers are practical and the patient is unable to attend PR because of employment, or carer responsibilities meaning adoption of a BCT to use 'verbal persuasion to improve self-efficacy is unlikely to be effective.

## 6.21 **Strengths and Limitations**

The inductive and deductive approaches of the BCW across a variety of empirical research investigations in this thesis has offered valuable insights that might have been missed if only following one approach and is a strength of this intervention development work. Attempts to overcome the absence of stakeholders and experts were made by including PHCP referral recommendations as was consideration of patient perspectives via published literature. This

work has also used psychological behaviour theory which has given valuable and important and new insights.

Alignment of the original data to COM-B and the BCW is largely subjective, meaning differing developers are likely to result in different mapping outcomes as was highlighted in chapter 4. PR providers were not directly included nor were the wider practicalities such as embedding recommended interventions within services such as differing primary care information systems notably Systmone and/or Emis considered.

Very few of the interventions suggested by the author in this chapter have been tested in primary care or have proven repeated effectiveness in increasing PR referral and uptake for patients with COPD, meaning true analysis of their overall effect are limited.

## 6.22 **Implications for practice**

Advocacy for interventions to be theory based are well reported both by the MRC framework (132) and others (250, 267). The TDF and COM-B, BCW approaches utilise differing (albeit similar) theoretical based behaviour change approaches to intervention design, yet to date neither approach has shown superiority in intervention design. Indeed it is likely that variations and subjectivity across intervention design steps such as intervention mode and BCT selection mean it is difficult to truly reach firm conclusions. However COM-B appears to address implicit bias and for that reason encouraging developers to consider motivation and its effect is important, but this can be achieved without utilising the whole of

the BCW process. This suggests awareness of psychological behaviour change theory is valuable, but interventions do not have to be built solely on theory, indeed the author would advise against this strategy.

For complex intervention design and development, embracing frameworks such as those offered by O'Cathain et al (143) and the MRC (132) are recommended. Their holistic focus, emphasis on context and drive to include expert insight are particularly important and offer a more outward view than the BCW.

It is hoped as the use of implementation science increases, intervention fidelity and its reporting will improve. Starting intervention design with a generalised qualitative inductive approach is recommended as it offers valuable contextual data and also offers an important systems perspective, indeed commencing HCP and/patient behavioural analysis with an inductive lens rather than deductive is a research recommendation (233).

## 6.23 **Key chapter findings**

This chapter has undertaken a combined model approach in order to design behaviour change interventions. This has previously been recommended as it collectively embraces behavioural theory with evidence and contextual data (143). It recommends assessing the system within which the element that requires change is functioning which allows competing factors to be exposed and addressed. It is also critical that interventions include multiple stakeholders and including a health psychologist is likely to be helpful (143, 171).

The work presented in this chapter has enabled the completion of thesis objective 4, Section 1:21, p 35 (making intervention recommendations that will increase PR referral for patients with COPD from primary health care) and has described a number of interventions that are likely to increase PR referral for patients with COPD by PHCPs.

## 6.24 **Next Steps**

The next and final chapter will briefly summarise the findings of all previous chapters relative to the thesis' overarching aims and objectives. It will offer reflections on this journey and present thesis strengths and limitations and considers the impact of these findings on current healthcare practice, climate and policy. It will also present areas relative to PR referral that are likely to benefit from novel and greater research before reaching its final conclusions.

# Chapter 7: SUMMARY OF ALL FINDINGS, DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS.

## 7.1 Introduction

The overarching aim of this thesis was to conduct and collate sequential primary research through a multiphase mixed methods approach in order to inform the design and development of interventions that improve referral of people with COPD to pulmonary rehabilitation. Its focus was twofold; firstly to identify and understand the barriers and enablers for PHCPs when considering or undertaking referral to PR for patients with COPD, and secondly to identify which of these barriers and enablers could be targeted by interventions to ultimately increase PR referral rates.

This thesis has undertaken and completed all of its overall aims by answering the research questions what are the barriers and enablers to PR referral for patients with COPD, experienced by PHCPs and what barriers and enablers could be targeted to inform the design of interventions that seek to increase PR referral rates for patients with COPD from primary care. As outlined in Section 1:21, p 35, it achieved this by completing specific objectives specified in Section1:21, p 35 which were to:

1. Identify effective previously tested interventions that support referral to, uptake and/or completion of PR for patients with COPD.

2. Identify barriers and enablers to PR referral by PHCPs captured through their descriptive experiences and analysed by two separate data analysis approaches one inductive and the second deductive, which applies behaviour change theory to PHCP findings.

3. Identify current nationwide PHCP practice for PR referral and agreement with nationwide practice identified in the qualitative findings, using a quantitative survey.

4. Develop new evidence based, theoretically informed interventions that will increase PR referral for patients with COPD from primary health care.

This final chapter seeks to offer reflections of this journey, whilst also reiterating the original contribution to the PR referral field that this work informs. It will sequentially recap the methods and main outcomes of each research investigation presented in chapter format in this thesis and it will highlight how these individually and collectively contributed to the thesis research questions and objectives. An overview of the research conducted in this thesis, along with its key findings and contribution to the thesis' overall aims and objectives are presented in table 28, p 249.

Individual study methodological rigour is presented in tabular format (table 29, p 254), following which discussions on the chapters individual key findings, their implications upon policy and practice along with personal health care professional reflections. This chapter will also highlight areas that are likely to benefit from additional research, followed by thesis conclusions.

**Table 28: An overview of individual investigations and their contribution to the overall aims of the thesis.**

| Investigation aims (ordered sequentially) | Methodology | A summary of the key findings | How the original research contributes to the aims of the thesis objectives |
|---|---|---|---|
| SR to summarise effectiveness of interventions aimed at increasing PR referral, uptake and adherence for patients with COPD | Systematic search of databases using Cochrane SR methodology up to May 2020 | Fifteen studies – two cluster RCTs, two RCTs, one quazi-randomised trial, two CCT and eight uncontrolled studies<br><br>There is no single effective intervention to enhance referral, uptake and adherence to PR<br><br>Education, training, environmental restructuring and empowerment are techniques that appear to enhance referral. | Objectives 1 and 4 |
| Inductive qualitative study to investigate the referral barriers and enablers for PHCPs | Qualitative interviews with 19 PHCPs on PR referral experiences.<br><br>Uses two separate data analysis approaches. | There are multiple barriers and few enablers for PHCPs in PR referral.<br><br>The impact of these barriers and enablers are considerably influenced by patients, PHCPs and PR providers, individually and collectively.<br><br>Generalised PR awareness is present, but specific clinical benefits and programme specifics are frequently unknown.<br>Practice nurses most likely to refer.<br>Patient characteristics influence PHCP referral behaviours.<br>PR referral is reported to be generally low. | Objective 2 |

| Investigation aims (ordered sequentially) | Methodology | A summary of the key findings | How the original research contributes to the aims of the thesis objectives |
|---|---|---|---|
| | Inductive (generalised qualitative approach) | Barriers: There is little time for PHCPs to refer to PR<br>Belief that patients are not motivated to attend<br>Perception that There is little to no engagement from PR providers<br><br>Enablers: Financial reward and professional peers influence and encourage referral | |
| Deductive application of TDF and COM-B models to the inductive generated data to identify differences between the data. | Deductive (data aligned to the 14 domain TDF, to report on theoretical behavioural analysis) | All 14 TDF domains are involved<br>Barriers:<br>TDF domains optimism, belief about capabilities and belief about consequences appear to have important inhibiting impacts on PHCP referral behaviour.<br>There are no sanctions for non-referral.<br>There are no in practice or personal goals to alter current behaviours.<br><br>Enablers:<br>PHCPs largely consider it their role to refer.<br>PR generally considered a good thing and would like to refer more.<br>Knowledge is largely gained from CPD events and peers<br>Referral process is largely easy. | |
| To test the generalisability of the qualitative findings amongst a larger population. | Online and paper based survey of 233 UK based PHCPs<br><br>Data from the systematic review, inductive and deductive investigations were brought together to formulate the n54 questioned survey on referral experience. | There is a positive correlation between referral practice and PHCP post education respiratory qualification<br><br>Referral rates differed with 113/222; 50.9% infrequent < monthly/or never and 109/222; 49.1% frequently >monthly/weekly referring<br><br>Both groups<br>Barriers: Poor relationships with PR providers<br>PHCPs pessimistic about patients motivations<br>Little promotional PR material available<br>No clear PR referrer<br>QoF not considered to influence referral rates | Objectives 3 and 4 |

| Investigation aims (ordered sequentially) | Methodology | A summary of the key findings | How the original research contributes to the aims of the thesis objectives |
|---|---|---|---|
| | These were then aligned to the TDF domains.<br><br>Additional free text open question, analysed thematically | Less than half of PHCPs felt patients would attend and complete PR<br>Patient characteristics are not reported to influence referral.<br><br>Enablers: There is time in practice to refer<br>PR is beneficial for patients<br>QoF considered to increase PR practice awareness<br><br>**Frequent referrers**<br>Barriers: Belief PR not suitable for patients in work.<br><br>Enablers: PR knowledge, i.e. knowing when to refer and being able to answer patients questions<br><br>**Infrequent referrers**<br><br>Barriers: Low levels of confidence in referring patients<br>Answered open questions more than infrequent referrers- raised concerns about transport and access to PR venues. Also requests for easier referral processes.<br><br>TDF domains: Belief about capabilities, Goals, optimism, and social influences all had barriers with no enablers. | |
| The aim of the multiphase design was to inform the development of theory informed interventions to improve PR | Sequential mixed methods study<br><br>The TDF deductive qualitative findings were mixed with the TDF survey results (part one) to ascertain behavioural | There are more barriers than enablers<br><br>Infrequent engagement from PR provider to referrer<br>PHCPs have concerns around patients abilities and motivations<br>There is no clear PR referrer<br><br>PHCPs believe in the benefits of PR | Objectives 2 and 3 |

| Investigation aims (ordered sequentially) | Methodology | A summary of the key findings | How the original research contributes to the aims of the thesis objectives |
|---|---|---|---|
| referral rates from primary care in future. | patterns in a larger representative population to gain greater insights. | On screen reminders are helpful, as is dedicated time to refer such as annual reviews<br>Respiratory interested colleagues support PR awareness and referral<br><br>Barriers are present in a number of TDF domains including belief about capabilities, social influences, environment and optimism. | |
| To establish and present PHCP perspectives on possible interventions. | Survey – (parts two and three) PHCPs suggested interventions. Questions based on the systematic review and published literature sources.<br><br>(between n207-138 completed these later parts of the survey)<br><br>Two-staged questions n23 questions closed 5-point Likert scale, followed by top 5 ranking. | Intervention suggestions:<br><br>Increasing PR provider to referrer engagement.<br>Face to face education for both PHCPs and patients.<br>Review referral timing opportunities, such as at AECOPD.<br>Increase promotional material.<br><br>The top rated interventions were those largely outward looking, meaning they did not necessarily require PHCPs to drive interventions. This maybe an important finding.<br><br>Demonstrating PR on a tablet device was rated low as an intervention by PHCPs, since this finding, an RCT has concluded this to be an ineffective intervention (179).<br><br>Individuals were not aware or did not want to acknowledge that their personal behaviours can be influenced by others. | Objective 4 |
| To design an Intervention to enhance PR referral. | Informed by the logic model for intervention design. All findings mapped to the BCW to identify behavioural | Educational session(s) on PR to general practice staff and patients (face to face or online) – ideally by local PR providers.<br><br>Clear time points for referral (diagnosis, annual review, post AECOPD) | Objective 4 |

| Investigation aims (ordered sequentially) | Methodology | A summary of the key findings | How the original research contributes to the aims of the thesis objectives |
|---|---|---|---|
| | theory informed interventions, followed by a critique of processes. | Standardised PR recital for referral to use when discussing/describing PR / possibly using VBA<br>Feedback and goal setting (PR provider and PHPCs) | |

Highlight text indicates thesis key findings as aligned to the overall objectives

## 7.2 **Methodological Rigour**

The key concepts of methodological rigour are first presented in chapter 1, section 1:23 p 41. These processes offer research quality assurances and are determined by the research paradigms. Table 29 below offers a summary of methodological rigour as aligned to study paradigm with the studies presented in this thesis. Study 1, the systematic review has not been included in this methodological table as research transparency and rigour has been presented by its preceding published protocol (see Appendix 2) and PROSPERO registration (294).

**Table 29: Study methodological rigour**

| | Study 2 – Inductive qualitative study | Study 3 – Survey Quantitative study | Study 4 –Mixed methods study |
|---|---|---|---|
| **Credibility** | Audio recording, transcriptions, inclusion of individual quotations.<br><br>Member checking of transcripts.<br><br>**Triangulation -**<br>Team triangulation of data, independent and collaborative.<br><br>Participant respondent feedback was utilised, this being where validation of other participants' experiences were brought to subsequent interviews. | | |
| **Transferability** | Purposeful sampling.<br><br>Thick description, accurately describing and interpreting social interactions within context, considers emotions, motivations and intentions (295). | | |
| **Dependability** | Pre-study protocol<br><br>Topic guide use<br><br>Computer assisted analysis - Nvivo | | |

| | Study 2 – Inductive qualitative study | Study 3 – Survey Quantitative study | Study 4 –Mixed methods study |
|---|---|---|---|
| **Confirmability** | Researcher journal kept to aid self-reflection and own bias'. | | |
| **Internal validity** | | Closed 5 point Likert scale questions, with midpoint rating– one answer option.<br><br>Reverse belief statements | |
| **Reliability** | | Closed 5 point Likert scale questions, with midpoint rating – one answer option.<br><br>Clear belief statements – internally team review and agreement.<br>Questionnaire pilot testing<br><br>Online and paper questionnaire instrument alignment. Online survey used.<br><br>Outputs consistently reported to agree/strongly agree<br><br>Computer assisted analysis STATA used.<br><br>Online survey directly imported, random quality check of manually uploaded questionnaires.<br><br>Attrition, questionnaire fatigue addressed.<br><br>Purposeful sampling | |
| **Transparency & methodological rigour in singular studies** | | | As described above for studies 2 and 3. |
| **Transparency in integration.** | | | Quant and Qual connected – (qual informed development of quant)<br>Qual and quant results integrated in discussion. |
| **Inferences made must be based on the research question** | | | Mixing research paradigms offers greater insight and enhances the validity of the |

| | Study 2 – Inductive qualitative study | Study 3 – Survey Quantitative study | Study 4 –Mixed methods study |
|---|---|---|---|
| | | | barriers and enablers to PR referral experienced by PHCPs – as aligned to the overall research thesis questions. |

## 7.3 Summary of key findings

Despite PR referral being persistently low there has been very little detailed analysis that seeks to understand why that is from the perspective of the main referrer, the PHCP. This thesis has presented the first systematic review to examine all three PR pathway points (referral, uptake and adherence) and the first published qualitative study of a range of UK based PHCPs experiences of referral. It also offers a cross section of UK based PHCPs referral experiences and their suggestions for referral enhancement in a survey before mixing the qualitative results with the quantitative. The mixed methods analysis underpinned by behaviour change theory was also original in this field.

Collectively these research investigations have found there is a general awareness about PR amongst PHCPs and that the most appropriate time to refer is at COPD annual review. PHCPs who have a general PR awareness understand the benefits and consider it a valuable treatment, however, knowledge about what PR involves also impedes referral by some PHCPs, as they use a subjective patient assessment to judge likely referral acceptance and PR attendance. PHCPs also report patients to be unmotivated and PR not being suitable for patients in work.

The survey found that PHCPs with one or more respiratory qualification reported referring more patients to PR than those without, a finding not previously reported. PHCPs would like to refer more patients but there are little to no individual or practice based goals in place to increase referral rates. PR advocacy from respiratory experts, such as respiratory consultants is considered valuable and motivating by PHCPs. Additionally, there is minimal PR promotional material for patients and or referrers and little to no engagement from PR providers. Combined, PHCPs beliefs, limited detailed PR knowledge such as PR timings, no tangible plans to increase referral and infrequent PR provider engagement appear to perpetuate persistently low PR referral rates. There are no current interventions that have been tested that address PHCPs unconscious beliefs which affects subsequent actions, nor are there published tested interventions that have explicitly enhanced PR provider engagement with patients and/or PHCPs at the point of referral. Yet, these are likely to be key interventions to increase PR referral rates.

## 7.4 **Original contributions**

In summary this thesis' original contributions to the field of PR referral for patients with COPD by primary health care practitioners includes:

- the first systematic review to include all three aspects of the PR journey,
- exposure that no intervention study published to date has sought to enhance relationships with/between referrers/patients and PR providers, yet this is considered important by PHCPs.

- an up to date detailed barrier and enabler analysis across a wide PHCP population.

Although the finding that PR knowledge is an important referral enabler in itself is not novel, findings that such knowledge leads to further subjective often unconscious assessment by PHCPs, of both PR providers' and patients' characteristics and subsequent anticipated patient behaviours are novel. The finding suggests a hierarchal relationship between programme knowledge and patient assessment, impacting on PR referral, which is an important key and original finding.

- The first reporting that PHCPs consider relationships with PR providers to be largely poor.
- higher PR referral rates and PHCP confidence in those with post CPD qualifications and PHCPs undertaking the patients COPD annual review are those most likely to refer.

These findings were strengthened by the additional and original utilisation of psychological theory which used a mixed methods approach and included the largest number of PHCPs to date to illustrate their PR referral experiences.

## 7.5 Summary of evidence: Chapter 2 - Systematic Review

Frameworks guiding complex intervention development advocate reviewing primary research literature (143), including assessing previous intervention efficacy (296). The systematic review reported in chapter 2 found a small number of studies (n=15) sought to increase referral, uptake and adherence to PR from both primary and secondary healthcare

settings, targeting patients and HCPs. This novel and up to date systematic review has highlighted the paucity of global research studies in this field, including the lack of theoretically informed interventions (297). Some of the ongoing studies address previous limitations, including theory and HCP and patient collaboration (201, 202, 205), but our search did not identify any studies that included PR providers as part of the intervention for improving referrals. One abstract reported using secondary care based virtual MDTs to undertake COPD reviews of two groups of community based patients and reported positive referral rates at 40% and 13% for each of the groups. In light of national drivers for integrated care working across the UK (39), implementing PR referral as a goal within virtual integrated MDTs may offer a simple and practical intervention.

## 7.6 Summary of evidence: Chapter 3 – Inductive Qualitative Study

The inductive analysis reported in chapter 3 was the first in depth qualitative study to investigate the referral experiences of PHCPs in the UK (76). Assessment and understanding of experiences, processes and behaviours in action allow the identification of causal determinants and is a key part of intervention design (143, 145, 154). The findings also supported the development of the content of the questionnaire reported in chapter 4.

Some key findings included the paradoxical contribution of PHCP knowledge as both a pre-requisite, and a potential barrier to referral, the low level of engagement with PR providers, and the finding that referral was often prompted by disease worsening; at a time when patients are least likely to accept a referral. Lack of insight into these issues among PHCPs

suggests that these behaviours are likely to persist without some intervention. This lack of PHCP insight is a particularly important as patients report HCPs to be key influencers in their referral uptake decisions (102). These findings demonstrated that relationships between PHCPs, patients and PR providers are interconnected and all have the potential to influence PR referral actions.

### 1.6.1 **Summary of evidence: Chapter 3 – Deductive analysis**

Behaviour change theory is considered key in identifying behaviours that would benefit from change (117). Using a theoretical deductive lens, by adopting the TDF to understand PHCP referral experiences was valuable in identifying key behaviours for change. Moreover, theory utilisation within intervention development is widely advocated (132, 143, 154) and increasingly being used by other PR researchers (201, 202, 205).

The key findings from the deductive analysis included identification of lack of sanctions for non-referral and absence of in-practice leadership strategies as contributors to low referral rates. Deductive findings also illuminated PHCPs' concerns around patient capabilities and anticipated outcomes of a referral offer, which negatively impacted on referral intentions and actions. These findings have not previously been reported and are considered important as these internal drivers are likely to perpetuate current referral behaviours, challenging these beliefs by increasing engagement with PR providers could be important and should be the target of future interventions.

## 7.7 Summary of evidence: Chapter 4 – Survey

Whilst the two types of qualitative analyses provided an overview of PHCPs experiences, variation in these experiences, specifically the impact of PHCP knowledge and beliefs on referral actions, strengthened the need for a survey. The initial part of the online and paper based survey ascertained the extent of PHCPs agreement with n54 belief statements generated from the preceding qualitative work. Utilisation of the TDF in both qualitative and quantitative research is a supported application (298) (226).

The key findings included a generalised awareness of PR was an enabler, but poor relationships with PR providers and the common belief that patients were poorly motivated, acted as barriers to referral.

## 7.8 Summary of evidence: Chapter 4 – Mixed Methods Study

Mixing qualitative and quantitative research is considered particularly beneficial when working within complex systems such as healthcare (149). These differing exploratory approaches conduced in a sequential manner sought to ensure fully inclusive methods and counterbalance paradigm individual limitations (233) and aligned the thesis to its multiphase design.

The key findings and agreements in the mixed methods analysis resulted in multiple intertwined referral barriers and few enablers, but overall there was a generalised awareness of PR amongst PHCPs, an understanding that PR was a positive intervention for patients with COPD and referral rates were low.

## 7.9 Summary of evidence: Difference in survey and qualitative findings

The exploratory sequential mixed methods approach seeks to understand what findings and patterns from the quantitative study supported those first reported in the qualitative study results, thereby offering greater certainty of the PR referral barriers and enablers (149).

The largest difference between the survey findings and the qualitative study findings related to perceptions on where responsibility for referring patients to PR should lie. Also the qualitative study found patient clinical characteristics influenced referral decisions, findings that were not confirmed in the survey. These first qualitative reported referral influencers remain relevant and important not only because evidence shows patients with greater disease burden are more likely to attend PR (299).

Differences were also evident in relation to views on 'financial reward increases referral' between the qualitative and quantitative investigations, further research will need to be undertaken particularly post QoF reward implementation to assess the true effect of that possible referral lever. Collectively these research studies have offered a thorough analysis of PR referral barriers and enablers and concluded thesis objective one.

## 7.10 **Summary of evidence: Chapter 5 – PHCP recommended interventions**

Stakeholders and field experts are important in informing intervention design (132, 143, 171). However, engaging NHS staff with research is known to be challenging (300), for primary care specifically, staff turnover is high when compared to other healthcare settings (259, 300). In this work a number of practical limitations, including time impeded utilisation of a stakeholder group and inviting PHCPs thoughts on potential referral interventions via the survey was a way to overcome this.

A high number of PHCPs voted for interventions that potentially removed them from the PR chain of referral interventions, including educational PR sessions to be delivered to practice staff and patients and PR providers contacting eligible patients directly. Understanding more about the reasons why PHCPs made those choices would have been particularly valuable and important for intervention design. Interventions with lower ratings had variable effectiveness based on findings from the systematic review. For example whilst PHCPs did not consider scorecards to be valuable, they were shown to significantly increase referral rates (182), but in contrast videos demonstrating PR did not improve referral, uptake or adherence rates (179). These examples highlight that including stakeholders and intervention users is valuable and whilst they may not be able to predict effectiveness, practical insights are important especially as user engagement impacts on intervention uptake and fidelity (301, 302). This research is therefore of particular importance in relation to intervention development and thesis aim two.

## 7.11 **Summary of evidence: Chapter 6 – Intervention design**

Intervention development is a complex process, with multiple interacting elements to consider (143, 297). Blending both the multiphase mixed methodology and logic intervention model (143) navigated steps through this intervention design process offering step by step transparency and enhancing rigour (143). This clarity additionally helped the thesis author transition through each phase and make sense of emergent findings. Furthermore, implementation science researchers report for intervention implementation to be successful, a blended implementation strategy is needed (154, 303).

Increasing PR provider engagement with both patients and PHCPs could simultaneously increase PHCP knowledge and awareness and enable further collaborative PR referral enhancing strategies such as problem solving, goal setting and feedback opportunities. To reduce PHCPs internal concerns about patients motivations and abilities to undertake PR a suggested intervention is the utilisation of VBA, given its success in smoking cessation work (283). VBA arose from a psychological theory known as PRIME (304) as presented in chapter 6. This highlights theoretical potential in behaviour change interventions. However evidence based interventions infrequently guide 'how to' best deliver proposed interventions (145, 302). It is proposed that the BCW overcome these challenges (171), but others including the author would argue this is not straightforward because of multiple possible interpretations throughout its many stages (267).

## 7.12 **Relation of findings to policy**

Given the clinical and functional effectiveness of PR, increasing patients' utilisation of PR is a key national policy driver and has been for a number of years (39). Low PR referral numbers are recognised nationally and in 2019 NHS improvement and NHS England specified a desired 60% increase in referral rates across England in 2020 (305). Planned expansion was set to be initiated and tested by a small number of fund awarded CCGs in 2020. However the Covid-19 pandemic halted not only this initiative but also face to face PR across the country from March 2020 (216). Furthermore, the pandemic has resulted in increased demands for rehabilitation to support the management of 'long COVID', for which rehabilitation is considered potentially effective (306, 307). Additionally there remains significant pre Covid-19 pandemic PR backlogs (308). These impacts will undoubtedly affect service provision and capacity in both the short and medium term.

The research within this thesis has outlined evidence-based strategies to increase referral to PR and is therefore considered by the author to be important to policy makers and health service providers. However, implementing interventions directed at populations with lower incomes and education may be more expensive because of greater investment needed in resources, communications, readability etc. and is described as the staircase effect (309). These cost factors may have subsequent implications for policy maker's decisions. Conversely, not addressing the large numbers of eligible patients with COPD who do not engage with PR increases COPD expenditure to other areas of healthcare and social care services. For example hospital admissions for those suffering with an AECOPD continues to

rise year on year (31) associated with which is re-admission (33). A systematic review and meta-analysis suggests that PR decreases emergency hospitalisation for AECOPD (299) and a 2016 Cochrane review found that PR reduces hospital readmission when compared to usual care (pooled odds ratio (OR): 0.44, 95% CI: 0.21–0.91) (*n* = 810) (55).

Emergency respiratory hospital admissions place considerable strain on healthcare services, increasing by up to 15% in the winter months (310, 311). These pressures have a subsequently significant effect on hospital elective services as in-patient bed capacity increases (312). As a result there are a growing number of urgent calls from government to manage COPD effectively in out of hospital settings in an effort to reduce overall emergency admissions (39, 312).

A further important consideration in relation to intervention design and something of likely importance, yet not addressed by the thesis researcher is the community effectiveness of interventions. This means the interventions effect will become diluted as a result of its delivery chain. White et al (313) offers the following description, an intervention may be efficacious in 50% of those to whom it is delivered, but the condition for which it is efficacious is only diagnosed in 80% of those with the condition, only 60% of those diagnosed gain access to the intervention, only 90% of providers deliver the intervention as intended, and only 70% of consumers adhere to the intervention as intended and/or interventions that are delivered in the same way to all recipients may result in differential outcomes. The intervention's overall community effectiveness will therefore be the product of the efficacy, multiplied by each of these modifiers (i.e. 0.5 x 0.8 x 0.6 x 0.9 x 0.7 = 0.15).

In other words, the intervention would have an overall community effectiveness in 15% of the target population. In the context of COPD, given approximately 30% of primary care patients diagnosed with COPD do not have COPD this potentially reduces the effectiveness to 13% if using the same model (0.5 x 0.7x 0.6x 0.9 x 0.7 =0.13). This thesis has only addressed approaches to increase referral within the chain leading to health outcomes. Further work is needed to consider how to increase uptake and completion, as well as how delivery can be effectively implemented.

Policy makers are likely therefore to bring differing views and expertise to intervention implementation and including public health policy makers in any feasibility study that seeks to increase referral and uptake to PR is important.

## 7.13 **Relation of findings to practice**

This work has highlighted many important factors relative not only to the physical functional process of PR referral but has also highlighted a number of interacting, influential barriers that affect individual and collective behaviours that impact upon health outcomes. Important findings for practice are that these barriers are not isolated to PR but also exist in other health promotion conversations, such as weight management where empowering individuals would improve overall health outcomes, so awareness and management across health systems of HCPs beliefs are of critical importance.

Knowing that poor relations with service providers, and patient characteristics including patient apathy influence the PR referral processes, are key findings. Efforts to reverse these barriers are particularly important. Building on our findings that respiratory CPD appears to enhance referral rates, professional educational interventions should be advocated. Collaboration with PR providers and respiratory interested practitioners to support educational interventions is a key finding and one that should be evaluated.

## 7.14 **PR and COVID-19**

In March 2020 the World Health Organisation (WHO) declared Covid-19 a global pandemic (314). This deadly viral infection saw national lockdowns implemented and the most vulnerable confined to their home with funded food boxes being delivered via central government. This isolation strategy sought to reduce viral transmission across human to human contacts (315) and forced multiple services including face to face PR to stop (216). Covid-19 is a virus expected to remain a global challenge for the foreseeable future meaning continued impacts on services including PR is inevitable. New barriers affecting uptake and attendance are likely to emerge including patient infection control concerns, reductions in programme capacity numbers as social distancing remains and increased PR service demand given rehabilitation is a post Covid-19 treatment (307, 308). Whilst the emergence of differing homebased PR for patients with COPD have evolved during this time, efficacy of these models are not yet proven (50), meaning PHCPs should continue to advocate for interventions that are evidence based.

## 7.15 **Reflections as a HCP**

As an HCP that has worked in primary, community and secondary care settings caring for patients with COPD and referring to PR, as well as supporting educational components of PR services, there are personal bias's and in field experiences that will have influenced a number of areas relevant to this thesis including recruitment, data collection and interpretation. Attempts to minimise this has been addressed by including independent and collaborative comparisons across the supervisory team at all stages of the research process and for each study.

Also as a front line clinician, the author observes that the NHS as an organisation is one that is frequently reactive rather than pro-active. Delivering evidence based care at pace is a significant practical challenge, meaning for intervention uptake to be successful and sustainable it must engage key whole system stakeholders in a timely efficient manner and must also be supported to respond to changes promptly and efficiently.

## 7.16 **Thesis Strengths and Limitations**

The strengths and limitations have been previously discussed within each chapter, however, there are some important strengths and limitations to consider overall. This thesis' exploration of current behaviours influenced by experiences captured through inductive and deductive methods is a strength and provides evidence on how to change behaviour. Moreover the application of psychological theory to those experiences was valuable as it

threaded through subsequent research investigations and informed overall intervention development. Combined research investigations and findings starting with the systematic review and the qualitative data to inform the questionnaire and also the combined results of the qualitative and quantitative research arising from the sequential mixed methods approach added insight to PHCPs experiences, highlighting areas for change. PHCPs views on possible practice-based referral enhancing interventions emphasised additional potential avenues. Therefore PHCPs have been used throughout this thesis, including within intervention design and development recommendations which is a key strength.

An incidental but important finding and further thesis strength is the application of PR barrier findings to other areas that require health promotion action, where for example HCPs seek to activate behaviour change in individuals, such as referral for weight management and smoking cessation services.

Important limitations to this thesis include those related to the qualitative data being generated from only two geographical areas, which may not represent wider UK PR services and sampling limitations, where only those interested in PR were likely to have offered support and this sampled population not being wholly representative of the general practice workforce. Whilst patients have not been directly consulted in this work, their voice has been captured through reviews of relevant and recent literature. PR provider perspectives are lacking however, and this is certainly an area worthy of further investigation. Intervention cost analysis and considerations were not included, yet is likely to be an important factor for intervention implementation. Also intervention development processes

are not formulaic and may have been influenced by the perspectives of the team and team interpretations of the data.

Data collection for this thesis occurred prior to the Covid-19 pandemic and the context of PR has changed significantly since this time. Whether services will return to pre-COVID models of working is yet to been seen, but recognition must be given that these findings may not be replicable to differing PR models.

Another key limitation is its focus on just one part of the community effectiveness chain, that being those eligible for PR referral. The whole chain starts before referral and completes at programme completion. Meaning the effectiveness of the intervention, fidelity of intervention delivery, adherence by patients are important additional factors that were not addressed here.

## 7.17 Recommendations for future research

Patient self-referral, also termed direct access has been under investigated in this PR field, although it is widely utilised in other healthcare services, such as MSK and CBT (316, 317) However, there is evidence that interventions that rely on voluntary behaviour change benefits only patients who can navigate the system, which disadvantages certain patients such as those with financial or employment challenges, poor health literacy, limited transport options or lack of an advocate or disempowerment which increases socioeconomic inequalities in health (318). So, self-referral may be a consideration for further research, but services need to be simple and not require patients to jump through numerous hoops, as

this tends to increase inequalities and is described as the staircase effect, where each step represents a step in the patient pathway (309).

Investigating the role of the PHCP in health promotion and patient activation more widely would also be an important area of further research. Equipping staff to manage difficult conversations, whilst recognising implicit bias is important and developing coaching or motivational interviewing skills may increase patient uptake and behaviour change. Interventions that also look at other aspects of community effectiveness would be valuable for example including PR provider engagement with patients and/or PHCPs before referral, differing delivery models such as a hybrid approach, where the initial session is face to face followed by online sessions that include with effectiveness measures and interventions testing PR adherence in community based PR settings. Additionally interventions that include PR cost-effective analysis on the wider health and social care system is important and recommended.

## 7.18 **Conclusions**

This thesis has conducted a number of primary research investigations, based on in depth barrier and enabler analysis and has used psychological theory. All research findings, including PHCP intervention suggestions have been mixed and collectively offer PR referral enhancing intervention recommendations, which aim to increase the referral rates of patients with COPD to PR. Key overall findings highlight targeting only one component of the referral pathway is unlikely to be effective and interventions need to consider how to target

patients, PHCPs and PR providers to work together in order to increase PR awareness, referral, uptake and completion. Interventions must also consider fidelity of delivery. Testing these recommendations ultimately within a cluster RCT are recommended next steps.

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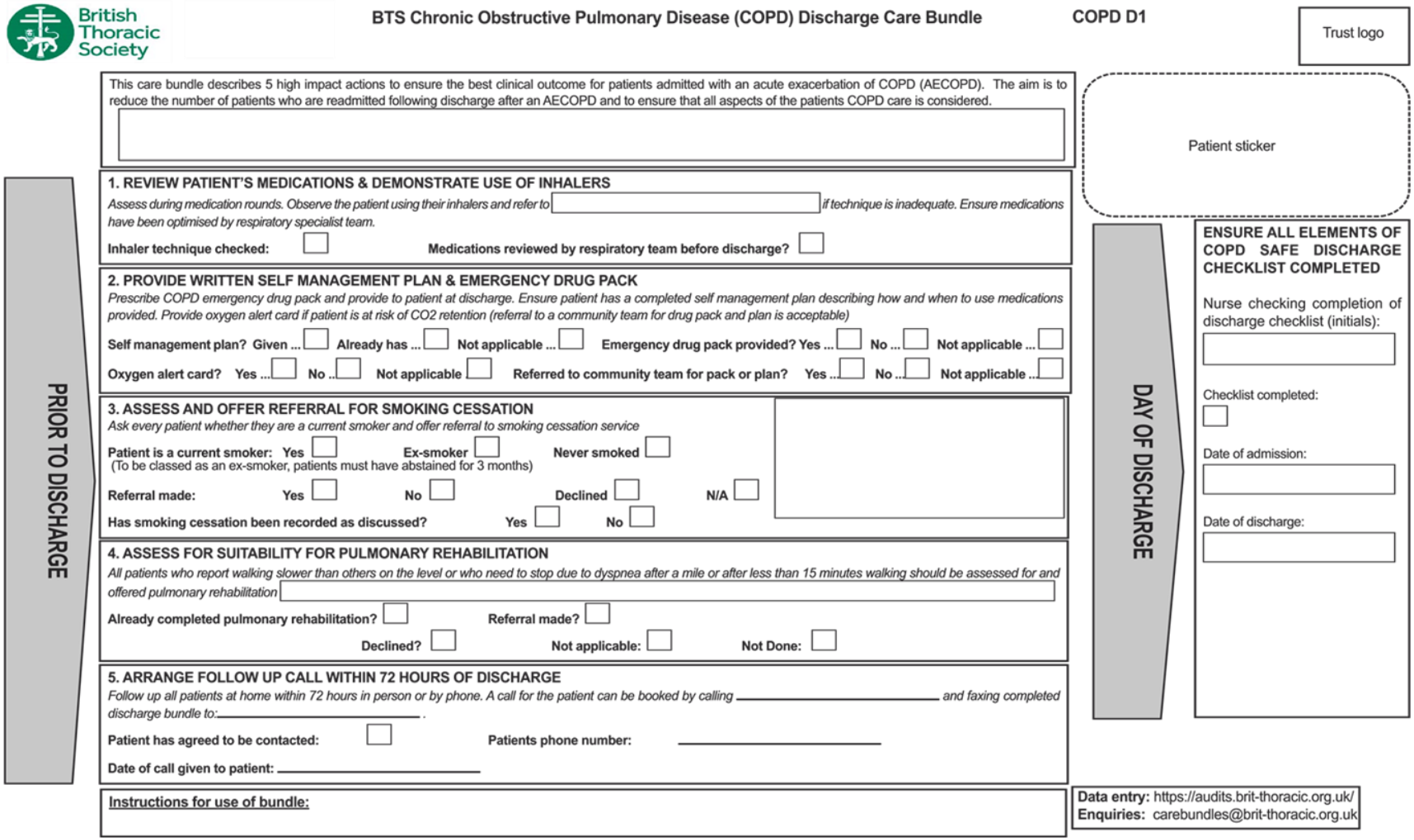
# APPENDICES

**Appendix 1: Discharge Bundle example** (reproduced from BTS, [https://www.brit-thoracic.org.uk/quality-improvement/clinical-resources/copd-spirometry/](https://www.brit-thoracic.org.uk/quality-improvement/clinical-resources/copd-spirometry/)



British Thoracic Society

**BTS Chronic Obstructive Pulmonary Disease (COPD) Discharge Care Bundle** COPD D1

Trust logo

This care bundle describes 5 high impact actions to ensure the best clinical outcome for patients admitted with an acute exacerbation of COPD (AECOPD). The aim is to reduce the number of patients who are readmitted following discharge after an AECOPD and to ensure that all aspects of the patients COPD care is considered.

Patient sticker

PRIOR TO DISCHARGE

**1. REVIEW PATIENT'S MEDICATIONS & DEMONSTRATE USE OF INHALERS**

*Assess during medication rounds. Observe the patient using their inhalers and refer to* _____ *if technique is inadequate. Ensure medications have been optimised by respiratory specialist team.*

**Inhaler technique checked:** ☐ **Medications reviewed by respiratory team before discharge?** ☐

**2. PROVIDE WRITTEN SELF MANAGEMENT PLAN & EMERGENCY DRUG PACK**

*Prescribe COPD emergency drug pack and provide to patient at discharge. Ensure patient has a completed self management plan describing how and when to use medications provided. Provide oxygen alert card if patient is at risk of CO2 retention (referral to a community team for drug pack and plan is acceptable)*

**Self management plan? Given ...** ☐ **Already has ...** ☐ **Not applicable ...** ☐ **Emergency drug pack provided? Yes ...** ☐ **No ...** ☐ **Not applicable ...** ☐

**Oxygen alert card? Yes ...** ☐ **No ..** ☐ **Not applicable** ☐ **Referred to community team for pack or plan? Yes ..** ☐ **No ..** ☐ **Not applicable ..** ☐

**3. ASSESS AND OFFER REFERRAL FOR SMOKING CESSATION**

*Ask every patient whether they are a current smoker and offer referral to smoking cessation service*

**Patient is a current smoker: Yes** ☐ **Ex-smoker** ☐ **Never smoked** ☐
(To be classed as an ex-smoker, patients must have abstained for 3 months)

**Referral made: Yes** ☐ **No** ☐ **Declined** ☐ **N/A** ☐

**Has smoking cessation been recorded as discussed? Yes** ☐ **No** ☐

**4. ASSESS FOR SUITABILITY FOR PULMONARY REHABILITATION**

*All patients who report walking slower than others on the level or who need to stop due to dyspnea after a mile or after less than 15 minutes walking should be assessed for and offered pulmonary rehabilitation* _____

**Already completed pulmonary rehabilitation?** ☐ **Referral made?** ☐

**Declined?** ☐ **Not applicable:** ☐ **Not Done:** ☐

**5. ARRANGE FOLLOW UP CALL WITHIN 72 HOURS OF DISCHARGE**

*Follow up all patients at home within 72 hours in person or by phone. A call for the patient can be booked by calling* _____ *and faxing completed discharge bundle to:* _____ .

**Patient has agreed to be contacted:** ☐ **Patients phone number:** _____

**Date of call given to patient:** _____

DAY OF DISCHARGE

**ENSURE ALL ELEMENTS OF COPD SAFE DISCHARGE CHECKLIST COMPLETED**

Nurse checking completion of discharge checklist (initials):

Checklist completed: ☐

Date of admission:

Date of discharge:

**Instructions for use of bundle:**

**Data entry:** https://audits.brit-thoracic.org.uk/
**Enquiries:** carebundles@brit-thoracic.org.uk

)

**Appendix 2 TDF domain alignment using construct labelling (reproduced from Cane et al, 2011)**

| Domain | Constructs |
|---|---|
| 1.Knowledge<br>(An awareness of the existence of something) | Knowledge (including knowledge of condition /scientific rationale)<br>Procedural knowledge<br>Knowledge of task environment |
| 2. Skills<br>(An ability or proficiency acquired through practice) | Skills<br>Skills development<br>Competence<br>Ability<br>Interpersonal skills<br>Practice<br>Skill assessment |
| 3. Social/Professional Role and Identity<br>(A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting) | Professional identity<br>Professional role<br>Social identity<br>Identity<br>Professional boundaries<br>Professional confidence<br>Group identity<br>Leadership<br>Organisational commitment |
| 4. Beliefs about Capabilities<br>(Acceptance of the truth, reality, or validity about an ability, talent, or facility that a person can put to constructive use) | Self-confidence<br>Perceived competence<br>Self-efficacy<br>Perceived behavioural control<br>Beliefs<br>Self-esteem<br>Empowerment<br>Professional confidence |
| 5. Optimism<br>(The confidence that things will happen for the best or that desired goals will be attained) | Optimism<br>Pessimism<br>Unrealistic optimism<br>Identity |
| 6. Beliefs about Consequences<br>(Acceptance of the truth, reality, or validity about outcomes of a behaviour in a given situation) | Beliefs<br>Outcome expectancies<br>Characteristics of outcome expectancies<br>Anticipated regret<br>Consequents |
| 7. Reinforcement<br>(Increasing the probability of a response by arranging a dependent relationship, or contingency, between the response and a given stimulus) | Rewards (proximal / distal, valued / not valued, probable / improbable)<br>Incentives |

| | |
|---|---|
| | Punishment<br>Consequents<br>Reinforcement<br>Contingencies<br>Sanctions |
| 8. Intentions<br>(A conscious decision to perform a behaviour or a resolve to act in a certain way) | Stability of intentions<br>Stages of change model<br>Transtheoretical model and stages of change |
| 9. Goals<br>(Mental representations of outcomes or end states that an individual wants to achieve) | Goals (distal / proximal)<br>Goal priority<br>Goal / target setting<br>Goals (autonomous / controlled)<br>Action planning<br>Implementation intention |
| 10. Memory, Attention and Decision Processes<br><br>(The ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives) | Memory<br>Attention<br>Attention control<br>Decision making<br>Cognitive overload / tiredness |
| 11. Environmental Context and Resources<br>(Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence, and adaptive behaviour) | Environmental stressors<br>Organisational culture /climate<br>Resources / material resources<br>Salient events / critical incidents<br>Person x environment interaction<br>Barriers and facilitators |
| 12. Social influences<br>(Those interpersonal processes that can cause individuals to change their thoughts, feelings, or behaviours) | Social pressure<br>Social norms<br>Group conformity<br>Social comparisons<br>Group norms<br>Social support<br>Power<br>Intergroup conflict<br>Alienation<br>Group identity<br>Modelling |
| 13. Emotion<br>(A complex reaction pattern, involving experiential, behavioural, and physiological elements, by which the individual attempts to deal with a personally significant matter or event) | Fear<br>Anxiety<br>Affect<br>Stress<br>Depression<br>Positive / negative affect<br>Burn-out |
| 14. Behavioural Regulation<br>(Anything aimed at managing or changing objectively observed or measured actions) | Self-monitoring<br>Breaking habit<br>Action planning |

## Published paper 2:

Reference: Young J, Jordan RE, Adab P, Enocson A, Jolly K.
Interventions to promote referral, uptake and adherence to pulmonary rehabilitation for people with chronic obstructive pulmonary disease (COPD). *Cochrane Database of Systematic Reviews* 2017, Issue 10. Art. No.: CD012813

Appendix 3: Systematic Review Protocol

Cochrane Library

Cochrane Database of Systematic Reviews

# Interventions to promote referral, uptake and adherence to pulmonary rehabilitation for people with chronic obstructive pulmonary disease (COPD) (Protocol)

Young J, Jordan RE, Adab P, Enocson A, Jolly K

Young J, Jordan RE, Adab P, Enocson A, Jolly K.
Interventions to promote referral, uptake and adherence to pulmonary rehabilitation for people with chronic obstructive pulmonary disease (COPD). *Cochrane Database of Systematic Reviews* 2017, Issue 10. Art. No.: CD012813.

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[Intervention Protocol]

# Interventions to promote referral, uptake and adherence to pulmonary rehabilitation for people with chronic obstructive pulmonary disease (COPD)

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A B S T R A C T

This is a protocol for a Cochrane Review (Intervention). The objectives are as follows:

To determine the effectiveness of interventions to increase patient referral, uptake, and adherence to pulmonary rehabilitation programmes, for patients with COPD.

## B A C K G R O U N D

### Description of the condition

Chronic obstructive pulmonary disease (COPD) is defined as 'a common, preventable, and treatable disease that is characterised by persistent respiratory symptoms and airflow limitation that are due to airway or alveolar abnormalities (or both), usually caused by significant exposure to noxious particles or gases' (Vogelmeier 2017).

### Burden of disease

COPD is a common and increasingly prevalent respiratory disease that presents major public health challenges worldwide (LopezCampos 2016). It accounts for 2.9 million deaths worldwide annually, and is currently the third leading cause of global death (Lozano 2012). It is estimated that 328 million people have been diagnosed with COPD worldwide (Lopez-Campos 2016), but it is accepted that this may represent less than half of the true disease burden, as there are many undiagnosed people living with COPD (Bernd 2015).

COPD accounts for high healthcare utilisation and subsequent cost worldwide (Lopez-Campos 2016). Emergency hospital admissions for COPD exacerbations are rising annually (Steiner 2015), although timely community management can reduce many COPD emergency hospital admissions (Blunt 2013).

### Risk factors for COPD

Tobacco smoke is the largest risk factor for COPD, although other factors, including outdoor air pollution, the burning of biomass fuels, exposure to passive smoking and other noxious gases and fumes, combined with genetic disposition, maternal tobacco exposure, and childhood respiratory infections, are important contributors to disease development. Increased exposure to risk factors for COPD (with the rising tobacco epidemic in low- and middle-income countries) and increasing population longevity contribute to the heavy forecasted societal and economic burden worldwide (Lopez-Campos 2016).

Pathology, symptoms, and progress

The pathophysiological effects of COPD are chronic inflammation of the airways and irreversible lung tissue damage, resulting in reduced airflow to the lungs (Szilasi 2006). COPD is diagnosed when spirometry demonstrates airflow obstruction that is not fully reversible (Qaseem 2011). COPD is a debilitating disease that worsens over time, with frequently reported symptoms of decreased exercise capacity, dyspnoea, and leg fatigue (Butcher 2012; Houchen 2009). Patients may experience exacerbations, when the symptoms of their disease worsen in response to stimuli, such as respiratory infections and air pollution (Anzueto 2007; White 2003). The frequency of exacerbations is variable, but tends to increase as the disease progresses (Hoogendoorn 2010). Exacerbations are one of the main causes of worsening prognosis, often leading to hospital admission, particularly for those with severe disease (Anzueto 2007). Hospital admission in those with COPD is associated with poor prognosis, lower quality of life, high post-admission mortality, and high 90-day re-admission rates (Alamagro 2010; Anzueto 2007; Steiner 2016).

Comorbidities

COPD co-morbidities are common, and include cardiovascular disease, diabetes, asthma, anxiety, and depression (Eisner 2010; Mannino 2015;Schneider 2010). These increase the overall burden to the individual, as well as to families, caregivers, and health and social care services, a burden that is increasing worldwide (GBD 2015).

COPD Management

Other than the treatment and prevention of exacerbations, therapy during stable COPD is aimed at reducing progression and managing symptoms. All patients should be offered smoking cessation advice at regular intervals, as this is the main disease-modifying treatment available at present (Vogelmeier 2017). Pharmacotherapy consists of short-acting and long-acting bronchodilator inhalers, with steroid inhalers added to manage symptoms and prevent exacerbations. Patients with more severe breathlessness (usually Medical Research Council (MRC) Grade 3 or worse, dyspnoea) are eligible for pulmonary rehabilitation (PR). All patients should receive influenza and pneumococcal vaccines, and advice about self-management (Bolton 2013; Vogelmeier 2017). In practice, evidence from the literature suggests that patients are often not appropriately managed, with over and under prescription of inhalers, and under-utilisation of other effective services (Perez 2011; Price 2014).

Details of pulmonary rehabilitation

Pulmonary rehabilitation (PR) is a structured multidisciplinary programme 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’ (Bolton 2013). One of the main aims of PR is to increase physical activity for those with COPD (Spruit 2013). Increasing physical activity requires behaviour change. PR emphasizes behaviour change through patient and interdisciplinary collaboration, and it is this collaborative approach that is key in achieving increasing physical activity in patients with COPD, over exercise-only interventions (Spruit 2015). PR programmes are commonly delivered to groups of patients in community or hospital settings, although other models of delivery, including home-based programmes, are also available. Evidence that supports home-based PR as an alternative, yet effective PR approach for COPD patients, is an emerging field (Grosbois 2015; Mohammadi 2013).

Recommendations state that for optimal effectiveness, programmes should run twice weekly for a minimum of six weeks (Bolton 2013; Vogelmeier 2017), although programmes that run twice weekly for a minimum for eight weeks are recommended by other guidelines (Rochester 2015).

Randomised controlled trials (RCTs) show that PR is effective in improving exercise capacity, breathlessness, functional independence, and psychological well-being (McCarthy 2015; Zoeckler 2014). PR also reduces healthcare utilisation, including hospital admissions and length of stay (California PRC Group 2004; Hui 2003). The effect on hospital admission appears to be related to the comprehensiveness of individual programmes, which is often variable (Moore 2016; Puhan 2016). Economic analyses suggest it is also cost-effective, at GBP 2000 to GBP 8000 per Quality-Adjusted Life Year (QALY), thus overall, it is an essential component in the management of COPD (Williams 2011).

Referral to PR

The American College of Physicians, American College of Chest Physicians, American Thoracic Society, and European Respiratory Society COPD clinical guidelines recommend PR for all symptomatic COPD patients with a Forced Expiratory Volume in one second ($FEV_1$) less than 50% predicted (Qaseem 2011). Recommendations are that PR is undertaken at a time of disease stability (Bolton 2013; Rochester 2015; Vogelmeier 2017), yet undertaking PR soon after an acute exacerbation of COPD is clinically valuable (Rochester 2015), particularly when hospitalisation for an exacerbation was required (Bolton 2013; Puhan 2016).

In European countries, most referrals to PR are undertaken by healthcare practitioners from primary, community, secondary, and tertiary care settings, whilst in North America, self-referral is relatively common (Spruit 2014). Referral to PR remains persistently poor worldwide, regardless of the availability of PR (Camp 2015; McNaughton 2016; Steiner 2015; Wadell 2013). In their New Zealand audit, McNaughton 2016 reported that only 2% of the expected COPD population was referred to PR, whilst in England and Wales, 68,000 (15.2%) of 446,000 eligible patients were referred (Steiner 2015). Reasons given for low patient referral by healthcare practitioners included a lack of knowledge about programme content, challenging or uncertain referral process (or both), time pressures for the prospective referrer, uncertainty of whose role it was to refer, and anticipated access difficulties for patients (Foster 2016; Harris 2008a; Johnston 2013). Conclusions from these studies were that these difficulties disempowered the healthcare practitioner (HCP), and that increasing knowledge of PR and its benefits would improve referral rates.

Attendance at pulmonary rehabilitation

Following referral, patients are required to attend a PR reassessment. This is commonly completed by the PR staff and includes a full patient history, physical examination, assessment of contraindications and risk factors, such as unstable cardiovascular disease (unstable angina, unstable arrhythmias, aortic aneurysm, hypertension), or other inhibiting conditions, such as severe arthritis or neurological conditions (Bolton 2013; Spruit 2013). It is also a time during which a detailed description of the programme is provided, and discussions about individual patient goals, motivations, expectations, including barriers and capabilities, should be discussed (Vogelmeier 2017).

In the England and Wales audit, it was reported that of the 68,000 COPD patients referred, 47,020 (69%) attended pre-assessment, following which, 10% to 14.8% of patients did not enrol in PR (Steiner 2015; Steiner 2016). Keating 2011 reported that uptake of PR has traditionally been poor, with up to half of the patients offered a course, not enrolling. Reasons for patients' lack of uptake or attendance at PR included limited understanding of COPD and a high COPD symptom burden, leading to fear and a sense of loss of control (Harris 2008b; Lewis 2014). Consequently, PR is often perceived as too difficult to complete, of limited benefit, or both (Cooke 2012; Hayton 2013; Keating 2011). Additional influencing factors include the referrer (Arnold 2006; Hogg 2012), and transport

difficulties, including access to transport and cost of travel (Almadana 2014; Keating 2011).

Patients decline to attend pulmonary rehabilitation at the initial assessment stage, the first PR session, or both (Cassidy 2014; Keating 2011). Following assessment, some COPD patients are deemed ineligible for PR, and in other cases, the patient themselves chooses to decline. However, the assessment of contraindications, including unstable angina, can often be subjective (Gunes 2009). Standardising this assessment would reduce current variation and ambiguity between guidelines (Bolton 2013; Spruit 2013).

PR adherence

Studies report variable and un-sustained attendance following enrolment in a PR course, with non-completers ranging from 42% in Keating 2011 to 58% in Steiner 2016. A Swedish audit reported PR completion rates ranging between 20% and 99% (Wadell 2013).

PR adherence reporting measures vary across studies. For example, Hayton 2013 reported that 71% of patients attended at least 63% of the planned eight sessions, and an audit in New Zealand showed that 46% to 75% of attendees attended all 16 planned PR sessions (McNaughton 2016).

Factors associated with lower attendance include advancing age, being female, being from a minority ethnic group, being a current smoker, having greater breathlessness, living alone, experiencing financial hardship, long term oxygen use, having anxiety and depression, and having a reduced baseline health-related quality of life (Boutou 2014; Cassidy 2014; Fischer 2007; Hayton 2013; Hogg 2012; Keating 2011; McNaughton 2016; Sabit 2008).

Description of the intervention

The purpose of this review is to focus on interventions to improve referral, uptake, and adherence to pulmonary rehabilitation by COPD patients, which is already recommended as an effective service.

Interventions identified in scoping reviews have identified that increasing HCP knowledge, and support to COPD patients to manage co-morbidities, such as anxiety and depression, improved patient uptake to PR (Hardy 2014). A quasi-randomised trial sought to increase patient empowerment by using tablet devices with a personal training diary. Investigators observed improvements in PR adherence in this intervention group compared with usual care (Ringbaek 2016).

Interventions may use a variety of delivery platforms, including digital technologies, avatar-based technologies and videos, or more traditional, written information, paying attention to the verbal and written language used (Johnston 2013; Williams 2011). The use of 'lay' advocates, such as 'expert patients' may also play a key role.

How the intervention might work

The intervention may use a variety of direct or indirect behaviour change approaches, either separately or in combination, targeted at each step or audience. The intervention may target the patient, their HCP, partner, family members, caregivers, friends, or a combination.

Within the behaviour change approaches, it is likely the interventions will seek to address capability, opportunity, or motivation issues within each of the specified participant groups (Michie 2013). This may, for example, include increasing the opportunities to discuss or access PR programmes; it may also include strategic interventions, which enhance referral processes or increase awareness of PR programmes and their benefits. **Why it is important to do this review**

COPD is an increasing global public health issue, with a high burden of morbidity and mortality (Lozano 2012; Murray 2015). PR is a clinically effective and cost effective intervention that can reduce mortality and improve prognosis.

However, referral to pulmonary rehabilitation programmes, and uptake and adherence rates are universally low. Interventions to tackle each of these outcomes will benefit patients' physical and psychological well-being, and reduce the use of unplanned and emergency healthcare services.

There is only one similar systematic review that has been published, which investigated interventions that sought to improve the uptake and completion of pulmonary rehabilitation in COPD (Jones 2017). This systematic review included only randomised controlled trials, of which there was only one (Ringbaek 2016). They concluded that they could not make any recommendations for practice. Three UK trials are currently underway, and there are non-randomised studies available, which will inform the evidence base and warrant inclusion.

There is also a systematic review that investigated interventions that increased uptake and adherence to cardiac rehabilitation for patients with coronary heart disease, including heart failure. This review reported limited evidence supporting intervention effectiveness within this field (Karmali 2014). Similar to Jones 2017, this systematic review only included RCTs.

Given the ongoing studies within in the pulmonary rehabilitation field, and the lack of evidence reported by previous systematic reviews that only included RCTs, this proposed systematic review, which will be regularly updated to include new evidence and will have clinical benefit for those with COPD and their caregivers.

## O B J E C T I V E S

To determine the effectiveness of interventions to increase patient referral, uptake, and adherence to pulmonary rehabilitation programmes, for patients with COPD.

## M E T H O D S

### Criteria for considering studies for this review

#### Types of studies

We anticipate that there will be limited trials available, therefore, we will include a broad range of study designs including: randomised controlled trials (RCT; individual or cluster-level) and observational studies, such as non-randomised controlled trials (including controlled before-and-after studies and non-controlled, before-and-after studies). We will include studies reported in full text, those published as an abstract only, and unpublished data. We will not apply any restrictions.

#### Types of participants

##### Inclusion criteria

Interventions to improve referral, uptake, and adherence rates may be applied to healthcare professionals or patients, partners, caregivers, family, or friends of the COPD patient. Therefore, we will include studies in which the population is either:

1. Healthcare practitioners (of any age) who care for patients with either stable or acute COPD, in all healthcare settings.

Or:

2. Adult participants (at least 18 years of age) who have a primary diagnosis of COPD, defined with or without spirometry confirmation. We will include studies in which the participants have any stage of COPD, with either stable disease or post-acute exacerbations, and who may have singular or multiple comorbidities. There will be no upper age limit.

Or:

3. Partners, caregivers, family, or friends (of any age), of the COPD patient, who may influence referral, uptake, or adherence to pulmonary rehabilitation.

##### Exclusion criteria

We will exclude studies in which the focus of the study is on participants receiving PR with the following primary diagnoses: asthma, bronchiectasis, lung cancer, interstitial lung disease (ILD), and congestive cardiac failure.

We will exclude interventions that are designed to target other programmes, such as maintenance pulmonary rehabilitation programmes.

#### Types of interventions

Interventions will be eligible if they aim to increase referral to, uptake of, or adherence to any type of PR programme.

Potential comparators could be usual care, or any concurrent control group that was not receiving an intervention that aimed to improve referral, uptake, or adherence to PR, or alternative intervention to improve referral/uptake/adherence.

Types of outcome measures

Primary outcomes

1. Referral to pulmonary rehabilitations programmes (as measured by referral sent or received)
2. Attendance at pulmonary rehabilitation programme assessment
3. Attendance at start of pulmonary rehabilitation programme
4. Adherence to pulmonary rehabilitation programme (as specified by study reports, but usually percent % of sessions attended)

We will present outcomes as proportions.

Rationale. In order to access and enrol in PR, patients are initially referred by a HCP, or in some circumstances, the patient may self-refer. Attending a PR assessment is the next step, which if successful, is followed by an opportunity to start a PR programme.

Adequate attendance at PR programmes is essential in order to gain clinical and psychosocial benefits, however, the literature informs us that these steps are areas of weakness in PR recruitment and retention. Interventions designed to increase uptake and sustainability at each stage are emerging. Identifying those that are effective is a key aim of the systematic review.

***Secondary outcomes***

There are no secondary outcome measures for this review.

Search methods for identification of studies

Electronic searches

We will search for randomised controlled trials in the Cochrane Airways Trials Register, which is maintained by the Information Specialist for the Group. The Cochrane Airways Trials Register contains studies identified from several sources (see Appendix 1 for details). We will conduct additional searches of the following databases, using appropriate search terms to identify both randomised and non-randomised trials:

1. Cochrane Central Register of Controlled Trials through the Cochrane Register of Studies Online (CENTRAL; search date) ;
2. MEDLINE Ovid (1946 to search date);
3. Embase Ovid (1974 to search date);
4. CINAHL EBSCO (Cumulative Index to Nursing and Allied Health Literature; all years to search date);
5. PEDro (Physiotherapy Evidence Database; search date)

We have described the proposed CENTRAL and MEDLINE search strategies in Appendix 2. We will adapt them for the other databases. We will search all databases from their inception to the present, and there will be no restriction on language of publication. We will search hand searched conference abstracts and grey literature through the CENTRAL database and the Cochrane Airways Trials Register.

We will search the following trials registries:

1. UK Clinical Trials Gateway (ukctg.nihr.ac.uk)
2. US National Institutes of Health Ongoing Trials Register ClinicalTrials.gov (www.clinicaltrials.gov/)
3. World Health Organization International Clinical Trials Registry Platform (ICTRP; apps.who.int/trial search/)

Searching other resources

We will check the reference lists of all primary studies and review articles for additional references. We will search relevant manufacturers' websites for study information.

We will search for errata or retractions from included studies published in full text on PubMed and report the date this was done in the review.

Data collection and analysis

Selection of studies

Two review authors (JY and RJ) will independently screen the titles and abstracts of the search results and code them as 'retrieve' (eligible or potentially eligible or unclear) or 'do not retrieve'. We will retrieve the full-text study reports of all potentially eligible studies, and two review authors (JY and RA) will independently screen them for inclusion, recording the reasons for exclusion of ineligible studies. We will resolve any disagreement through discussion, or if required, we will consult a third review author (PA). We will identify and exclude duplicates and collate multiple reports of the same study, so that each study, rather than each report, is the unit of interest in the review. We will record the selection process in sufficient detail to complete a PRISMA flow diagram and 'Characteristics of excluded studies' table (Moher 2009).

Data extraction and management

We will use a pre-designed data collection form for these study characteristics and outcome data, which will be piloted on at least one study in the review.

1. Methods: study design, aim of study, total duration of study, details of any 'run-in' period, number of study centres and location, study setting, withdrawals, and date of study. Study inclusion and exclusion criteria
2. COPD patients: N, mean age, age range, gender, severity of condition, diagnostic criteria, baseline lung function, smoking history, medication, prior history of PR
3. Healthcare practitioner: N, mean age, gender, job role, length of time in job role, contracted hours in job role, prior academic experience, knowledge of and experience with PR
4. Interventions: type of behaviour change intervention, duration of intervention and comparator, description of target PR service
5. Outcomes: primary and secondary outcomes specified and collected, and time points reported
6. Notes: funding for studies, and notable conflicts of interest of trial authors.

Two review authors (JY and RJ) will independently extract outcome data from included studies. We will note in the 'Characteristics of included studies' table if outcome data were not reported in a usable way. We will resolve disagreements by consensus, or by involving a third review author (PA). One review author (JY) will transfer data into the Review Manager 5 file (RevMan 2014). We will double-check that data are entered correctly by comparing the data presented in the systematic review with the study reports. A second review author (AE) will spot-check study characteristics for accuracy against the study report.

Assessment of risk of bias in included studies

Two review authors (JY and RJ) will independently assess risk of bias for each study using the criteria outlined in the *Cochrane Handbook for Systematic Reviews of Interventions* (Higgins 2011). We will resolve any disagreements by discussion or by involving another author (PA). We will assess the risk of bias according to the following domains:

1. random sequence generation;
2. allocation concealment;
3. blinding of participants and personnel;
4. blinding of outcome assessment;
5. Incomplete outcome data; 6. selective outcome reporting;
7. Other bias.

We will judge each potential source of bias as high, low, or unclear, and provide a quote from the study report and a justification for our judgement in the 'Risk of bias's table. We will summarise the risk of bias judgements across different studies for each of the domains listed. We will consider blinding separately for different key outcomes where necessary (e.g. for unblinded outcome assessment, risk of bias for objectively recorded PR attendance may be different than for patient-reported attendance). Where information on risk of bias relates to unpublished data or correspondence with a trialist, we will note this in the 'Risk of bias's table.

When considering treatment effects, we will take into account the risk of bias for the studies that contribute to that outcome.

Methodological quality or risk of bias for non-randomised studies will be assessed using the ROBINS-I tool (Sterne 2016).

When including non-randomised studies, we will assess whether the authors have accounted for potential confounding factors including characteristics of the patients (e.g. age, sex, ethnicity, smoking status, severity of disease, co-morbidities, prior attendance at PR, caring responsibilities, distance from programme) and characteristics of the healthcare professionals (type, experience, age, academic history).

Assessment of bias in conducting the systematic review

We will conduct the review according to this published protocol, and justify any deviations from it in the 'Differences between protocol and review' section of the systematic review.

Measures of treatment effect

We will analyse dichotomous data as odds ratios (OR), and continuous data as the mean difference (MD) or standardised mean difference (SMD).

We will undertake meta-analyses of RCTs and CCTs only when this is meaningful; that is, if the treatments, participants, outcomes, and the underlying clinical question are similar enough for pooling to make sense.

We will use RevMan 5 software to calculate pooled effect sizes, to test for heterogeneity, and to perform subgroup analysis (RevMan 2014).

We will only combine RCTs and CCTs if there is minimal clinical and methodological diversity between the controlled studies.

If there is large heterogeneity, we will explore reasons for it, including undertaking subgroup analyses of the RCTs and CCTs separately.

We will use a narrative format to describe skewed data (for example, as medians and interquartile ranges for each group).

For non-controlled before and after studies we intend to describe the presence of the study and describe the results together with caveats about the lack of control group.

It is likely that only end point studies will be available.

Unit of analysis issues

The unit of analysis will be the patient, and/or the healthcare practitioner. We will only meta-analyse data from cluster-RCTs if the available data have been adjusted (or can be adjusted), to account for the clustering. For cluster-randomised trials, we will make adjustments to the sample sizes for each intervention, based on the method described in the *Cochrane Handbook for Systematic Reviews of Interventions* ( Higgins 2011).

Dealing with missing data

We will contact investigators or study sponsors to verify key study characteristics and obtain missing numerical outcome data where needed (e.g. when a study is identified as an abstract only). When this is not possible, and the missing data are thought to introduce serious bias, we will take this into consideration in the GRADE rating for affected outcomes.

When we identify relevant studies of mixed populations with no subgroup data, we will contact the study authors to request them. If we are still unable to acquire these data, and if less than 80% of the participants are from the population of interest, we will describe these studies in a narrative format, but exclude them from metaanalyses.

Assessment of heterogeneity

If appropriate we will use the I2 statistic to measure heterogeneity among the studies in each analysis. We will consider an $I_2$ value greater than 50% to indicate substantial statistical heterogeneity, we will report it and explore the possible causes by pre-specified subgroup analysis (see below).

Assessment of reporting biases

If we are able to pool more than 10 studies, we will create and examine a funnel plot to explore possible small study and publication biases.

Data synthesis

We will use a random-effects model and perform a sensitivity analysis with a fixed-effect model (if appropriate).

'Summary of findings' table

We will create a 'Summary of findings' table with the following outcomes: referral to pulmonary rehabilitations programmes, attendance at PR programme assessment, attendance at start of PR programme, and attendance for the duration of PR programme.

We will use the five GRADE considerations (risk of bias, indirectness, consistency of effect, imprecision, and publication bias) to assess the quality of a body of evidence as it relates to the studies that contribute data for the pre-specified outcomes. We will use the methods and recommendations described in Section 8.5 and Chapter 12 of the *Cochrane Handbook for Systematic Reviews of Interventions* (Higgins 2011), and GRADEpro software (GRADEpro GDT). We will justify all decisions to downgrade the quality of studies in footnotes, and we will make comments to aid the reader's understanding of the review where necessary.

Subgroup analysis and investigation of heterogeneity

We plan to carry out the following subgroup analyses where possible:

1. Type of referring healthcare practitioner (nurse, doctor, other)

Rationale: the type of healthcare practitioner could influence whether patients are referred, and the likelihood of uptake and adherence after referral.

2. Origin of referral (self, community, hospital)

Rationale. Motivation for adherence and completion may vary according to who made the referral.

3. Pulmonary rehabilitation programme setting (home versus centre-based)

Rationale. Perceived convenience of attending has been highlighted as a barrier to attendance in qualitative studies. Therefore, the setting could influence uptake, adherence, or completion.

4. Patient age (up to 65 years, over 65 years)

Rationale. Patient age and working status are reported to be an influencing characteristic, particularly in adherence. The age cutoff is based on approximate age for retirement.

5. COPD severity (as determined by stable disease or post exacerbation)

Rationale. Motivation to attend and complete may differ according to whether the patient has had a recent exacerbation.

We will use the following outcomes in subgroup analyses:

1. Referral to PR programmes (as measured by study reports);
2. Attendance at PR programme assessment (as measured by study reports);
3. Attendance at start of PR programmes (as measured by study reports);
4. Adherence to PR programmes (as measured by study reports).

We will use the formal test for subgroup interactions in Review Manager 5 (RevMan 2014).

Sensitivity analysis

We will undertake sensitivity analyses, where possible to

- compare the results from a fixed-effect model with the random effects models;
- restrict the analyses to those with an active comparator only;
- if only non-randomised controlled clinical trials are available, remove studies that are at 'serious' or 'critical' risk of bias, according to the ROBINS-I tool

We will exclude RCT studies with high risk of bias (two or more domains judged to be at high risk of bias).

A C K N O W L E D G E M E N T S

The Background and Methods sections of this protocol are based on a standard template used by Cochrane Airways.

Chris Cates was the Editor for this review and commented critically on the review.

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Appendix 1. Sources searched for the Cochrane Airways Trials Register

Electronic searches: core databases

| **Database** | **Frequency of search** |
|---|---|
| CENTRAL (crso.cochrane.org/) | Monthly |
| MEDLINE Ovid | Weekly |
| Embase Ovid | Weekly |
| PsycINFO Ovid | Monthly |

| | |
|---|---|
| CINAHL EBSCO | Monthly |
| AMED EBSCO | Monthly |

**Handsearches: core respiratory conference abstracts**

| Conference | Years searched |
|---|---|
| American Academy of Allergy, Asthma and Immunology (AAAAI) | 2001 onwards |
| American Thoracic Society (ATS) | 2001 onwards |
| Asia Pacific Society of Respirology (APSR) | 2004 onwards |
| British Thoracic Society Winter Meeting (BTS) | 2000 onwards |
| Chest Meeting | 2003 onwards |

*(Continued)*

| | |
|---|---|
| European Respiratory Society (ERS) | 1992, 1994, 2000 onwards |
| International Primary Care Respiratory Group Congress (IPCRG) | 2002 onwards |
| Thoracic Society of Australia and New Zealand (TSANZ) | 1999 onwards |

Appendix 2. Database search strategies

CENTRAL (Cochrane Register of Studies Online)

#1 MESH DESCRIPTOR Pulmonary Disease, Chronic Obstructive EXPLODE ALL TREES
#2 MESH DESCRIPTOR Bronchitis, Chronic
#3 (obstruct*) near3 (pulmonary or lung* or airway* or airflow* or bronch* or respirat*)
#4 (COPD OR COAD OR COBD OR AECOPD):TI,AB,KW
#5 #1 OR #2 OR #3 OR #4
#6 MESH DESCRIPTOR Rehabilitation EXPLODE ALL TREES
#7 MESH DESCRIPTOR Respiratory Therapy EXPLODE ALL TREES
#8 MESH DESCRIPTOR Physical Therapy Modalities EXPLODE ALL TREES
#9 (rehabilitat* or fitness* or exercis* or train* or physiotherap* or
(physical* NEXT therap*)):TI,AB,KY #10 #6 OR #7 OR #8 OR #9
#11 MESH DESCRIPTOR Patient Compliance EXPLODE ALL TREES
#12 MESH DESCRIPTOR Patient Acceptance of Health Care EXPLODE ALL TREES
#13 MESH DESCRIPTOR Patient Dropouts
#14 (adhere* or nonadhere* or non-adhere*):TI,AB,KY
#15 (complet* or complian* or noncomplian* or non-complian*):TI,AB,KY
#16 (refusal or refuse*):TI,AB,KY
#17 concord*:TI,AB,KY
#18 conform*:TI,AB,KY
#19 accept*:TI,AB,KY
#20 comply*:TI,AB,KY
#21 MESH DESCRIPTOR Referral and Consultation EXPLODE ALL TREES
#22 MESH DESCRIPTOR Health Promotion EXPLODE ALL TREES
#23 MESH DESCRIPTOR Health Knowledge, Attitudes, Practice
#24 referral
#25 referred:TI,AB,KY
#26 promot*:TI,AB,KY
#27 (uptake or up-take):TI,AB,KY
#28 (increase* NEAR participat*):TI,AB,KY
#29 attend*:TI,AB,KY
#30 engage*:TI,AB,KY
#31 #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR
#23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30
#32 #5 AND #10 AND #31

MEDLINE Ovid

1. exp Pulmonary Disease, Chronic Obstructive/
2. Bronchitis, Chronic/
3. (obstruct$ adj3 (pulmonary or lung$ or airway$ or airflow$ or bronch$ or respirat$)).tw.
4. (COPD or COAD or COBD or AECOPD).tw.
5. or/1-4
6. exp Rehabilitation/
7. exp Respiratory Therapy/
8. exp Physical Therapy Modalities/
9. (rehabilitat$ or fitness$ or exercis$ or train$ or physiotherap$ or physical$ NEXT therap$).tw.

10. or/6-9
11. exp Patient Compliance/
12. exp Patient Acceptance of Health Care/
13. Patient Dropouts/
14. (adhere$ or nonadhere$ or non-adhere$).tw.
15. (complet$ orcomplian$ or noncomplian$ or non-complian$).tw.
16. (refusal or refuse$).tw.
17. concord$.tw.
18. conform$.tw.
19. accept$.tw.
20. comply$.tw.
21. exp Health Promotion/
22. exp "Referral and Consultation"/23. Health Knowledge, Attitudes, Practice/ 24. referral.tw.
25. referred.tw.
26. promot$.tw.
27. (uptake or up-take).tw.
28. (increase$ adj3 participat$).tw.
29. attend$.tw.
30. engage$.tw.
31. or/11-30
32. 5 and 10 and 31
33. (controlled clinical trial or randomized controlled trial).pt.
34. (randomized or randomised).ab,ti.
35. placebo.ab,ti.
36. dt.fs.
37. randomly.ab,ti.
38. trial.ab,ti.
39. groups.ab,ti.
40. or/33-39
41. cohort studies/ or longitudinal studies/ or follow-up studies/ or prospective studies/ or retrospective studies/ or cohort.ti,ab. orlongitudinal.ti,ab. or prospective.ti,ab. or retrospective.ti,ab.
42. Case-Control Studies/ or Control Groups/ or Matched-Pair Analysis/ or ((case* adj5 control*) or (case adj3 comparison*) or controlgroup*).ti,ab,kw.
43. comparative study.pt.
44. (pre test or pretest or post test or posttest or preintervention or postintervention).tw.
45. (case$ adj3 series).tw.
46. or/41-45
47. 40 or 56
48. 32 and 47
49. Animals/
50. Humans/
51. 49 not (49 and 50)
52. 48 not 51

## CONTRIBUTIONS OF AUTHORS

JY will co-ordinate the review; design search strategies in collaboration with Cochrane Airways Group's Information Specialist; will undertake study selection, data extraction, and entry into RevMan 5; will contribute to data analysis and interpretation of data.

RJ will undertake study selection, data extraction, and entry into RevMan 5; will contribute to data analysis and interpretation of data.

AE will spot-check study characteristics for accuracy against the study report and will contribute to the interpretation of data.

PA will be the third reviewer of included studies in the case of uncertainty. PA will also provide a clinical perspective and general advice on the review.

KJ will provide a methodological perspective, a clinical perspective, and general advice on the review; KJ will be the third reviewer of 'risk of bias' issues in the case of uncertainty.

All authors contributed to the reading, writing, and approval of this protocol.

The review will be updated by all authors.

## DECLARATIONS OF INTEREST

JY: none known

RJ: none known

PA: none known


## SOURCES OF SUPPORT

Internal sources

- University of Birmingham, UK. Salary and expert support
- Anglia Ruskin University, UK. Salary support

External sources

- KJ is part funded by the Collaboration for Leadership in Applied Health Research and Care West Midlands, UK

## Appendix 4: Initial email to practice manager

### Understanding barriers and enablers for Doctors, Nurses and Health Care Assistants in primary care when referring patients with Chronic Obstructive Pulmonary Disease (COPD) to Pulmonary Rehabilitation: a qualitative study: Email PM invitation.

Subject**:** Remunerated research study: The University of Birmingham are seeking your help in understanding your experiences in practice of supporting patients with COPD.

Dear Practice Manger,

We at the University of Birmingham are keen to reduce primary care workload by increasing the self-management ability of those with COPD and keeping them out of hospital. Pulmonary rehabilitation is an intervention that is proven to be effective and can help.

We would like to talk to a range of primary care staff including doctors, practice nurses, nurse practitioners and health care assistants who are currently involved in caring for patients with COPD in a one off interview, for which there will be financial reimbursement to your practice.

The aims of the research are to understand what the barriers and enablers are in referring patients with COPD to pulmonary rehabilitation (PR) and to identify what interventions could be adopted within primary care setting to enhance PR referral for COPD patients.

The research has full University of Birmingham ethical approval and Health Research Authority approval. The lead investigator is an NHS employee and has a letter of access which has been issued from NHS England.

Within the next few weeks we plan to email and invite primary care staff that are working in your practice to take part in this research. A participation information sheet has been attached for your reference.

Thank you for taking the time to read this email and should you have any queries please don't hesitate to get in touch.

Kind Regards

Jane Young

**(RN, BSc Hon, MSc, PG Cert Ed)**

Senior Lecturer in Community Nursing, Department of Nursing and Midwifery, Anglia Ruskin University.
PhD Student – University of Birmingham, Department of Applied Health Research
T:
M:
or or

## Appendix 5: Initial email to PHCPs

### Understanding barriers and enablers for primary care health staff when referring patients with Chronic Obstructive Pulmonary Disease (COPD) to Pulmonary Rehabilitation: a qualitative study: Covering email invitation

Subject: Remunerated research study: The University of Birmingham are seeking your help in understanding your experiences in practice of supporting patients with COPD.

Dear Colleague,

We at the University of Birmingham are keen to reduce primary care workload by increasing the self-management ability of those with COPD and keeping them out of hospital. Pulmonary rehabilitation is an intervention that is proven to be effective and can help.

We would like to talk to a range of primary care staff including doctors, practice nurses, nurse practitioners and health care assistants who are currently involved in caring for patients with COPD in a one off interview, for which there will be financial reimbursement to your practice.

If you are interested in taking part and would like to find out more, please refer to the attached participation information sheet and kindly complete and return the reply slip.

Thank you for taking the time to read this email and should you have any queries please don't hesitate to get in touch.

Kind regards

Jane Young

**(RN, BSc Hon, MSc, PG Cert)**

Senior Lecturer in Community Nursing, Department of Nursing and Midwifery, Anglia Ruskin University.
Advanced Nurse Practitioner, Cornford House Surgery Cambridge.
PhD Student – University of Birmingham, Department of Applied Health Research
T:
M:
or or

## Appendix 6: Follow up email to PHCPs

### Understanding barriers and enablers for Doctors, Nurses and Health Care Assistants in primary care when referring patients with Chronic Obstructive Pulmonary Disease (COPD) to Pulmonary Rehabilitation: a qualitative study: Email invitation, reminder.

Subject**: REMINDER**: Remunerated research study: The University of Birmingham are seeking your help in understanding your experiences in practice of supporting patients with COPD.

Dear Colleague,

An email was sent 2 weeks ago highlighting a new research study that we at The University of Birmingham are undertaking in your area. We would be very grateful if you were able to support this important research.

We are keen to reduce primary care workload by increasing the self-management ability of those with COPD and keeping them out of hospital. Pulmonary rehabilitation is an intervention that is proven to be effective and can help.

We would like to talk to a range of primary care staff including doctors, practice nurses, nurse practitioners and health care assistants who are currently involved in caring for patients with COPD in a one off interview, for which there will be financial reimbursement to your practice.

If you are interested in taking part and would like to find out more, please refer to the attached participation information sheet and kindly complete and return the reply slip.

Thank you for taking the time to read this email and should you have any queries please don't hesitate to get in touch.

Kind Regards

Jane Young

**(RN, BSc Hon, MSc)**

Senior Lecturer in Community Nursing, Department of Nursing and Midwifery, Anglia Ruskin University.
Advanced Nurse Practitioner, Cornford House Surgery, Cambridge.
PhD Student – University of Birmingham, Department of Applied Health Research
T:
M:
or

## Appendix 7: Participation Information Sheet

# Understanding barriers and enablers for Doctors, Nurses and Health Care Assistants in primary care when referring patients with Chronic Obstructive Pulmonary Disease (COPD) to Pulmonary Rehabilitation: a qualitative study.

You are being invited to take part in an interview as part of a research study undertaken at the University of Birmingham. Please read this information leaflet to gain an overview of why this research is being done. If you have any questions about the study please contact Jane Young (contact details below).

**What is the purpose of this study?**

COPD places a significant burden upon patients and health care services. Exacerbations of the disease account for significantly high health care utilisation and financial cost, often resulting in emergency hospital admissions.

Pulmonary rehabilitation (PR) is both a clinically and cost effective intervention for patients with COPD. Nationwide referral and patient acceptance of PR referral is much lower than expected when measured against COPD prevalence. Whilst there is research that offers insight into the demographics of patients likely to accept and engage with PR, there has been little research exploring the views of primary care workers. The views of these individuals are extremely important in order that we can understand and identify barriers and enablers that exist when considering or referring patients with COPD to local pulmonary rehabilitation programmes.

**Why have I been chosen?**

We hope to interview 25-30 health care workers, including GPs, practice nurses/advanced nurse practitioners and health care assistants (HCA) who care for patients with COPD. This would typically include nurses and HCAs that conduct COPD annual reviews, administer Flu/Pneumovax immunisation and/or undertake spirometry. All invited health care workers will be working in general practices across Cambridgeshire and the West Midlands.

**What do I have to do?**

If you agree to take part, we would like to conduct a one to one interview with you at a time and location convenient to you such as your practice. Ideally we would prefer a face to face interview but If you would prefer the interview to be conducted over the telephone this can be arranged. We expect each interview to last approximately 30 minutes. The interviews will be tape recorded. After which they will be transcribed and sent back to you for verification. Your practice will be reimbursed for your participation.[1]

**Do I have to be interviewed?**

Participation in the study is entirely voluntary. If you decide to take part we will ask you to sign a consent form. If you decide to take part but later change your mind, you are free to withdraw at any

[1] *£80/hour for GPs, £21.96/hour for nurses, and £10.66/hour for health care assistants.

time prior to the undertaking of an interview and/or prior to the return of your verified transcript, without giving a reason. However, once the transcript has been verified and returned it will not be possible to remove your contribution.

**What are the possible benefits of taking part?**

At a time with increasing pressure upon primary care services and a growing need to encourage self-management for patients with COPD, understanding the barriers and enablers to uptake and referral to PR are important. The data collected from this research study, will inform interventions, designed to support the primary care PR discussion and subsequently increase current referral numbers to PR. This will ultimately reduce symptoms, emergency hospital admissions and mortality, thus improving health and well-being for patients.

**Will my participation in the study be kept confidential?**

Your name will not be on the recording and we will remove your name from the interview transcripts to keep your identity confidential. Direct quotes may be used in publications but these will be numbered and any information which could identify you will be removed.
Nothing that you say will be fed back to other staff involved at your practice or organisation.

**Precautions**

In keeping with professional code of conduct should there be any patient or staff safeguarding concerns raised during the interviews then appropriate action will need to be taken and escalation of concerns to ensure participants and others (if necessary) safety is maintained. This may include reporting to and following local healthcare providers trust policy and/or the National Whistle Blowing Helpline.

**Data Protection Act 1998**

The information you give us in the interviews will only be used for the purposes of the study. The information will be kept securely for a period of 10 years after the study ends and then will be destroyed.

**Where can I find more information?**

For more information please contact: **Jane Young (RN, BSc Hon, PG Cert Ed, MSc)**

Senior Lecturer in Community Nursing, Department of Nursing and Midwifery, Anglia Ruskin University.

PhD Student – University of Birmingham, Department of Applied Health Research

T: M:
or

**Appendix 8: Participant Reply Slip**

Practice ID: ____ Participant ID: _____

[For office use only]

.....

Please tick one of these boxes:

I would like to take part in the study ☐ I would prefer **not** to take part in the study ☐

(It would be very helpful if you could provide a reason for why you do not wish to take part in the box below):

| |
|---|
| |

2. If you do wish to take part, please fill in the following details

Dr/Mr/Mrs/Miss ☐ Professional Role (GP/Nurse/HCA) ☐

First name ☐ Gender ☐

Surname ☐

Practice Name, Area & type of practice (Rural/Urban) ☐

Telephone number (include area code) ☐

Mobile telephone number ☐

Preferred email address ☐

Approximate number of COPD patients seen per week: 0-10 ☐ 10-20 ☐ 20 + ☐

Please indicate your approximate current referral's to Pulmonary Rehabilitation Programmes

Rarely (<1 a month) ☐ Sometimes (< 1/2 a week) ☐ Often ( > 2 a week) ☐

Please indicate if you have undertaken specific respiratory training & at what level (e.g.: Spirometry/ Respiratory Diploma

| |
|---|
| |

3. In order for us to arrange an appointment, please tick one of the following:

I am happy to be contacted by telephone Yes ☐ No ☐

I am happy to be contacted by email Yes ☐ No ☐

PLEASE RETURN THIS FORM ELECTRONICALLY TO

Jane Young at: [redacted]

**THANK YOU FOR TAKING THE TIME TO REPLY!**

## Appendix 9- Topic guide for interviews

## Understanding barriers and enablers for primary care health staff when referring patients with Chronic Obstructive Pulmonary Disease (COPD) to Pulmonary Rehabilitation: a qualitative study. Topic Guide for Interviews.

**Interview Objectives:**

- To explore the experience of primary care practitioners in relation to referral of patients with COPD to pulmonary rehabilitation.
- To gain an understanding of the main perceived barriers and enablers for referring COPD patients for pulmonary rehabilitation.
- To gain insight into whether any patient characteristics influence whether or not people with COPD are referred for pulmonary rehabilitation.

Understanding current behaviour

To start the discussion, participants will be asked to talk about their experiences of managing patients with COPD in primary care and any experience of referral for pulmonary rehabilitation

1/ could you tell me in what context do you currently see COPD patients? (Exposure to population/target intervention within working role e.g. planned – annual review/flu jab or unplanned - exacerbation)

2/ on average how many COPD patients do you think you see per week?

3/ Do you currently refer to PR programmes?

Capability, Opportunity, Motivation – including External Context

4/ what is your understanding/view surrounding Pulmonary Rehabilitation programs in general? And in relation to your local provider?

5/ Do you think pulmonary rehabilitation is beneficial for patients? In what ways? Or why not?

6/ how easy or difficult is it for you to refer to your local PR provider?

(Egg. Is it your role to refer? When is it appropriate to refer COPD patients to PR?)

7/ what motivates you to refer patients to PR?

(E.g. Do patients/carers ever ask you about pulmonary rehabilitation? Does the post PR patient summary motivate you, are you reminded by prompts or other guidance?)

8/ What do you think stops you from referring patients to pulmonary rehabilitation?

Images Alternating images (between 1-4)

9/ If this person was in your COPD patient, would you consider discussing PR with them? Why? Why not?

Future

10/ is there anything that you think could improve the primary care discussion surrounding PR and/or encourage you to make referrals to PR?

Possible prompts: Do you think a short video clip would help you motivate patients? Or computerised prompts to follow? Or a further telephone call to encourage patients? Or a firm appointment slot to discuss PR with them?

## Appendix 10 – COPD images for use within interviews

1/

Via Christi Health (2013) *COPD patient benefits from Via Christi Home Medical services* Available at: https://i.ytimg.com/vi/Pkl-1SMGpvo/maxresdefault.jpg Photograph from Video Available at: https://www.youtube.com/watch?v=Pkl-1SMGpvo [Accessed 21st November 2016]

2/

Lifebeginsat50mm (No date) an old lady selling flowers by the bus stop (Photograph online) Available at https://c2.staticflickr.com/4/3559/3488428578_b20dd7cdef_b.jpg [Accessed 21st November 2016].
Sourced Google images labelled for non-commercial reuse

3/

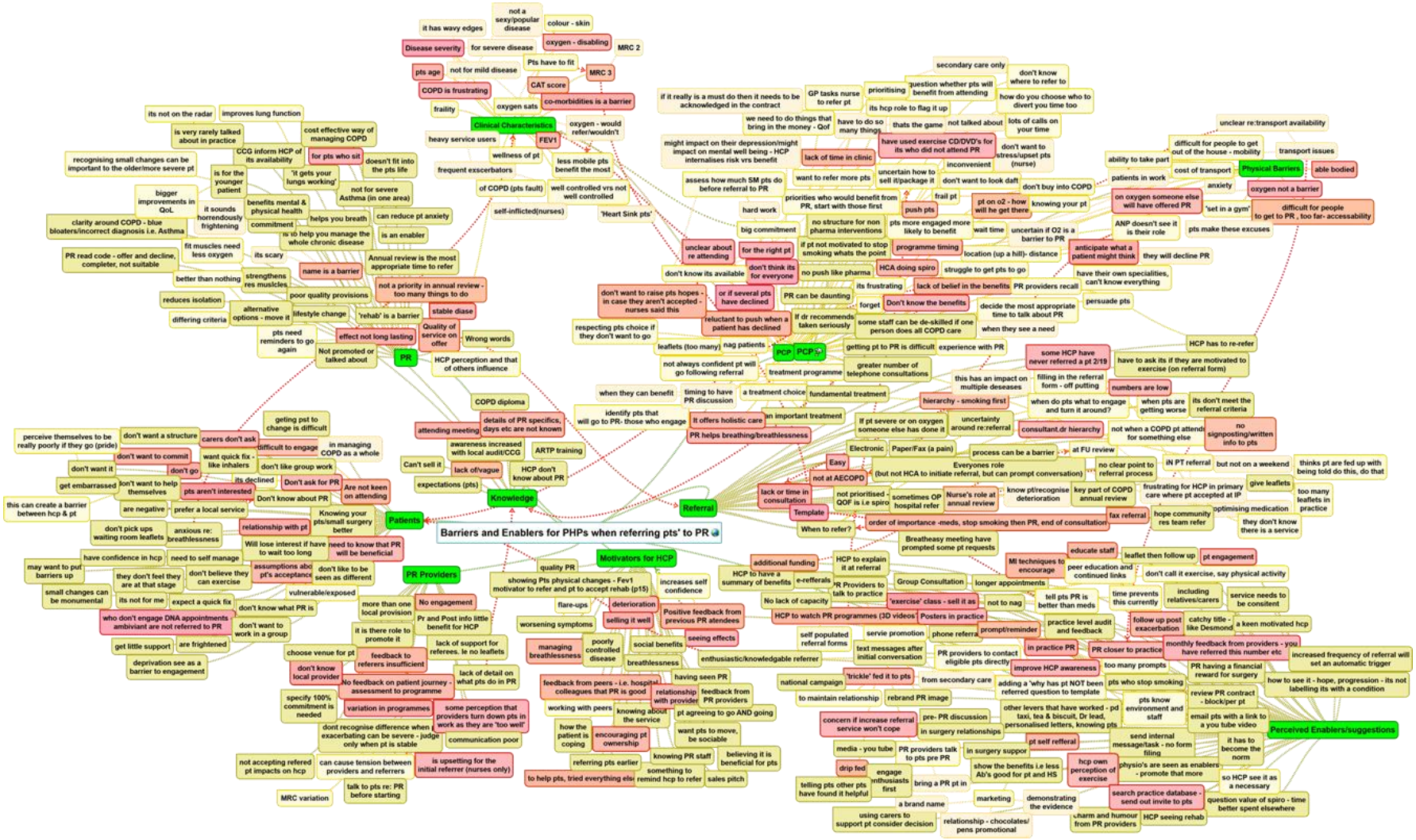
American Lung Association (2011) *COPD patient warns against smoking.* Available at: https://i.ytimg.com/vi/dzpBCymhSp0/maxresdefault.jpg Photograph from Video Available at: https://www.youtube.com/watch?v=dzpBCymhSp0 [Accessed 21st November 2016]

Advice sought from the Copyright and Licensing Advisor at UoB, to ensure that any use of third party materials falls within acceptable levels of risk, within the permitted exceptions available under UK copyright law. The images above are within these parameters.

Written permission given by individual in photograph (14th November 2016)

4/

# Appendix 11: Inductive qualitative themes



**Appendix 12: Standards for Reporting Qualitative Research: chapter 3)**

| | |
|---|---|
| Title | Pg. 1 of paper |
| Abstract | Pg. 1 of paper |
| Introduction: problem formation<br>Purpose or research question | Pg. 1 and 2 of paper |
| Methods: qualitative approach and research paradigm | Described in title and abstract (pg. 1) and |
| Researcher characteristics and reflexivity | Pg. 8 |
| Context | Pg. 2of paper |
| Sampling strategy | Pg. 2 of paper |
| Ethical issues pertaining to human subjects | |
| Data collection methods | Pg. 2 and 3 |
| Data collection instruments and technologies | Pg. 2 and 3 |
| Units of study | Pg. 3 |
| Data processing | Pg. 3 |
| Data analysis | Pg. 3 |
| Techniques to enhance trustworthiness | Interview recording and verbatim transcription checked by JW, participants invited to undertake member checking, in team validation of emergent themes pg. 3 |
| Results and Findings: Synthesis and interpretation | Pg. 3- 8 |
| Links to empirical data | Participants quotes – pg. 4- 7 |
| Discussion: Integration with prior work, implications, transferability | Pg. 7 - 9 |
| Limitations | Pg. 8 |
| Other: conflicts of interest | Pg. 9 |
| Funding | Pg. 9 |

**Appendix 13: Participation Information Sheet: Online survey**

Electronic 'Online Survey' Eligibility/Consent and PIS information.

Eligibility Criteria: Are you a health care professional who works and cares for patients with COPD in General Practice?

Answer Yes No – no further engagement (ineligible)

**Next Screen** Participant Information Sheet

Pulmonary Rehabilitation (PR) is an intervention for patients with COPD, yet referral numbers are low. We want to understand what helps and what stops you referring patients with COPD to PR. This will enable us to consider possible interventions to support your clinical practice. This study forms part of a PhD award, being supervised by Dr Rachel Jordan and has been awarded Ethical approval from the University of Birmingham.

As a Primary Care Respiratory Society (PCRS) member you are being asked to complete a questionnaire on your general practice PR referral experiences for patients with COPD. The questionnaire is completely anonymous. As a token of appreciation there is an opportunity for you to enter a prize draw and win an Apple IPad. In order to enter the competition you will need to submit your contact email address on the final page of the questionnaire. This is 'unlinked' to your questionnaire data, meaning your answers will remain anonymous. If you wish to remove your 'opt in' to the competition after you have submitted your email details, please email the study contact (below).

Please **do not** share the link with primary care colleagues and please only complete one questionnaire.

**Some guidance notes:**

Please do not think too long about the questions and please give the answer that immediately comes to mind. The questionnaire is made up of 4 elements and should take no more than 15 minutes to complete. You do not have to answer the whole questionnaire at once as there is no timing-out within the survey, meaning you can return to it at a later stage.

Your consent will be implied through the completion of this questionnaire. You can withdraw consent at any time by failing to finish the questionnaire. All data will be anonymised and securely stored, within the University of Birmingham IT systems and in accordance with GDPR rules and policies. All submitted personal email addresses will be destroyed once the IPad winner has been notified (approximately 8 weeks after study commencement). This means that once you submit your anonymous responses you are then unable to withdraw your data from the study. The results from this study will be analysed, written up and published.

Many thanks for your support with this research and completing the questionnaire. If participants have any queries or concerns about this study please contact: Jane Watson (RN, BSc Hon, MSc, PG Cert Ed) PhD Student – University of Birmingham, Institute of Applied Health Research email:

## Appendix 14: Survey

### General Practice Staff experiences of referring patients with COPD to PR

Thank you for taking the time to complete this questionnaire, which aims to gather perspectives from staff working in primary care. This survey is designed for us to find out some of the barriers staff face when considering referring a patient with COPD to PR so please answer the questions as honestly as you can. This should only take you around 15 minutes to complete. First, please complete the following information

| | |
|---|---|
| Geographical location of practice<br><br>(please circle) | England<br><br>North East North West Yorkshire and the Humber East Midlands West Midlands<br><br>East of England London South East South West<br><br>Scotland Wales NI |
| Profession (please circle) | GP/Trainer Practice Nurse ANP Other (ECP/HCP/Pharmacist) |
| Age (years) | 18-29 30- 39 40 – 49 50- 59<br>60 + |
| Gender | Female Male |
| What is your ethnic group? Please circle one option that best describes your ethnic group or background | **White**<br>**British**<br>English Welsh Scottish Northern Irish<br>British Irish<br>Gypsy, Traveller or Irish Traveller<br>Any other White background:<br><br>background:<br><br>**Mixed/ Multiple ethnic groups**<br>White and Black Caribbean<br>White and Black African<br>White and Asian<br>Any other Mixed/ Multiple ethnic background:<br><br>group:<br><br>**Black/ African/ Caribbean/Black British**<br>African<br>Caribbean<br>Any other Black/ African/ Caribbean background<br><br>**Asian/ Asian**<br><br>Indian<br>Pakistani<br>Bangladeshi<br>Chinese<br>Any other Asian<br><br>**Other ethnic group**<br>Arab<br>Any other ethnic |
| Do you see patients with COPD for (please circle as many as relevant) | Acute management Chronic management Both<br>Neither |
| No. of years in general practice | Years: …….. Months: …… |
| Respiratory Qualifications | None COPD Diploma Asthma Diploma ARTP Spirometry<br>Other |

| | |
|---|---|
| Do you currently refer patients with COPD to pulmonary Rehabilitation? | Yes - If yes - Weekly Monthly Less than monthly<br><br>No - if no please explain why<br>…… |

This questionnaire is designed to ask you about your experiences with referring (or considering referring) patients with COPD to Pulmonary Rehabilitation and should take no more than **15 minutes** to complete. Please don't spend too long thinking about each question.

The questionnaire is made up of 4 elements. When rating your level of agreement with each phrase, please think about **all the things that might affect you being able to discuss pulmonary rehabilitation with your patients as well as refer.**

**Please indicate your level of agreement with the following statements:**

| Question list | Strongly Disagree | Disagree | Neither disagree nor agree | Agree | Strongly Agree |
|---|---|---|---|---|---|
| 1. I am aware of the content of Pulmonary Rehabilitation (PR) Programmes | 1 | 2 | 3 | 4 | 5 |
| 2. I am aware of PR programme objectives. | 1 | 2 | 3 | 4 | 5 |
| 3. I am unsure of the evidence base for PR | 1 | 2 | 3 | 4 | 5 |
| 4. I know where geographically my local PR programme is delivered | 1 | 2 | 3 | 4 | 5 |
| 5. I know when it is appropriate to refer a patient with COPD to PR | 1 | 2 | 3 | 4 | 5 |
| 6. I can answer questions patients have about PR | 1 | 2 | 3 | 4 | 5 |
| 7. I know how to contact my local PR provider | 1 | 2 | 3 | 4 | 5 |
| 8. My local PR providers regularly engage with me | 1 | 2 | 3 | 4 | 5 |
| 9. It is easy to refer a patient to PR | 1 | 2 | 3 | 4 | 5 |
| 10. I am confident my local PR provider offers a good service for my patients. | 1 | 2 | 3 | 4 | 5 |
| 11. Referral to PR is the practice nurse role | 1 | 2 | 3 | 4 | 5 |
| 12. Other General Practice staff in my practice (excluding Practice Nurse) refer patients to PR | 1 | 2 | 3 | 4 | 5 |

| | | | | | |
|---|---|---|---|---|---|
| 13. Referring patients to PR is something I have been advised to do | 1 | 2 | 3 | 4 | 5 |
| 14. I am confident in my ability to encourage patients to attend PR, even when they are not motivated | 1 | 2 | 3 | 4 | 5 |
| 15. I do not find it easy to discuss PR with patients. | 1 | 2 | 3 | 4 | 5 |
| 16. I don't believe patients will attend PR after I have referred | 1 | 2 | 3 | 4 | 5 |
| 17. Patients in work are not able to attend PR | 1 | 2 | 3 | 4 | 5 |
| 18. PR is not beneficial to patients who are breathless | 1 | 2 | 3 | 4 | 5 |
| 19. Patients who use home oxygen are unable to take part in PR | 1 | 2 | 3 | 4 | 5 |
| 20. Patients who smoke are not motivated to take part in PR | 1 | 2 | 3 | 4 | 5 |
| 21. Patients without their own transport won't be able to get to PR | 1 | 2 | 3 | 4 | 5 |
| 22. Patients who live alone won't like to take part in group PR | 1 | 2 | 3 | 4 | 5 |
| 23. I only refer patients if they have quit smoking | 1 | 2 | 3 | 4 | 5 |
| 24. I only refer patients if they are optimised on their respiratory medication | 1 | 2 | 3 | 4 | 5 |

| **Question list** | **Strongly Disagree** | **Disagree** | **Neither disagree nor agree** | **Agree** | **Strongly Agree** |
|---|---|---|---|---|---|
| 25. PR is most suited to COPD patients who have frequent exacerbations | 1 | 2 | 3 | 4 | 5 |
| 26. My practice receives financial incentives for referral to PR (Before April 2019) | 1 | 2 | 3 | 4 | 5 |
| 27. My practice regularly reviews COPD registers to ensure eligible COPD patients are offered PR | 1 | 2 | 3 | 4 | 5 |
| 28. There are set targets within the practice to improve PR referral rates | 1 | 2 | 3 | 4 | 5 |
| 29. I often forget to refer patients with COPD to PR | 1 | 2 | 3 | 4 | 5 |
| 30. There is not enough time in practice to refer | 1 | 2 | 3 | 4 | 5 |
| 31. I believe patients may be harmed by taking part In PR | 1 | 2 | 3 | 4 | 5 |

| | | | | | |
|---|---|---|---|---|---|
| 32. Prompts to refer patients to PR within annual review templates are important reminders for me | 1 | 2 | 3 | 4 | 5 |
| 33. The best time to discuss PR referral with patients is when they are stable. | 1 | 2 | 3 | 4 | 5 |
| 34. Patients are motivated to attend PR | 1 | 2 | 3 | 4 | 5 |
| 35. PR is best suited to those patients with worsening breathlessness | 1 | 2 | 3 | 4 | 5 |
| 36. PR is best suited to those who have frequent exacerbations | 1 | 2 | 3 | 4 | 5 |
| 37. I believe in encouraging patients to attend PR | 1 | 2 | 3 | 4 | 5 |
| 38. PR reduces hospital admissions | 1 | 2 | 3 | 4 | 5 |
| 39. I believe most patients will attend and complete PR following my referral | 1 | 2 | 3 | 4 | 5 |
| 40. PR reduces risk of mortality | 1 | 2 | 3 | 4 | 5 |
| 41. If patients attend PR this will reduce their general practice visits | 1 | 2 | 3 | 4 | 5 |
| 42. PR reduces exacerbations | 1 | 2 | 3 | 4 | 5 |
| 43. PR improves breathlessness | 1 | 2 | 3 | 4 | 5 |
| 44. PR reduces a patient's anxiety and/or depression. | 1 | 2 | 3 | 4 | 5 |
| 45. If I keep pushing patients to attend PR this will disadvantage my relationship with them. | 1 | 2 | 3 | 4 | 5 |
| 46. There are good relationships in practice with PR providers | 1 | 2 | 3 | 4 | 5 |
| 47. PR providers are good at communicating outcomes of referrals I have made | 1 | 2 | 3 | 4 | 5 |
| 48. Resources about PR (i.e. written information) are readily available | 1 | 2 | 3 | 4 | 5 |
| 49. PR is something that patients ask for | 1 | 2 | 3 | 4 | 5 |
| **Question list** | **Strongly Disagree** | **Disagree** | **Neither disagree nor agree** | **Agree** | **Strongly Agree** |
| 50. I will refer more patients to PR now there are practice QoF incentives (from April 2019) | 1 | 2 | 3 | 4 | 5 |
| 51. There will be greater awareness of PR within practices because of the new QoF incentives. | 1 | 2 | 3 | 4 | 5 |

| | | | | | |
|---|---|---|---|---|---|
| 52. More health care practitioners will discuss PR with patients because of the QoF incentive. | 1 | 2 | 3 | 4 | 5 |
| 53. I believe patient attendance to PR will increase because of the QoF Incentive. | 1 | 2 | 3 | 4 | 5 |
| 54. I believe the QoF incentive will not increase patients PR attendance | 1 | 2 | 3 | 4 | 5 |

2/Please consider the interventions below. Please rate each possible intervention based on which you think would be the most helpful in improving your rates of referral to PR?

3/ Then please indicate the top 5 that you think will be the most effective in increasing PR referral within your practice. Please rank them in order 1 (highest) – 5 (lowest) in the 'Rank" column.

| Question list | Strongly Disagree | Disagree | Neither disagree nor agree | Agree | Strongly Agree | Rank (1-5) |
|---|---|---|---|---|---|---|
| 1. Health Care Professional (HCP) referring patients to PR at the time of COPD diagnosis. | 1 | 2 | 3 | 4 | 5 | |
| 2. HCP prescribing PR at the time of COPD acute exacerbation. | 1 | 2 | 3 | 4 | 5 | |
| 3. A standardised summary (i.e.: a 2 sentences) that describes PR succinctly for HCP to recite to eligible patients. | 1 | 2 | 3 | 4 | 5 | |
| 4. Face to face educational sessions for general practice staff. | 1 | 2 | 3 | 4 | 5 | |
| 5. Online educational sessions for general practice staff. | 1 | 2 | 3 | 4 | 5 | |
| 6. Face to face educational sessions for potential patients, carers and family. | 1 | 2 | 3 | 4 | 5 | |
| 7. Online educational sessions for patients, carers & family. | 1 | 2 | 3 | 4 | 5 | |
| 8. Practice staff loaning DVDs which demonstrate PR to patients. | 1 | 2 | 3 | 4 | 5 | |
| 9. HCP showing patients PR recording within practice or consultation i.e. on a tablet device. | 1 | 2 | 3 | 4 | 5 | |
| 10. Past PR patient attenders directly engage with eligible patients to highlight benefits. | 1 | 2 | 3 | 4 | 5 | |
| 11. PR providers directly contacting eligible practice patients. | 1 | 2 | 3 | 4 | 5 | |

| Question list | Strongly Disagree | Disagree | Neither disagree nor agree | Agree | Strongly Agree | Rank |
|---|---|---|---|---|---|---|
| 12. PR providers engaging with practice staff by coming into surgeries. | 1 | 2 | 3 | 4 | 5 | |
| 13. Personalised letters to eligible patients from general practice advocating PR. | 1 | 2 | 3 | 4 | 5 | |
| 14. Group consultations with patients, general practice staff and PR provider. | 1 | 2 | 3 | 4 | 5 | |
| 15. Patients being able to refer themselves to PR. | 1 | 2 | 3 | 4 | 5 | |
| 16. Patients having their own COPD health care record, similar to a COPD passport, meaning they are prompted to ask for PR. | 1 | 2 | 3 | 4 | 5 | |
| 17. PR promotional material within patient pharmacy medication packs | 1 | 2 | 3 | 4 | 5 | |
| 18. Greater awareness of PR in practice. i.e. Posters highlighting local PR provider, benefits, etc. | 1 | 2 | 3 | 4 | 5 | |
| 19. General practice staff being able to refer patients by telephone rather than manually completing referral form. | 1 | 2 | 3 | 4 | 5 | |
| 20. If my practice referred more COPD patients this would increase my own referral numbers. | 1 | 2 | 3 | 4 | 5 | |
| 21. Changing the name of PR to something more user friendly. | 1 | 2 | 3 | 4 | 5 | |
| 22. General practice staff being taught motivational interviewing techniques would improve referral to PR. | 1 | 2 | 3 | 4 | 5 | |
| 23. Lead practice PR referrer to educate and show PR video to other practice staff at practice meetings, to encourage a whole practice approach. | 1 | 2 | 3 | 4 | 5 | |

4/ Please add any further comments/suggestions you may have……

……

Many thanks for completing this questionnaire. Please return to the return box to collect your chocolate(s)

## Appendix 15: TDF aligned questionnaire

| TDF Domain | TDF Questions (n54) |
|---|---|
| Knowledge | I am aware of the content of Pulmonary Rehabilitation (PR) Programmes |
| Knowledge | I am aware of PR programme objectives. |
| Knowledge (reversed question) SD+D | I am unsure of the evidence base for PR |
| Knowledge | I know where geographically my local PR programme is delivered |
| Knowledge | I know when it is appropriate to refer a patient with COPD to PR |
| Knowledge | I can answer questions patients have about PR |
| Knowledge | I know how to contact my local PR provider |
| Skill | It is easy to refer a patient to PR |
| Social & Professional Role | Referral to PR is the practice nurse role |
| Social & Professional Role | Other General Practice staff in my practice (excluding Practice Nurse) refer patients to PR |
| Social & professional role | I believe in encouraging patients to attend PR |
| Environment | Resources about PR (i.e. written information) are readily available |
| Environment (Reverse Question) | There is not enough time in practice to refer |
| Social Influences | My local PR providers regularly engage with me |
| Social influences | PR is something that patients ask for |
| Social influences | There are good relationships in practice with PR providers |
| Social Influences | PR providers are good at communicating outcomes of referrals I have made |
| Optimism | I am confident my local PR provider offers a good service for my patients. |
| Optimism (pessimism) (Reverse Question) D & SD | I don't believe patients will attend PR after I have referred |
| Optimism (Reverse Question) D & SD | Patients who smoke are not motivated to take part in PR |

| | |
|---|---|
| Optimism (Reverse Question) D & SD | Patients who live alone won't like to take part in group PR |
| Optimism | Patients are motivated to attend PR |
| Belief about Capabilities (self) | I am confident in my ability to encourage patients to attend PR, even when they are not motivated |
| Belief about Capabilities (self) (reversed) D and SD | I do not find it easy to discuss PR with patients. |
| Belief about capabilities | Patients without their own transport won't be able to get to PR |
| Belief about capabilities | Patients in work are not able to attend PR |
| Belief about capabilities (Reversed) SD and D | Patients who use home oxygen are unable to take part in PR |
| Belief about consequences | If I keep pushing patients to attend PR this will disadvantage my relationship with them. |
| Belief about consequences | I believe patients may be harmed by taking part In PR |
| Belief about consequences | I believe most patients will attend and complete PR following my referral |
| Belief about consequences (Reverse Question) D and SD | PR is not beneficial to patients who are breathless |
| Belief about consequences | PR is best suited to those patients with worsening breathlessness |
| Belief about consequences | PR is **best** suited to those who have frequent exacerbations |
| Decision Making (memory) | PR is **most** suited to COPD patients who have frequent exacerbations |
| Belief about consequences | PR reduces hospital admissions |
| Belief about consequences | PR reduces risk of mortality |
| Belief about consequences | If patients attend PR this will reduce their general practice visits |
| Belief about consequences | PR reduces exacerbations |
| Belief about consequences | PR improves breathlessness |
| Belief about consequences | PR reduces a patient's anxiety and/or depression. |
| Goals | Referring patients to PR is something I have been advised to do |

| | |
|---|---|
| Goals | My practice regularly reviews COPD registers to ensure eligible COPD patients are offered PR |
| Goals | There are set targets within the practice to improve PR referral rates |
| Memory | I often forget to refer patients with COPD to PR |
| Memory | Prompts to refer patients to PR within annual review templates are important reminders for me |
| Decision Making (memory) Reversed question SD D | I only refer patients if they have quit smoking |
| Decision Making (memory) | I only refer patients if they are optimised on their respiratory medication |
| Decision Making (memory) | The best time to discuss PR referral with patients is when they are stable. |
| Reinforcement | More health care practitioners will discuss PR with patients because of the QoF incentive. |
| Reinforcement | My practice receives financial incentives for referral to PR (Before April 2019) |
| Reinforcement | I believe patient attendance to PR will increase because of the QoF Incentive. |
| Reinforcement Reversed Qu SD/D | I believe the QoF incentive will not increase patients PR attendance |
| Reinforcement | There will be greater awareness of PR within practices because of the new QoF incentives. |
| Behavioural regulation/Intentions | I will refer more patients to PR now there are practice QoF incentives (from April 2019) |

## Appendix 16: Paper survey distribution and return rate

| Conference | Attendee number and profile | Number distributed | Number Returned |
|---|---|---|---|
| Conference 1 – GPN | Unable to obtain attendance number (Community & general practice nurses) @ 170 | 117 | 33 (28%) |
| Conference 2 - RCGP | 141 (68 GPs Inc. registrars) | 48 | 24 (50%) |
| Conference 3 - NIP-N | 171 (Community & general practice nurses) | 47 | 26 (55%) |
| Conference 4 - NIP-M* | 382 (Community & general practice nurses) | 382 - 400 | 36 (9.4-9%) |
| Conference 5 – NIP-C | 236 (Community & general practice nurses) | 51 | 31 (61%) |
| Workshop – PCRS | 27 (Community & general practice nurses, 4 GP's, pharmacist x2) | 8 | 4 (50%) |
| Total | @ 1,127 | 653-671 | 154 (23-23.6%) |

*Surveys placed in conference bags

GPN = General Practice Nurses, RCGP = Royal College of General Practitioners, NIP = Nursing in Practice (N=Northampton, M =Manchester, C =Cardiff), PCRS = Primary Care Respiratory Society.

**Appendix 17: Guidelines for Conducting and Reporting Mixed Research for Counsellor Researchers (Leech & Onwuegbuzi, 2010)**

| **Research Formulation** | |
|---|---|
| 1.1.1. Treat each relevant article as data that generate both qualitative (e.g., qualitative findings, literature review of source article, source article author's conclusion) and quantitative (e.g., p values, effect sizes, sample size score reliability, quantitative results) information that yield a mixed research synthesis.<br>1.1.2. Subject each document selected as part of the literature review to summarization, analysis, evaluation, and synthesis.<br>1.1.3. Provide literature reviews that are comprehensive, current, and rigorous; that have been compared and contrasted adequately; and that contain primary sources that are relevant to the research problem under investigation, with clear connections being made between the sources presented and the present study.<br>1.1.4. Present clearly the theoretical/conceptual framework.<br>1.1.5. Assess the findings stemming from each individual study and the emergent synthesis for trustworthiness, credibility, dependability, legitimation, validity, plausibility, applicability, consistency, neutrality, reliability, objectivity, confirmability, and/or transferability.<br>1.1.6. Present the goal of the study (i.e., predict; add to the knowledge base; have a personal, social, institutional, and/or organizational impact; measure change; understand complex phenomena; test new ideas; generate new ideas; inform constituencies; and examine the past). | 134-137 |
| 1.2.1. Specify the objective(s) of the study (i.e., exploration, description, explanation, prediction, and influence).<br>1.3.1. Specify the rationale of the study.<br>1.3.2. Specify the rationale for combining qualitative and quantitative approaches (i.e., participant enrichment, instrument fidelity, treatment integrity, and significance enhancement).<br>1.4.1. Specify the purpose of the study. | 135-136 |

| | |
|---|---|
| 1.4.2. Specify the purpose for combining qualitative and quantitative approaches (e.g., identify representative sample members, conduct member check, validate individual scores on outcome measures, develop items for an instrument, identify barriers and/or facilitators within intervention condition, evaluate the fidelity of implementing the intervention and how it worked, enhance findings that are not significant, compare results from the quantitative data with the qualitative findings).<br>1.5.1. Avoid asking research questions that lend themselves to yes/no responses.<br>1.5.2. Present mixed research questions (i.e., questions that embed both a quantitative research question and a qualitative research question within the same question) when possible. | Pg. 135-136 |
| **Research Planning**<br><br>2.1.1. Specify the initial and final sample sizes for all quantitative and qualitative phases of the study.<br><br>2.1.2. Present all sample size considerations made for the quantitative phase(s) (i.e., a priori power) and qualitative phases (e.g., information-rich cases).<br>2.1.3. Present the sampling scheme for both the quantitative and qualitative phases of the study.<br><br>2.1.4. Describe the mixed sampling scheme (i.e., concurrent–identical, concurrent–parallel, concurrent–nested, concurrent–multilevel, sequential–identical, sequential–parallel, sequential–nested, and sequential–multilevel).<br>2.1.5. Clarify the type of generalization to be made (i.e., statistical generalization, analytic generalization, and case-to-case transfer) and link it to the selected sampling design, sampling scheme, and sample size(s).<br><br>2.2.1. Outline the mixed research design.<br>2.2.2. Specify the quantitative research design (i.e., historical, descriptive, correlational, causal–comparative/quasi-experimental, and experimental).<br>2.2.3. Specify the qualitative research design (e.g., biography, ethnographic, auto-ethnography, oral history, phenomenological, case study, grounded theory) | Qualitative sampling reported in Inductive paper (pg. 137)<br>Quantitative pg. 138-139<br><br>Pg. 136 - 137 |
| **Research Implementation**<br><br>3.1.1. Outline the mixed data collection strategy. | Pg. 136, 138-139 |

| | |
|---|---|
| 3.1.2. Present information about all quantitative and qualitative instruments and the process of administration. | Pg. 139-141 |
| 3.2.1. Outline the mixed data collection strategy (i.e., data reduction, data display, data transformation, data correlation, data consolidation, data comparison, and data integration). | Figure 7 – pg. 136 and pg. 160 |
| 3.2.2. Provide relevant descriptive and inferential statistics for each statistical analysis.<br>3.2.3. Discuss the extent to which the assumptions (e.g., normality, independence, equality of variances) that underlie the analyses were met, as well as any observations that might have distorted the findings (e.g., missing data, outliers).<br>3.2.4. Specify the statistical software used.<br>3.2.5. Specify where the responsibility or authority for the creation of categories resided (i.e., participants, programs, investigative, literature, or interpretive), what the grounds were on which one could justify the existence of a given set of categories (i.e., external, rational, referential, empirical, technical, or participative), what was the source of the name used to identify a given category (i.e., participants, programs, investigative, literature, or interpretive), and at what point during the research process the categories were specified (i.e., a priori, a posteriori, or iterative) | Pg. 140-141<br>Pg. 157-60 |
| 3.2.6. Specify the name of the technique used to analyse the qualitative data (e.g., content analysis method of constant comparison, discourse analysis, componential analysis, keywords in context, analytic induction, word count, domain analysis, taxonomic analysis).<br>3.2.7. Specify the qualitative software used. | Pg. 137-138 |
| 3.3.1. Discuss the threats to internal validity, external validity, and measurement validity and outline the steps taken to address each of these threats to internal validity, external validity, and measurement validity.<br>3.3.2. Discuss the threats to trustworthiness, credibility, dependability, authenticity, verification, plausibility, applicability, confirmability, and/or transferability of data and outline all verification procedures used.<br>3.3.3. Discuss mixed research legitimation types (i.e., sample integration legitimation, insider–outsider legitimation, weakness minimization legitimation, sequential legitimation, conversion legitimation, paradigmatic mixing legitimation, commensurability legitimation, multiple validities legitimation, and political legitimation). | Pg. 167-169 |

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|---|---|
| 3.4.1. Interpret relevant types of significance of the quantitative findings (i.e., statistical significance, practical significance, clinical significance, and economic significance). | Pg. 157-159 |
| 3.4.2. Conduct post hoc power analysis for all statistically non-significant findings. | NA |
| 3.4.3. Interpret the significance (i.e., meaning) of qualitative findings. | Pg. 166-167 |
| 3.4.4. Discuss criteria for evaluating findings in mixed research studies (e.g., within-design consistency, conceptual consistency, interpretive agreement, interpretive distinctiveness, design suitability, design fidelity, analytic adequacy, interpretive consistency, theoretical consistency, integrative efficacy). | throughout paper |
| 3.5.1. Describe all steps of the mixed research process. | |
| 3.5.2. Describe the context in which the mixed research study took place. | |
| 3.5.3. Ensure that the mixed research report is accurate and complete; does not distort differences within and among individuals and groups; is free from plagiarism or misrepresentation of the ideas and conceptualizations of other scholars; and contains findings that are adequately accessible for reanalysis, further analysis, verification, or replication. | |
| 3.5.4. Present all ethical considerations that were addressed in the study (e.g., informed consent, confidentiality, incentives, funding sources, potential conflicts of interest, and biases). | pg. 136,139 and pg. 174<br>Page 174 |
| 3.5.5. Specify study approval in accordance with an institutional review board either in the report or in the cover letter submitted to the editor. | Page 169-170 |
| 3.5.3. Present recommendations for future research that culminate in a validation, replication, or extension of the underlying study. | |