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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 (Protocol)

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## [Qualitative Protocol]

# 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

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## ABSTRACT

This is a protocol for a Cochrane Review (Qualitative). The objectives are as follows:

- To identify factors that influence referral to pulmonary rehabilitation for COPD from the perspective of service users, their family/carers, and healthcare providers.
- To identify factors that influence uptake of pulmonary rehabilitation for COPD (i.e. at least one attendance of an assessment or first programme session) from the perspective of service users, their family/carers, and healthcare providers.
- To identify factors that influence attendance at pulmonary rehabilitation programmes for COPD from the perspective of service users, their family/carers, and healthcare providers.
- To develop an inductive explanatory framework for how these factors may interact to contribute to better or poorer uptake or completion of pulmonary rehabilitation in order to guide actions of healthcare decision-makers to improve opportunities for people with COPD to benefit from pulmonary rehabilitation.

#### BACKGROUND

Chronic Obstructive Pulmonary Disease (COPD) is a major contributor to ill health, disability, and mortality. It is the third leading cause of death (Lozano 2012), and the fifth leading cause of total years with disability worldwide, with 328 million people in the world estimated to have the disease (Vos 2012). COPD contributes to reduced exercise capacity, problems with breathlessness and chronic cough (often with sputum), and occasionally poorer mental health, and therefore limits people's abilities to participate in daily activities, social roles, and work (Alahmari 2014; Grønseth 2017). COPD is known to contribute substantially to problems with anxiety and depression (Yohannes 2014). It is a growing problem worldwide and is currently ranked as the eighth leading cause of disability-adjusted life years (DALYs) worldwide, where one DALY is equivalent to the loss of one year of health life; this is up from the 11th ranked cause in 2006 and 12th ranked cause in 1990 (GBD 2016 DALYs and HALE Collaborators 2017). COPD also places a significant financial burden on individuals and societies worldwide. For example, people with COPD in the USA are less likely to be employed (odds ratio (OR) 0.58, 95% confidence interval (CI) 0.50 to 0.67; controlling for initial health status and sociodemographic factors) and much more likely to be collecting disability-related insurance or income than their peers without COPD (Thornton Snider 2012). At a societal level, the direct annual healthcare costs for COPD are estimated to be USD 18 billion in the USA and EURO38.7 billion in the EU (López-Campos 2016), with COPD being equally problematic in the Asia-Pacific region (Wang 2016) and Africa (Adeloye 2015). Factors leading to development of COPD include smoking, recurrent respiratory infection, asthma, exposure to air pollutants (particularly from occupational exposure and indoor fires), poor nutrition, and low socioeconomic status (Global Initiative for Chronic Lung Disease 2018). While cigarette smoking is the best known risk factor, nonsmokers are also susceptible to the disease, with 30% of people with COPD having never smoked (Eisner 2011). COPD is diagnosed on the basis of lung function tests (persistent airflow limitation, indicated by a post-bronchodilator forced expiratory volume in one second (FEV1) that is less than 70% of a person's forced vital capacity (FVC)) and clinical history (breathlessness, chronic cough or sputum production, and exposure to risk factors for COPD) (Global Initiative for Chronic Lung Disease 2018).

Pulmonary rehabilitation is a low cost, high value intervention known to reduce the burden of disease associated with COPD. Typically, pulmonary rehabilitation involves six to 12 weeks of outpatient or community-based exercise and self-management education. It has been demonstrated that pulmonary rehabilitation improves quality of life and both functional and maximal exercise capacity in people with COPD (McCarthy 2015), both during stable periods of the disease and after acute exacerbations (Puhan 2016). Home-based pulmonary rehabilitation programmes have also been shown to be beneficial (Liu 2014; Holland 2017). For

instance, pulmonary rehabilitation improves Chronic Respiratory Questionnaire (CRQ) scores for quality of life related to dyspnoea by 0.79 units (95% CI 0.56 units to 1.03 units; N = 1283), which is above the minimal clinically important difference (MCID) of 0.5 units for this measure (McCarthy 2015). Pulmonary rehabilitation also improves performance on a maximal exercise capacity test by 6.77 Wmax (95% CI 1.89 Wmax to 11.65 Wmax; N = 779; MCID 4 WMax) (McCarthy 2015). Pulmonary rehabilitation is thus universally recommended for the management of all people with COPD (National Clinical Guidelines Centre 2010; Spruit 2013; Yang 2017; Global Initiative for Chronic Lung Disease 2018). Uptake of pulmonary rehabilitation is also strongly endorsed by COPD consumer advocacy groups worldwide (American Lung Association 2018; Asthma and Respiratory Foundation New Zealand 2018; British Lung Foundation 2018; European Lung Foundation 2018; Lung Foundation Australia 2018).

However, the potential health benefits associated with pulmonary rehabilitation are limited by referral, uptake, and attendance rates. Use of pulmonary rehabilitation is extremely poor worldwide, with an estimated 1.2% of all people with COPD entering pulmonary rehabilitation internationally (Desveaux 2015). Furthermore, when people are offered a place in a pulmonary rehabilitation programme they frequently decline that opportunity. Approximately 30% of people referred to pulmonary rehabilitation do not attend their first session, and 40% of those initially enrolled in a pulmonary rehabilitation programme do not complete it (Keating 2011; Jones 2014). As such, there has been a recent call for research to address problems of uptake and attendance at pulmonary rehabilitation for COPD (Steiner 2016).

## Description of the phenomena of interest

Pulmonary rehabilitation improves health outcomes for people with COPD through a variety of mechanisms. At a physiological level, the exercise component of pulmonary rehabilitation does not reverse a person's lung damage, so does not tend to affect their performance on lung function tests. Instead, exercise has a positive effect on the function of other body systems, particularly muscle strength and endurance, resulting in higher exercise capacity with less fatigue, less shortness of breath, and less dynamic hyperinflation (Casaburi 2009). Pulmonary rehabilitation also helps desensitise people with COPD to the experience of breathlessness, making them feel less out of breath when being physically active and therefore able to achieve more in their daily life (Casaburi 2009). The self-management component of pulmonary rehabilitation helps people better manage their health condition and better cope with the symptoms of COPD, while improving health literacy (i.e. knowledge and understanding of COPD and its medical management) and promoting healthy behaviours (e.g. smoking cessation, healthy eating, adherence to medical interventions)

(Casaburi 2009). The social component of pulmonary rehabilitation - meeting and interacting with other people with COPD - is also thought to be an important component of the intervention, with positive health benefits such as increased self-confidence, self-efficacy, and motivation arising from opportunities to share and discuss everyday challenges with peers and from mutual support (Halding 2010).

The focus of this Cochrane Review is on people's experiences of factors that influence referral to pulmonary rehabilitation, uptake of these programmes when offered, and attendance at pulmonary rehabilitation once enrolled. For the purpose of this review, 'referral' will refer to a health professional acting to direct a person with COPD to a pulmonary rehabilitation programme or to a person with COPD self-referring to pulmonary rehabilitation when this is permitted. The term 'uptake' will refer to a person with COPD attending an initial assessment for pulmonary rehabilitation or first programme session. The term 'attendance' will refer to the extent to which people participate in scheduled pulmonary

rehabilitation classes beyond the initial assessment. The focus of this review includes descriptive accounts of people's experiences, as well as their perceptions and beliefs regarding referral to, uptake of, and attendance at pulmonary rehabilitation. We are interested in the accounts of people who are users of pulmonary rehabilitation services (i.e. people with COPD), of their family members/ carers, and of health professionals who either refer to or provide pulmonary rehabilitation programmes. This review is intended to identify factors influencing the effective implementation of pulmonary rehabilitation. As such, it will inform the application of evidence to clinical practice identified by McCarthy 2015, which is the primary effectiveness review associated with this qualitative evidence synthesis (see Figure 1 for an overview of the relationship between the primary effectiveness review by McCarthy 2015 and this qualitative evidence synthesis). However, this review is being conducted alongside another effectiveness review of interventions designed to improve referral to, uptake of, and adherence to pulmonary rehabilitation (Young 2017).

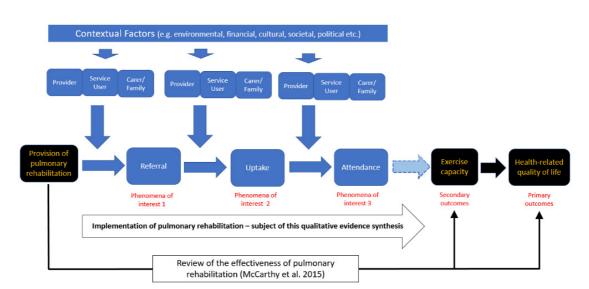


Figure 1. Relationship between McCarthy 2015 and this qualitative evidence synthesis

A number of possible reasons for poor referral to, uptake of, and attendance at pulmonary rehabilitation have been suggested. Some issues are pragmatic: transport, timing of programmes, disruption of usual routines, and the distance required to travel to pulmonary rehabilitation venues (Keating 2011; Cox 2017). However, more recent studies have highlighted that underpinning these practical justifications are cultural and psychosocial factors that make people with COPD reluctant to engage in pulmonary rehabilita-

tion. People with COPD are highly likely to experience shame or stigma associated with their condition, perceiving themselves to be personally culpable for their situation (Harrison 2015). This can lead them to be very sensitive to feeling criticised or judged by healthcare professionals, which increases avoidant behaviours (Harris 2008; Harrison 2015). Another important factor is that after acute respiratory events, people with COPD struggle to main-

tain a sense of agency, which limits their ability to take charge of their health (Harrison 2015). Fear of breathlessness further contributes to exercise avoidance (Harris 2008; Bulley 2009), and lack of belief in the efficacy of pulmonary rehabilitation makes it hard for people to commit to the intervention (Keating 2011). The nature of interactions with healthcare professionals, and how information about pulmonary rehabilitation is presented, can reinforce all of these beliefs and perceptions, and thus can moderate or influence patient decisions to take up pulmonary rehabilitation opportunities (Arnold 2006; Bulley 2009; Levack 2016; Cox 2017). Demographic factors, such as age (Robles 2014), gender (Selzer 2012), or ethnicity (Levack 2016), have also been proposed as factors that potentially influence uptake of pulmonary rehabilitation.

## Why it is important to do this review

McCarthy 2015 is the fourth update of the review comparing pulmonary rehabilitation to conventional care in COPD, with prior versions published in 1996, 2002, and 2006. Following its publication, the Cochrane Airway editorial board decided to close this review to further updates (Lacasse 2015). The reason for this decision was that these past reviews had established clear evidence on the broad effectiveness of pulmonary rehabilitation for people with COPD, and no further clinical trials on this review topic could be expected to either improve the quality of the evidence or precision of the effect estimates calculated in the meta-analyses in the review. (Lacasse 2015 concluded that future clinical trials and reviews should be directed towards other clinical questions related to pulmonary rehabilitation, such as mode of delivery and intensity of training). One of the main clinical issues now, however, is how to "bridge the large gap between the documented benefits of pulmonary rehabilitation and its practical implementation in real-world settings" (Steiner 2016).

People with COPD may miss out on the known benefits of pulmonary rehabilitation if they are not referred, do not take up, or attend few classes in a pulmonary rehabilitation programme. Understanding what makes it easier or harder for people with COPD to engage in pulmonary rehabilitation is an important step towards designing better ways of aiding people to make use of this intervention. This Cochrane Review might also contribute to explanations regarding the heterogeneity observed in outcomes following pulmonary rehabilitation (Lacasse 2015), as its effectiveness is likely to be influenced by the degree of engagement of service users within it.

Some systematic reviews of qualitative research on the topic of uptake and completion of pulmonary rehabilitation have been published (e.g. Keating 2011; Cox 2017). However, these publications are either dated (Keating 2011), or used a pre-determined framework for identification and categorisation of factors influencing uptake and attendance rather a fully inductive approach (Cox 2017), so may have missed relevant qualitative evidence related to this review question. Pre-determined frameworks for inductive qualitative analysis can be informative and can further

thinking on a particular phenomenon, but can also be limiting if they are based on preconceptions that force concepts into prespecified patterns (Charmaz 2014). The Theoretical Domains Framework used by Cox 2017, for instance, has been derived from the opinions of behavioural scientists and health service researchers responding to questions about theoretical constructs that explain behaviour change in health professionals who are asked to implement evidence-based practice in any healthcare context (Cane 2012; Michie 2013). The Theoretical Domains Framework was not developed to explain the behaviour of health services users, such as people with COPD, regarding uptake of a specific intervention, such as pulmonary rehabilitation. Qualitative research examining the perspectives and experience of other people can raise issues that do not map well onto these pre-determined frameworks, so risk being omitted or not completely included. As one example, a study of the experiences of a group of indigenous people with COPD in New Zealand identified whakawhanaungatanga as a factor that influenced their willingness to attend and continue with pulmonary rehabilitation programmes (Levack 2016). This concept, which does not translate easily into English but can loosely be interpreted to refer to the making of culturally meaningful connections with others, does not align with any of the concepts in the Theoretical Domain Framework. Whakawhanaugnatanga could be forced into the concepts of 'social identity', 'group identity', or 'organisational culture' in the Theoretical Domains Framework, but these concepts are intended to refer to the culture of the health professionals delivering an intervention, not the culture of the service users (Cane 2012; Michie 2013). Even if these concepts were broadened in their scope to accommodate whakawhanaungatanga, the nuance of meaning of this finding would be lost. One additional point regarding past reviews on this topic relates to the use of critical appraisal in the report of finding. While one publication included an evaluation of the quality of the evidence (Cox 2017), the authors did not use these evaluations to make statements about confidence in the synthesised evidence reported in their findings. A Cochrane qualitative evidence synthesis could strengthen understanding on this topic by addressing issues regarding the confidence in evidence underpinning findings arising from this review.

## **OBJECTIVES**

- To identify factors that influence referral to pulmonary rehabilitation for COPD from the perspective of service users, their family/carers, and healthcare providers.
- To identify factors that influence uptake of pulmonary rehabilitation for COPD (i.e. at least one attendance of an assessment or first programme session) from the perspective of service users, their family/carers, and healthcare providers.

- To identify factors that influence attendance at pulmonary rehabilitation programmes for COPD from the perspective of service users, their family/carers, and healthcare providers.
- To develop an inductive explanatory framework for how these factors may interact to contribute to better or poorer uptake or completion of pulmonary rehabilitation in order to guide actions of healthcare decision-makers to improve opportunities for people with COPD to benefit from pulmonary rehabilitation.

#### **METHODS**

## Criteria for considering studies for this review

## Types of studies

We will include studies that used qualitative methods for both data collection (e.g. interviews, focus group discussions, document analysis, and observations) and analysis (e.g. thematic analysis, phenomenological analysis, grounded theory). We will exclude studies that only analysed qualitative data with quantitative methods or only analysed quantitative data qualitatively. We will include mixed-methods studies where qualitative methods have been used for data collection and analysis, and where the qualitative component of the study can be separately extracted and analysed. We will include studies regardless of whether or not they have been carried out alongside studies of effectiveness of pulmonary rehabilitation or strategies to increase referral to, uptake of, or attendance at pulmonary rehabilitation.

We will consider including non-English language studies. If we find a non-English language study that appears relevant to the review, we will include it if we: a) can recruit a review author who is native speaker of the language that the study is published in, so that at least one review author will extract data from the untranslated paper before translating findings; and b) are able to find support or resources to translate the study into English for a second review author to evaluate and extract data from. This is because qualitative analysis requires a nuanced understanding of the cultural meaning of language. Even if we do follow these principles to include non-English language studies, we will only combine results from non-English language studies with those from Englishlanguage studies if we can be confident that the concepts and ideas emerging from each group of studies are sufficiently similar from a cultural perspective.

## Types of participants

We will include studies that have included: a) people with COPD who have been invited to participate in a pulmonary rehabilitation

programme regardless of whether or not they have taken that opportunity up; b) the family members/carers of people with COPD who have been invited to participate in a pulmonary rehabilitation programme; or c) health professionals who refer people with COPD to pulmonary rehabilitation or are involved in providing pulmonary rehabilitation programmes for people with COPD. We will exclude studies where it is not possible to separate out the experience of people with COPD or about people with COPD from the experiences of or about people with other respiratory conditions and diseases. Following the criteria used by McCarthy 2015, we will include studies where more than 90% of the participants had COPD, defined as a clinical diagnosis of COPD, with a best recorded FEV1/FVC ratio of less than 0.7. We will include studies where any or all of the participants are on continuous oxygen. We will exclude studies that focus on participants who are mechanically ventilated or who had an acute exacerbation of COPD within four weeks of commencing pulmonary rehabilitation.

## Types of setting

We will include studies where pulmonary rehabilitation has been provided in a hospital, home, or community (including primary care) setting.

#### Phenomena of interest

We will include studies that explore people's experiences, beliefs, perceptions, and views of factors that influence referral to pulmonary rehabilitation for COPD, uptake of these programmes when offered, and attendance at pulmonary rehabilitation when enrolled. In line with the definition of pulmonary rehabilitation in the Cochrane Reviews of its effectiveness (McCarthy 2015), we will consider a pulmonary rehabilitation programme to be any inpatient, outpatient, home-based, or community-based rehabilitation programme of at least four weeks' duration that includes exercise therapy with or without any form of education or psychological support delivered to patients with exercise limitation attributable to COPD.

We will include studies that have considered people's perspectives and experiences of pulmonary rehabilitation when it was delivered as part of a clinical trial, but in these cases we will be careful to separate out themes related to referral, uptake, and attendance at the pulmonary rehabilitation sessions versus themes related to the participation in a clinical trial. For these types of studies we will identify, and acknowledge as a limitation of these data, any difficulties differentiating between experiences or perception of participation in pulmonary rehabilitation versus participation in a clinical trial. If we are unable to determine whether data relate to experiences of participation in pulmonary rehabilitation versus participation in a clinical trial as a whole, we will exclude these data.

#### Search methods for identification of studies

## **Electronic searches**

We will develop search strategies using guidelines developed by the Cochrane Qualitative and Implementation Methods Group (CQIMG) on searching for qualitative evidence (Noyes 2011). We will search MEDLINE (Ovid), Embase (Ovid), PsycINFO (Ovid), CINAHL (EbscoHOST), and Web of Science and will adapt our search strategy as appropriate for each database. When designing search strategies we will draw upon search terms routinely used by Cochrane Airways to identify research on pulmonary rehabilitation for COPD combined with the hybrid search strategies for qualitative studies developed and tested by DeJean 2016. The MEDLINE search strategy is in Appendix 1. We will search Proquest Dissertations and Theses database for grey literature. We will search all databases from their inception to the present, and we will impose no restriction on language of publication.

## Searching other resources

We will search the reference lists of all included studies and other key references (i.e. relevant systematic reviews). We will use the Epistemonikos database ( www.epistemonikos.org/) to search for relevant systematic reviews. After initial screening and selection of studies, we will contact all corresponding authors of included studies to inquire about other potentially relevant research that has been completed or is pending. We will also put out a call for suggestions of papers that we may have missed via social media (specifically Twitter, Facebook, and ResearchGate).

## Data collection and analysis

#### **Selection of studies**

Two review authors will independently screen the titles and abstracts of each of the potential studies we identify from the search, and categorise them as either 'retrieve' (eligible or potentially eligible/unclear) or 'do not retrieve'. We will retrieve the full-text study reports/publications and two review authors will independently screen the full-text and identify studies for inclusion, identifying and recording reasons for exclusion of the ineligible studies. One review author (WL) will screen all titles, abstracts, and full-text studies for inclusion; JW, JHS, CD, TI, and BJ will share the role of second review author for study selection. We will use Covidence to manage the study selection process (Covidence 2018). We will resolve any disagreement through discussion or, if required, will consult a third review author. We will record the selection process in sufficient detail to complete a PRISMA flow diagram and 'Characteristics of excluded studies' table.

## Data extraction and management

Two review authors will independently extract data on study quality and study characteristics in Covidence before comparing findings. One review author (WL) will extract data on all included studies; JHS, CD, and BJ will share the role of second review author for data extraction. We will resolve any differences of opinion regarding study characteristics and study quality by consensus between the two screening review authors. If these two review authors are unable to reach a consensus, they will consult a third review author (JHS, CD, TI, BJ, or MC). For data on study characteristics we will record details, where available, on: the first author, corresponding author, date of publication, language of data collection, language of publication, country of study, context of the pulmonary rehabilitation programme (location, duration, frequency, content, referral process), characteristics of participants with COPD (age, gender, ethnicity, lung function - as reported in the study, diagnostic criteria, smoking history, medication, prior history of involvement in pulmonary rehabilitation, method of transport to pulmonary rehabilitation, time between referral to pulmonary rehabilitation and first attendance), characteristics of family members/carers (gender, relations to the people with COPD), characteristics of health professional participants (profession, role in pulmonary rehabilitation), theoretical/conceptual perspective of the study, research methods, sample size, and method of analysis. We will contact study authors to address any gaps in our understanding of the reported study method and its implementation or data on study or participant characteristics. We will report on contextual factors related to the studies included in this review.

We will extract data on study findings in NVivo 12 Pro (QRS International 2018). We will resolve differences in opinion regarding study data by discussion between the review authors or, where necessary, we will consult a third review author. Differences in opinions regarding study data could result in: one perspective being chosen over the other; both perspectives being retained; both perspectives being merged into a new shared perspective; or both perspectives being replaced by other representations of the data. We will extract findings related to concepts, ideas, analytical themes, or categories reported in the 'Findings' section of included papers. We will extract both the study authors' interpretation of themes and our interpretation of all reported study data as findings for this review. Where additional qualitative analysis of qualitative data has been reported in the 'Discussion' section of a paper (such a further abstraction of findings) or in supplementary files, we will also extract this as study data. We will consider prior frameworks for understanding patient behaviour, such as the Behavior Change Taxonomy (Michie 2013), referred to in Young 2017, or for understanding referral and participation in pulmonary rehabilitation, such as the Theoretical Domains Framework (Cane 2012), used by Cox 2017. However, we will use this prior reading to increase our theoretical sensitivity to content relevant to the study topic rather than to generate pre-conceived codes to apply during data

extraction and analysis. In other words, we will focus on inductive identification of relevant ideas and concepts from the included studies rather than imposing a pre-conceived theoretical framework on the review data. We will remain open to the possibility of alternative data extraction methods, suitable for the best method of data synthesis as identified later in the study.

# Assessment of methodological strengths and weaknesses

Two review authors will independently evaluate study quality against predetermined criteria. One review author (WL) will evaluate study quality for all included studies, and JHS, CD, and BJ will share the role of second review author for the purposes of evaluating study quality, using Covidence to manage this process (Covidence 2018). We will use the Critical Appraisal Skills Programme (CASP) checklist for qualitative research as the criteria for study quality. This includes evaluation of 10 items.

- The clarity of the aims of the research (one item).
- The appropriateness of a qualitative method, research design, recruitment strategy, and data collection methods for the aims of the research (four items).
- Whether the relationship between the researchers and participants was adequately considered (one item).
- Whether ethics issues were appropriately considered and addressed (one item).
  - The rigour of the analysis (one item).
- The clarity of the findings, including reporting on the credibility of the findings and relationship to the study aim (one item).
  - The value of the research (one item).

Following this critical appraisal, we will categorise the seriousness of concerns with methodological limitations as either 'no or very minor concerns', 'minor concerns', 'moderate concerns', or 'serious concerns', following the recommendations of the CIQMG for this categorisation (Munthe-Kaas 2018). Two review authors (the same authors who extracted data on study quality of each individual study) will independently assess all included studies for study quality, and will resolve any disagreements through discussion or, when required, consulting a third review author. We will endeavour to contact study authors to seek missing information or clarify aspect of study design when needed.

## **Data synthesis**

We will take a sequential approach to synthesising the qualitative evidence from this Cochrane Review with evidence from the Cochrane effectiveness review by McCarthy 2015 (Noyes et al, forthcoming update to Noyes 2011). In a sequential approach, there is a degree of independence between the two syntheses. Each synthesis follows their respective research tradition and findings

across the two syntheses are then integrated using a common framework (Harden 2018).

The best method of data synthesis cannot be predetermined before knowing about the type and richness of available qualitative evidence. Therefore, we will first determine the type and richness of the available data relevant to this review question before selecting an appropriate method of synthesis, following CQIMG guidance and advice (Booth 2016). One review author (MC, who is a member of the CQIMG) will ensure integration of this advice into the review. We will first analyse and synthesise data related to the experience of people with COPD, family members/carers without COPD, and health professionals separately before considering whether it is appropriate to synthesise data between these groups.

Study findings are likely to include themes, concepts, or categories of information derived from the included studies. When selecting methods of data synthesis, we will consider whether it is only appropriate to integrate or aggregate findings from individual studies, or whether the synthesis can include reinterpretation of findings to produce new conceptual or theoretical understandings of the phenomena under review. We will base integration or aggregation of findings on observed similarity in meaning of findings within and across studies, but will not involve the development of new understanding of factors influencing the uptake and completion of pulmonary rehabilitation arising from the interpretative analysis of findings across studies. Reinterpretation of findings to produce new theory is the preferred type of approach - as this is more likely to result in new ideas for improving the uptake and completion of pulmonary rehabilitation - but will require data of sufficient quantity, quality, and depth, collected across a number of studies in different contexts, to be feasible. If there is sufficient evidence, and where appropriate, we will examine variations in findings across different settings for pulmonary rehabilitation (e.g. community, home, hospital) and client characteristics (e.g., gender, disease severity, and ethnicity). The review team will develop 'nodes' in NVivo to organise studies based on common attributes (i.e. setting and client characteristics) and facilitate codebased searches.

Figure 1 provides a logic model to guide the extraction and synthesis of data with a view to subgroup analysis. The logic model provides an initial set of broad deductive codes to aid in the generation of inductive codes from primary studies. If the data are 'thin' we will consider using a synthesis method, such as thematic synthesis (Booth 2016), to code the factors according to perspective (i.e. provider, service user, care/family member) for referral to, uptake, and attendance in pulmonary rehabilitation for COPD. If we identify thematic synthesis as the most appropriate method, we will follow the thematic synthesis methods proposed by Thomas 2008, first coding line-by-line, then developing descriptive themes and finally analytic themes. If the data are 'thick' we will consider using a synthesis method, such as meta-ethnography (Booth 2016), to develop an inductively driven explanatory framework

for how these factors may interact to contribute to better or poorer uptake or completion of pulmonary rehabilitation. Both thematic synthesis and meta-ethnography are recommended methods for undertaking a qualitative evidence synthesis for subsequent integration with a Cochrane intervention effectiveness review (Noyes et al, forthcoming update to Noyes 2011).

Regardless of the methods used for data synthesis, we will provide a summary of our analytical themes in the form of a 'Summary of qualitative findings' table. This table will summarise the key findings, our confidence in the evidence for each finding, and an explanation of how we arrived at our confidence in the evidence for each finding.

We will use CERQual to evaluate confidence in evidence arising from this review (Lewin 2018). CERQual uses evaluation of study quality in conjunction with evaluation of the coherence of the findings, adequacy of data, and relevance of data to the review question to draw conclusions regarding confidence in these findings. The overall assessment of confidence in each finding will be a product of a weighting of these respective components, and we will assess it as either 'very low', 'low', 'moderate', or 'high' (Lewin 2018).

# Integrating the qualitative findings with the linked Cochrane intervention review

The overall aim of our review is to aid explanation of review findings from McCarthy 2015, to address known problems with referral to, uptake of, and attendance at pulmonary rehabilitation (Steiner 2016), and to assist with development of strategies to help successfully implement pulmonary rehabilitation in practice. We will explore options for refining the logic model in Figure 1 during the synthesis and integration of evidence in this review (Anderson 2011; Allmark 2013; Baxter 2014; Harden 2018). To do this, we will begin with the summary statements that we develop from our data synthesis. If feasible, we will examine these summary statements to develop a series of chains of reasoning that logically link specific aspects of these summary statements together, with an overview view of providing a better understanding of how factors combine or interact to influence referral to, uptake of, and attendance at pulmonary rehabilitation by people with COPD to impact exercise capacity and health-related quality of life.

Note that we will specify the exact methods of integration once we know what qualitative data is available and the extent to which it 'matches' the context of the primary trial studies from the McCarthy 2015 review. Following CQIMG guidance, we recognise sufficient complimentary contextual factors are needed to integrate evidence from the two reviews (Noyes et al, forthcoming update to Noyes 2011). In this regard we have a review author (BM), who was the lead author on the McCarthy 2015 review, to

facilitate the synthesis and integration of this qualitative evidence synthesis with that Cochrane effectiveness review.

We will also consider findings from Young 2017, which is being conducted concurrently with this review, to inform our development of a logic model. As the first author of Young 2017 is also an author on this Cochrane Review, we will be able to keep in close communication with the authors from Young 2017 during this process. However, the degree to which we can integrate our qualitative findings with findings from Young 2017 will depend on the type and richness of data that are available and on the degree of alignment between contexts of studies in each review. We will also articulate gaps in evidence for future research.

## **Consumer consultation**

During the development of this protocol, we consulted members of a community-based COPD group in New Zealand (SYLO - Sing Your Lungs Out, a community choir for people with COPD), most of whom had first-hand experience of attending pulmonary rehabilitation. Feedback from this group was incorporated into the Objectives and Methods sections of this protocol. We plan, on completion of our analysis, to return to this group to provide information on the summary findings and to seek feedback on interpretation of these findings and their implications for research and clinical practice, which we will incorporate into our write-up of the results of this qualitative evidence synthesis.

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\* Indicates the major publication for the study

#### **APPENDICES**

# Appendix I. MEDLINE search strategy

- 1. Lung Diseases, Obstructive/
- 2. exp Pulmonary Disease, Chronic Obstructive/
- 3. emphysema\$.tw.
- 4. (chronic\$ adj3 bronchiti\$).tw.
- 5. (obstruct\$ adj3 (pulmonary or lung\$ or airway\$ or airflow\$ or bronch\$ or respirat\$)).tw.
- 6. (COPD or COAD or COBD or AECB or AECOPD).tw.
- 7. or/1-6
- 8. exp Rehabilitation/
- 9. exp Physical Therapy Modalities/
- 10. (rehabilitat\* or fitness\* or exercis\* or train\* or physiotherap\* or (physical\* adj2 therap\*)).tw.
- 11. or/8-10
- 12. 7 and 11
- 13. qualitative research/
- 14. Interview/
- 15. (theme\$ or thematic).mp.
- 16. qualitative.af.
- 17. Nursing Methodology Research/
- 18. questionnaire\$.mp.
- 19. ethnological research.mp.
- 20. ethnograph\$.mp.
- 21. ethnonursing.af.
- 22. phenomenol\$.af.
- 23. (grounded adj (theor\$ or study or studies or research or analys?s)).af.
- 24. (life stor\$ or women\* stor\$).mp.
- 25. (emic or etic or hermeneutic\$ or heuristic\$ or semiotic\$).af. or (data adj1 saturat\$).tw. or participant observ\$.tw.
- 26. (social constructs or (postmoderns or post-structurals) or (post structurals or poststructurals) or post-moderns or feminis or interprets).mp.
- 27. (action research or cooperative inquir\$ or co-operative inquir\$).mp.
- 28. (humanistic or existential or experiential or paradigm\$).mp.
- 29. (field adj (study or studies or research)).tw.
- 30. human science.tw.
- 31. biographical method.tw.
- 32. theoretical sampl\$.af.
- 33. ((purpos\$ adj4 sampl\$) or (focus adj group\$)).af.
- 34. (account or accounts or unstructured or open ended or open ended or text\$ or narrative\$).mp.
- 35. (life world or life-world or conversation analys?s or personal experience\$ or theoretical saturation).mp.
- 36. ((lived or life) adj experience\$).mp.
- 37. cluster sampl\$.mp.
- 38. observational method\$.af.
- 39. content analysis.af.
- 40. (constant adj (comparative or comparison)).af.
- 41. ((discourse\$ or discurs\$) adj3 analys?s).tw.
- 42. narrative analys?s.af.
- 43. colaizzi\$.tw.
- 44. spiegelberg\$.tw.
- 45. (van adj manen\$).tw.
- 46. (van adj kaam\$).tw.
- 47. (merleau adj ponty\$).tw.

- 48. husserl\$.tw.
- 49. foucault\$.tw.
- 50. (corbin\$ adj2 strauss\$).tw.
- 51. glaser\$.tw.
- 52. or/13-51
- 53. 12 and 52

# **CONTRIBUTIONS OF AUTHORS**

All review authors contributed to the conceptualisation of the review. WL prepared the first draft of the protocol, with input from all review authors during the development of this protocol. All review authors read and approved the final protocol version.

# **DECLARATIONS OF INTEREST**

WL, EJCHS, TI, and BJ are employed as academics by the University of Otago in New Zealand.

JW is employed as an academic by Anglia Ruskin University in the UK.

MC is employed as an academic by the University of Canberra.

CD is employed as a manager for the Tu Kotahi Mā ori Asthma Trust in New Zealand.

CH and BM are employed as academics by NUI Glaway in Ireland.

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## Internal sources

- Rehabilitation Teaching and Research Unit, Department of Medicine, University of Otago (Wellington), New Zealand.
- WL, EJCHS, BJ, and TI all hold posts in the Department of Medicine, funded by the University of Otago
  - Anglia Ruskin University, UK.

JW holds a post at Anglia Ruskin University, UK

• Tu Kotahi Mā ori Asthma Trust, New Zealand.

CD is employed by Tu Kotahi Mā ori Astham Trust

• Health Research Institute, University of Canberra, Australia.

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• School of Nursing and Midwifery, National University of Ireland (NUI) Galway, Ireland.

CH and BM hold posts in the School of Nursing and Midwifery, funded by NUI Galway

External sources
We declare there were no external sources of funding for this systematic review, Other.