



Review article

A systematic review of the content and delivery of education in pulmonary rehabilitation programmes

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ABSTRACT

Introduction: Pulmonary rehabilitation (PR) is a core component of Chronic Obstructive Pulmonary Disease (COPD) management with well recognized benefits. While suggestions for educational content within pulmonary rehabilitation have been detailed in clinical guidance, it is unclear what educational content is delivered as part of pulmonary rehabilitation, who delivers it, and how it is delivered.

Methods: A systematic review was conducted to identify what educational content is delivered as part of pulmonary rehabilitation, how is this delivered and who delivers it. Databases were searched from 1981 to 2017 using multiple search terms related to “pulmonary rehabilitation” and “education”.

Results: Fourteen studies were identified. This included 6 survey studies, 5 quasi-experimental studies and 3 RCTs. Five key topics that were consistently included within PR programmes were identified as:

- 1) Anxiety/depression and stress management.
- 2) Early recognition of signs of infection.
- 3) Dyspnea and symptom management.
- 4) Nutrition.
- 5) Techniques using inhalers and nebulizers.

Broader topics such as welfare/benefits, sexuality, and advance care directives did not frequently feature. Only four studies used tools to measure knowledge or learning pre and post rehabilitation in an attempt to evaluate the effectiveness of the education delivered as part of PR.

Conclusions: The delivery of education in PR programmes is variable and does not follow suggested educational topics. Education needs to take a patient centered motivational approach to ensure effective delivery. Further research into appropriate educational outcome measures are needed, in order to evaluate the changes in behaviour associated with education.

1. Background

There are over 1 million people in the United Kingdom (UK) living with Chronic Obstructive Pulmonary Disease (COPD). This figure is expected to rise further over the next couple of decades and represents a considerable burden to the National Health Service (NHS) in the UK, costing around 9.9 billion pounds each year [1]. Pulmonary rehabilitation (PR) has been defined as “a comprehensive intervention based on a thorough patient assessment followed by patient-tailored therapies, which include, but are not limited to, exercise training, education and behaviour change, designed to improve the physical and

psychological condition of people with chronic respiratory disease and to promote the long-term adherence to health-enhancing behaviors” [2]. Pulmonary rehabilitation is offered to patients who are considered to be functionally disabled from their COPD (MRC grade 3 and above) [3].

PR is a core component of COPD management [4,5] with recognized benefits [6–10]. Benefits focus primarily on improving and maximizing lung function through physical activity and slowing disease progression [11–14]. However, other benefits have been identified including increased lung function, reduced length of hospital stay, reduced number and severity of exacerbations, fewer emergency consultations,

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increased functional ability, increased confidence, positive impact on anxiety and depression as well as improved ability to cope [7–10,15]. Those who attend PR sessions often do so because they have a desire to learn how to better self-manage their condition and meet others with similar problems [7].

Hill et al. highlighted the range of components within PR which can include facilitating smoking cessation, optimizing therapy, education around identification and management of symptoms as well as establishing social support networks and promoting mental health [16]. Self-management of COPD is a key component of pulmonary rehabilitation to improve chronic disease management [17]. It is essential that PR equips participants with the right tools to encourage and support people to take control of their condition, which should include the acquisition and use of self-management skills. Self-management is only associated with improvement in outcomes if the patient identifies deteriorating symptoms and implements the therapeutic interventions contained within their self-management plan [19,20]. PR should thus combine self-management support with motivating and empowering participants, and key skills are needed by the staff to deliver this i.e. motivational interviewing and shared decision-making [21]. Key components of self-management education are summarised by Effing et al. [22] and include smoking cessation, self-recognition and treatment of exacerbations, nutritional advice and management of dyspnea. It is important that the education component of PR does not just facilitate knowledge transfer but facilitates sustained behavior change [2,12,23,24].

Educational sessions delivered as part of pulmonary rehabilitation are an important mechanism in the promotion of effective and appropriate self-management in COPD. Published research has identified that there is significant variation in the content and delivery of education within PR programmes [25–27] and variation around which staff members are involved and specific interventions are included [28]. Although suggestions for educational topics are given, the most recent guidance on pulmonary rehabilitation [29] does not specify the core components of education in PR and how this should be delivered in practice. The aim of this systematic review was to appraise the existing published literature to identify the content of educational sessions within pulmonary rehabilitation and the method of delivery. This is important to inform future guidance and research on effective delivery styles and information content in education as part of pulmonary rehabilitation.

2. Methods

2.1. Search strategy

The following databases were searched: MEDLINE, EMBASE, CINAHL, PsycINFO, ERIC, Cochrane Library, Open Grey and DaRE. A

range of search terms and synonyms were used relating to “pulmonary rehabilitation” and “education” as shown in Table 1 (an example search is shown in Appendix 1), using truncation symbols and Boolean operators where appropriate. The databases were searched from January 1981 to July 2017 and were selected based on the following inclusion and exclusion criteria. Bibliographic software (Zotero) was used to store and manage the results of database searches. The review has been logged on PROSPERO (CRD42018091807).

2.2. Inclusion and exclusion criteria

Included studies were: qualitative, quantitative or mixed methods studies published in English; must have included an evaluation of a PR intervention or pulmonary rehabilitation programmes delivered to people with COPD, delivered in any setting and in any country worldwide; and which offered a description of the education component of the pulmonary rehabilitation programme. By “sufficient description” we meant that studies had to provide more than simply a basic topic guide or list, but additional details of what education was delivered, as well as how and/or who delivered the education. Studies which included only an educational session topic guide/list and no further information about the educational component were excluded. Systematic reviews and clinical guidelines were not included in the review, but their reference lists were scanned to identify relevant references potentially missed in the database searches.

2.3. Study screening

Two reviewers (NJR, LK) screened the study titles and abstracts, if available, of bibliographic records retrieved by the searches. Full-text copies of all papers reporting studies which met the inclusion criteria were retrieved. All of the studies were reviewed independently by both reviewers.

2.4. Data extraction and synthesis

A data extraction template was developed specifically for the purpose of the review. Study details that were extracted included: authors, country, population, sample size, setting (hospital, community or primary care), staffing i.e course lead/expertise (healthcare professional (HCP) or peers/lay experts), duration of PR, a description of the educational content, and educational tools used within the PR programme, and specific methods and formats of delivery. Data extraction was performed by one reviewer (NR) and double checked for accuracy by a second reviewer (LK). A narrative synthesis approach was used to compare and describe the educational topics that were included within the PR studies and their methods of delivery.

Table 1
Search terms.

SETTING	“hospital based” OR “community based” OR remote OR tele-delivery
POPULATION	“COPD” OR “pulmonary disease” OR “chronic obstructive” OR “emphysema”
INTERVENTION	Pulmonary Rehabilitation- “pulmonary rehabilitation”, OR “pulmonary” OR “rehabilitation”; AND Education - “Health education” OR “patient education”, OR “education”, OR “education content”, OR “educational delivery”, OR “disease management”, OR “delivery of health care”, OR “patient participation”, OR “educational content”, OR “educational delivery”, “topic” OR “session, OR “content “OR “tailoring” AND/OR Delivery of education - “health coach” “lay educator”, “expert patient”, OR “healthcare professional” OR “nurse” OR “Physiotherapist” OR “occupational therapist” AND/OR Behaviour Change Techniques (BCTs) – “self-management support”, OR “self-management” OR “self-management education” OR “self-care”, OR “social support” OR “problem-solving”, OR “counselling”, OR “counselling”, “action planning”, OR “action plan”, OR “health related QOL”, OR “QOL”, “mood”, OR “perceived well-being”, OR “self-efficacy”, OR “feedback”, “reinforcement”, OR “relapse prevention education”, OR “exacerbation management” OR “motivational strategies” OR “goal-setting” OR “motivational interviewing”, OR “behavior change”, OUTCOME
	“knowledge”, OR “outcomes”

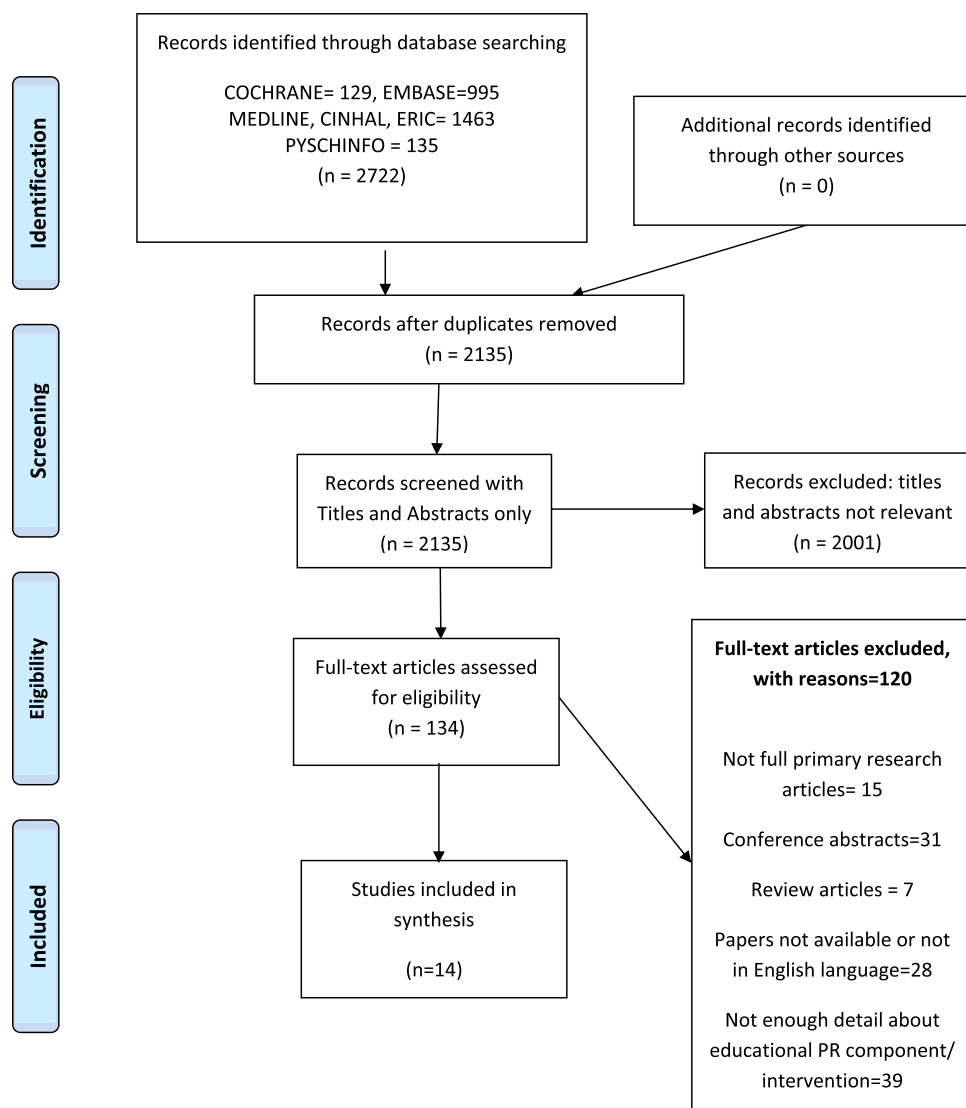


Fig. 1. PRISMA flow diagram.

2.5. Quality appraisal

The purpose of quality appraisal in this review was to assess the strengths and weaknesses in the included studies rather than as a basis for inclusion/exclusion. Two reviewers (NJR, LK) independently assessed the methodological quality of each of the included papers using a standardized critical appraisal tool appropriate to the study design [30–33]. Disagreements were resolved through discussion or involvement of a third reviewer (JC). Studies were grouped together according to study design (e.g. experimental RCT or quasi experimental or observational, or qualitative, and appropriate quality appraisal tools selected).

3. Results

3.1. Included studies

The database search produced 2722 articles of which 587 duplicates and 2001 articles were excluded based on title and abstract screening (PRISMA Fig. 1). Full texts of the remaining 134 articles were then

assessed for eligibility, of which 120 were excluded which did not meet the inclusion criteria. Thirty-nine contained limited information about the educational component of pulmonary rehabilitation, 28 did not have full text articles freely available or were not in English. Thirty-one were conference abstracts, with an additional 15 which were not full primary research articles (e.g. commentaries, editorials, discussion papers, guideline statements), and the final seven excluded papers were review articles. This left a remaining 14 studies which were eligible for inclusion in the review.

Of the fourteen studies, six were observational survey studies [34–39], five were quasi-experimental studies [40–44] and three were randomised controlled trials [45–47]. No qualitative studies were identified from the search. The characteristics of included studies are detailed in Appendix 4.

3.2. Quality assessment

Quality appraisal tables are shown in Appendix 2a-d. The included studies were of variable quality, with the quasi-experimental, case control studies [40,41] being of the poorest quality. The RCT studies

Table 3
Topics not well covered across the extracted studies.

Coping with lung disease	How to improve confidence, self-efficacy and self-management ^a	Benefits and welfare rights ^a
Travel ^a and leisure activities	Patient Support groups ^a	Medical tests
Oxygen ^a /NIV	Swallowing and COPD	Self-management
Smoking cessation ^a	Communicating with your healthcare provider	Action plans
Sexuality ^a	Family role	Identifying and changing beliefs and behavior ^a
Falls prevention	Sleep	Chest clearance ^a
Continence and COPD	Psychological impacts	Indoor and outdoor pollution
Home adaptation	End of life decisions	Advance directives ^a

^a These topics are identified as suggested topic areas in the BTS guidelines 2013 [26].

guidelines. Crisafuli et al. [40] gave participants information on non-included topics to cover their individual needs but this was not described in detail.

One of the key findings from this review is that educational content of PR is often poorly described in reports or studies, studies. The most common five PR educational content topics (full details in Table 2) across all of the included studies were:

- 1) Anxiety/depression and stress management,
- 2) Early recognition of signs of infection,
- 3) Dyspnea and symptom management,
- 4) Nutrition,
- 5) Techniques using inhalers and nebulizers.

These are key educational topics and these are highlighted in many clinical guidelines and expert reviews [24,29]. Other key areas which need to be included as part of PR education are key to developing self-management skills and promoting behavior change and include: goal setting, reflection, verbal persuasion and making a change plan. Such self-management goals were not well represented across the studies and this has been previously pointed out by Bourbeau et al. that often self-management is focussed on education rather than behavior change [48].

The remaining common topics includes the benefits of exercise, medication management, activities of daily living, anatomy and physiology and chest clearance (Table 2). As part of the review a long list of expected PR session topics was derived from the existing published literature but many did not appear in the review in more than a few of the studies (Table 3).

The study period for this review covers a significant period of time and some studies were published before 2000. Pulmonary rehabilitation is still a relatively new area and guidance for delivery of education within it has been limited. Some of the key concepts of self-management are still not well embedded into pulmonary rehabilitation and likewise some of the more patient-centred topics that participants will be keen to know such as travel and leisure activities, family roles, advanced directives and end of life decisions and sexuality are not well integrated. Similar findings were found by a national survey by Yohannes et al. who identified topics (sexuality, advice on travel and coping with the disease) which were not covered in 2004 [25]. There is also a disparity between what healthcare professionals wanted to deliver and what pulmonary rehabilitation participants wanted to be included in the educational sessions. Holland et al. identified that those with interstitial lung disease wanted to know about end-of-life planning and were happy to have this in a group setting [49] in contrast to

Wilson et al. who found participants with COPD thought it was inappropriate to have these discussions as part of a group setting [50]. Clinicians identified that they did not feel it is appropriate to provide info about prognosis in PR, as they were not the primary treating physician and therefore felt it is not their role [49]. In contrast Casey et al. found that health professionals suggested that topics such as end of life issues and oxygen should be included [51]. This highlights that a standard package of education may not be appropriate for all participants. The differences in content delivered may also be in part due to the skillset or availability of staff, which dictates content rather than patient-led feedback and redesign. Wilson et al. stated that when the appropriate health professional was not available the topic was frequently just omitted [50].

Key staff involved in PR most frequently included, physicians (11/14), nurses (11/14), nutritionists (8/14), occupational therapists (8/14), social workers (7/14), pharmacists (7/14), psychologists (7/14), physiotherapists/specialist physiotherapist (6/14) and respiratory therapists (5/14).

4.3. Style of educational delivery

Very few of the studies recorded how the education was delivered although six of the studies reported the use of lectures [34,35,39,42–44]. Information seems to be offered in a very traditional way with lectures and written information, and health literacy does not seem to be considered. Lectures need to be interactive and include participation and other approaches may be more effective to share information with adult learners. Shame and self-guilt are prominent emotions in COPD and so educational content has to be offered in supportive ways.

One of the studies not included in the review by Rodgers et al. as it did not have enough detail about the content and staffing of the PR programme, did report some interesting findings from their qualitative study. This study found that PR participants wanted sessions to be more interactive rather than didactic [52]. Rodgers et al. also highlighted the lack of clarity raised by participants as to whether family members can attend alongside participants during PR [52]. Family and carers are an important resource for those with COPD helping with everyday living and managing breathlessness and providing social support and are often not included in potential interventions and management plans [53]. In most of the studies education was delivered in a group format, although some of the surveys showed that a proportion of participants had the option of one-to-one PR. Three of the studies [33,34,42] reported a range of programmes which were delivered on an individual basis ranging from 22% [35] to 82.9% [44].

There was significant use of supplementary educational materials such as handouts, manuals, written action plans, booklet and leaflets in nearly all of the studies.

There was no detail given in any of the studies around the use of tailoring or the assessment of learning needs, nor the use of tools such as VARK (visual, aural, read/write, kinaesthetic) or motivational interviewing to deliver educational materials. Adapting pulmonary rehabilitation for those with low literacy skills was not highlighted. Sadeghi et al. highlighted the impact of health literacy as a barrier to effective communication in pulmonary rehabilitation, highlighting approaches such as incorporating family support, and improving visual and written materials [54].

4.4. Outcome measure tools used

Only four of the studies used tools to measure knowledge pre and post rehabilitation [40,41,43,45]. It should be noted that the studies assessed knowledge in different ways. Some looked specifically at knowledge learnt, using the Bristol Knowledge questionnaire [43] or the ESQ in the study by Crisafulli et al. [40]. Others looked at understanding, self-efficacy around self-management skills [43], the impact of education on perceived ability to self-manage [45], and levels of confidence around being able to self-manage in the future [41]. The BTS PR guidelines and the service specification do suggest that Patient satisfaction tools/surveys such as, Lung Information Needs Questionnaire or the Bristol Chronic Obstructive Pulmonary Disease Knowledge questionnaire or other validated questionnaires should be used to ensure the educational content is reviewed and improved regularly [55,56].

While health professionals can develop a PR programme which include key areas of knowledge and topic areas that they believe patients should acquire, there needs to be a dominant realisation that such knowledge acquisition may not be acted upon without appropriate personalisation and motivational techniques. These should involve identifying what it is the patient wants to achieve, encouraging patients to experiment, stimulating the patient to take responsibility for their health by asking questions rather than giving advice and solutions, and focusing on the positive benefits of optimal behaviors (not the negative of maladaptive behaviors) [22]. In addition to this the potential behavior changes need to be measured by an appropriate outcome measure. In a national survey carried out in 2004 no educational outcome measures were recorded, instead generic quality of life measures and Hospital Anxiety and Depression Scale (HADS), Borg Perceived rating of exertion and activities of daily living were used with shuttle walk tests or 6 min walk tests [25]. Outcome measures need to evaluate patient's knowledge, attitudes and self-efficacy or activation as well as their healthy behaviors gained through PR [48]. Both the recent American Thoracic Society/European Respiratory Society workshop report and a recent article by Stolikova et al. highlight the same issues raised here; the need for improved educational content that aligns with appropriate educational outcomes for sustained behavior change and longer term maintenance of quality of life and wellbeing for people attending PR [57,58].

5. Conclusion

PR is known to improve breathlessness, exercise tolerance and quality of life. There is limited research published into the delivery and educational content of pulmonary rehabilitation. The published literature focusses mostly on the benefits of the exercise component of

pulmonary rehabilitation rather than the role/impact of the educational component. Over the same time period there has been an increase in the delivery of generic and specific self-management programmes that have focussed specifically on behavior change and self-management of long term conditions such as COPD but little has been researched about specifically updating and improving existing pulmonary rehabilitation and rolling this out at scale. Often programmes are designed and run by the healthcare professionals without any patient input or feedback. Programmes are delivered dependent on existing staff expertise and resources rather than according to guidelines. Although a broad range of educational topics for PR have been identified in the literature, PR education is mostly confined to aspects of the disease, physiotherapy skills, nutrition, energy conservation, and coping with anxiety and depression.

This review has shown that even in published studies and surveys there is significant variation in the content of delivery of education in PR. Most of the published literature focused on topic guides and education topics, not on methods of delivery and enhancing skills to promote behavior change, and educational outcomes were not measured consistently. Education does not appear to be tailored to the needs of the adult learners attending pulmonary rehabilitation. As noted in this review, the delivery of education in PR was mostly lecture style with powerpoint slides, although some studies used different materials such as cue cards and posters. Most studies provided core written materials either from national organizations, others had developed their own materials but there was no mention on whether these could be tailored for different populations and very few had assessed the literacy levels of these. There was very little in the published papers around the use of outcome measures to assess the educational component. Only four studies used tools to evaluate participants' knowledge, confidence, understanding, self-efficacy around self-management skills after education [40,41,43,45]. There were no educational outcome measures described for the educational component for the survey studies.

Wilson et al. [50] researched the patient's perspective about education in pulmonary rehabilitation. The findings from this study recommended group formats with practical demonstrations of treatment strategies using visual aids. The timing of educational sessions was identified as important, often participants were too tired after exercise so it should be the first activity of the session [50]. All felt peer support and shared knowledge were important. The study by Wilson et al. was published in 2007 and it is interesting that some of these findings are not evident in a lot of the studies in this review. None of the studies identified used expert patients or volunteers. Patients were largely unaware of the existence of support groups, again a topic often not covered by programmes.

The delivery of pulmonary rehabilitation education is variable and does not cover all of the suggested educational topics. Guidance on core education topics and delivery is needed taking a patient centred motivational approach to ensure education is delivered effectively. Further research into appropriate educational outcome measures are needed to ensure behavior change is captured.

Declarations of interest

None

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Appendix 1. Search strategy

EBSCOhost

Searching: CINAHL, MEDLINE, ERIC Show Less Choose Databases

Library Logo

Select a Field (optional) Search Clear

AND Select a Field (optional)

AND Select a Field (optional) + -

Basic Search Advanced Search Search History

Search History/Alerts

Print Search History Retrieve Searches Retrieve Alerts Save Searches / Alerts

Select / deselect all Search with AND Search with OR Delete Searches Refresh Search Results

Search ID#	Search Terms	Search Options	Actions
S35	S1 AND S33 AND S34	Search modes - Find all my search terms	View Results (1,660) View Details Edit
S34	S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31	Search modes - Find all my search terms	View Results (4,945,238) View Details Edit
S33	S4 OR S32	Search modes - Find all my search terms	View Results (2,791,831) View Details Edit
S32	educational	Search modes - Find all my search terms	View Results (901,141) View Details Edit
S31	goal setting	Search modes - Find all my search terms	View Results (29,491) View Details Edit
S30	behavior change	Search modes - Find all my search terms	View Results (132,524) View Details Edit
S29	behaviour change	Search modes - Find all my search terms	View Results (75,850) View Details Edit
S28	motivational strategies	Search modes - Find all my search terms	View Results (3,790) View Details Edit
S27	exacerbation management	Search modes - Find all my search terms	View Results (4,582) View Details Edit
S26	relapse prevention education	Search modes - Find all my search terms	View Results (1,030) View Details Edit
S25	reinforcement	Search modes - Find all my search terms	View Results (56,559) View Details Edit
S24	feedback	Search modes - Find all my search terms	View Results (174,802) View Details Edit
S23	self-efficacy	Search modes - Find all my search terms	View Results (53,442) View Details Edit
S22	perceived well-being	Search modes - Find all my search terms	View Results (8,322) View Details Edit
S21	mood	Search modes - Find all my search terms	View Results (85,367) View Details Edit
S20	QOL	Search modes - Find all my search terms	View Results (35,286) View Details Edit
S19	health related QOL	Search modes - Find all my search terms	View Results (8,849) View Details Edit
S18	action plan	Search modes - Find all my search terms	View Results (20,048) View Details Edit
S17	action planning	Search modes - Find all my search terms	View Results (23,029) View Details Edit
S16	counseling	Search modes - Find all my search terms	View Results (180,624) View Details Edit
S15	counseling	Search modes - Find all my search terms	View Results (34,692) View Details Edit
S14	problem solving	Search modes - Find all my search terms	View Results (97,851) View Details Edit
S13	social support	Search modes - Find all my search terms	View Results (213,177) View Details Edit
S12	self-care	Search modes - Find all my search terms	View Results (66,758) View Details Edit
S11	self-management education	Search modes - Find all my search terms	View Results (11,142) View Details Edit
S10	self-management support	Search modes - Find all my search terms	View Results (6,780) View Details Edit
S9	self-management	Search modes - Find all my search terms	View Results (22,942) View Details Edit
S8	tailoring	Search modes - Find all my search terms	View Results (15,097) View Details Edit
S7	content	Search modes - Find all my search terms	View Results (749,923) View Details Edit
S6	session	Search modes - Find all my search terms	View Results (133,628) View Details Edit
S5	topic	Search modes - Find all my search terms	View Results (1,192,608) View Details Edit
S4	education	Search modes - Find all my search terms	View Results (2,603,845) View Details Edit
S3	patient education	Search modes - Find all my search terms	View Results (337,638) View Details Edit
S2	health education	Search modes - Find all my search terms	View Results (679,510) View Details Edit
S1	pulmonary rehabilitation	Search modes - Find all my search terms	View Results (12,795) View Details Edit



Appendix 2. Quality Appraisal tables

Appendix Table 2a
Observational studies

	Bickford (a)	Bickford (b)	Borkgren	O'Neill	Heffner	Wadell
1. Did the study address a clearly focused question/issue?	Yes	Yes	Yes	Yes	Yes	Yes
2. Is the research method (study design) appropriate for answering the research question?	Yes	Yes	Yes	Yes	Yes	Yes
3. Is the method of selection of the subjects (employees, teams, divisions, organizations) clearly described?	No	No	Yes	Yes	Yes	Yes
4. Could the way the sample was obtained introduce(selection)bias?	Yes	Yes	Yes	No	Yes	No
5. Was the sample of subjects representative with regard to the population to which the findings will be referred?	Yes	Yes	Yes	Yes	Yes	Yes
6. Was the sample size based on pre-study considerations of statistical power?	No	No	No	No	No	No
7. Was a satisfactory response rate achieved?	Can't tell	Can't tell	Yes	Yes	Yes	Yes
8. Are the measurements (questionnaires) likely to be valid and reliable?	Yes	Yes	Yes	Yes	Yes	Yes
9. Was the statistical significance assessed?	No	No	No	No	No	No
10. Are confidence intervals given for the main results?	No	No	No	No	No	No
11. Could there be confounding factors that haven't been accounted for?	Yes	Yes	Yes	Yes	Yes	Yes
12. Can the results be applied to your organisation?	Can't tell	Can't tell	Yes	Yes	Yes	Yes

Appendix Table 2b
Quality appraisal - Experimental designs (non-RCT)

	McDonnell	Burkow
1. Did the trial address a clearly focused issue?	Yes	Yes
2. Was the cohort recruited in an acceptable way?	Can't tell	Can't tell
3. Was the exposure accurately measured to minimise bias?	Yes	Yes
4. Was the outcome accurately measured to minimise bias?	Yes	Yes
5. (a) Have the authors identified all important confounding factors?	No	Yes
5. (b) Have they taken account of the confounding factors in the design and/or analysis?	Can't tell	Yes
6. (a) Was the follow up of subjects complete enough?	Yes	Yes
6. (b) Was the follow up of subjects long enough?	Yes	No
7. What are the results of this study? HINT: Consider • what are the bottom line results • have they reported the rate or the proportion between the exposed/unexposed, the ratio/rate difference • how strong is the association between exposure and outcome (RR) • what is the absolute risk reduction (ARR)	Significant improvement in outcomes between baseline and 8 weeks, 52 weeks	mean change in the SGRQ total score (pre/post intervention) – 6.53 (CI 95% – 0.38 to – 12.68, <i>p</i> = 0.04) indicates a probable clinically significant effect
8. How precise are the results? HINT: • look for the range of the confidence intervals, if given	Means ± SD given only no confidence intervals	SGRQ median and 25th percentile–75th percentile, mean and confidence interval were calculated.
9. Do you believe the results?	Yes	Yes
10. Can the results be applied to the local population?	Can't tell	Can't tell
11. Do the results of this study fit with other available evidence?	Yes	Yes

Appendix Table 2c
Quality appraisal Case control studies

	Scherer	Crisafulli
1. Did the study address a clearly focused question/issue?	Yes	Yes
2. Did the authors use an appropriate method to answer their question?	Yes	Yes
3. Were the cases recruited in an acceptable way?	Can't tell	Can't tell
4. Were the controls selected in an acceptable way?	Can't tell	No
5. Was the exposure accurately measured to minimise bias?	No	Can't tell
6. (a) Aside from the experimental intervention, were the groups treated equally?	No	Yes
6. (b) Have the authors taken account of the potential confounding factors in the design and/or in their analysis?	No	No
7. How large was the treatment effect?	Significantly improvement in CSES in those with exercise and education programme after 6 mths (<i>p</i> = 0.001)	Similar improvement in PR outcomes was recorded in both groups at Tend, whereas ESQ total (learning effect questionnaire) and partial scores significantly increased in 'Completers' only (<i>p</i> < 0.001).
8. How precise was the estimate of the treatment effect?	0.22 (0.59) No confidence intervals	No confidence intervals
9. Do you believe the results?	No	No
10. Can the results be applied to the local population?	Yes	Can't tell
11. Do the results of this study fit with other available evidence?	Yes	Yes



Appendix Table 2d
Quality appraisal RCT designs

	Blackstock	Hickey	Marquese
1. Did the study address a clearly focused issue?	Yes	Yes	Yes
2. Was the assignment of patients to treatments randomised?	Yes	Yes	Yes
3. Were all of the patients who entered the trial properly accounted for at its conclusion?	Yes	Yes	Yes
4. Were patients, health workers and study personnel “blind” to treatment?	Yes	No	Yes
5. Were the groups similar at the start of the trial	Yes (although no p values given)	Yes	Yes
6. Aside from the experimental intervention, were the groups treated equally?	Yes	Can't tell	Yes
7. How large was the treatment effect?	No difference between the two treatment groups for disease-specific HRQoL, Chronic Respiratory Disease Questionnaire, Hei Q and 6-min walk distance	No difference was found in the prevalence of good technique post training or at final assessment between the two groups.	Patients (P = 0.048) and family members (P = 0.004) in the family-based PR had significantly greater improvements in family coping, sexual relationships (P = 0.026) and in psychologic distress (P = 0.033)
8. How precise was the estimate of the treatment effect?	95% Confidence intervals	CI information not presented	Reported as mean ± SD/CI information not presented
9. Can the results be applied to the local population, or in your context?	Can't tell	Can't tell	Can't tell
10. Were all clinically important outcomes considered?	No Literacy levels, completion rates of educational sessions, qualitative views of participants	No Literacy levels Qualitative views of participants	No Literacy levels Qualitative views of participants
11. Are the benefits worth the harms and costs?	Yes	Yes	Yes

Appendix 3
Educational tools and style of delivery in the review studies (n = 14)

	Bickford	Bickford	Borkgren	McDonnell	Cosgrove	Heffner	Wadell	O'Neill	Blackstock	Hickey	Marquese	Crisafulli	Burkow	Scherer
No information reported on how education is delivered	X		X			X		X				X		X
P-point presentation									X					
Formal lecture	X			X	X		X						X	
Discussion groups							X		X				X	
Video/internet	X			X									X	
Demonstration and practice										X				
Case scenarios														
Peer observation														
Expert Patient/volunteer														
Inclusion of family members							X	X						X
Additional materials	Patient education manual Materials included, leaflets and syllabus	Patient education manual Materials included, slides, video - tapes and audio - tapes	Multiple media used (American Lung Assoc materials) or own developed materials. One site used Pre-/post- quiz to test knowledge	Educational video Comprehensive manual containing the educational materials	introductory guide, scripted HP manuals, cue cards, patients information booklet, key messages, written action plan) UGOPD questionnaire and Bristol COPD knowledge questionnaire	Written materials and guides			Education booklet Impact of education measured by heiQ	Leaflet information on how to use your inhaler	Handouts provided after educational sessions	ESQ learning questionnaire pre/post PR	Videoconferencing was used to deliver education	Handouts given as part of the class

Appendix 4
Literature table of included studies

Full reference (country)	Study details (design, setting, sample size and population/participants)	Staffing (lead and facilitators; i.e. healthcare professional, lay)	Screening for entry to PR/ baseline and description of the overall programme	Education sessions (details of individual education sessions, materials used, structure - group/one-to-one set ups, family/carer participation)	Outcome measures	Findings
1. Bickford LS, Hodgkin JE. National Pulmonary Rehabilitation survey. J Cardio-pulmonary Rehabil 1988; 11: 473–491 (USA)	Descriptive survey; 30 item questionnaire sent to directors and medical directors of PR programs nationwide (outpatient and inpatient programmes) to describe services. The survey tool is not described in any detail. Topic areas included programme size and length, programme setting, type of facility, patient type. Referral source, patient testing, staffing, programme content, charges and reimbursement and documentation and monitoring. Response rate not given. 150 responses, from 37 states, Recruitment through 3 networks (AACRC111/150, AACVPR 17/150, NCPRN 22/150)	PR teams consisted of: physician 88%, dietitian 85%, registered respiratory therapist (RRT) 76%, RN, 65%, social worker 63%, physical therapist 57%, certified respiratory therapist (CRT) (51%), pharmacist (35%), occupational therapist 55%, pastoral care (20%), exercise physiologist (13%), technician (4%), counsellors (1%), home care individual (0.66%), massage therapist (0.66%), speech therapist (0.66%)	Physician referral required for 96% of programmes. Spirogram needed in 89%, chest x ray (70%), pulmonary exercise stress tests (65%), blood gases (45%), 12 min walk test (34%) and psychological testing (28%) Programmes met from between 1 and 8 h per day (mean 2.2hrs) on 1–7 days (mean 2.6days) per week ranging from 1 to 52 weeks (mean 8.3 weeks). An individual program is used by 28% of respondents, group format by 30% and combination by the remainder 42%	Formal lecturers used in 95% of programmes, less than half 47% include a lecture on smoking cessation (47%) Patient education materials (including videotapes, pamphlets, syllabi) developed by 124 programmes (83%) and 69% willing to share materials An individual program is used by 28% of respondents, group format by 30% and combination by the remainder 42%	Descriptive study only	A wide range of staff shown to be involved in PR, most specifically need referral from a physician and pre-screening before entry to PR. Content mostly formal lectures. A wide range of materials used for the education.
2. Bickford LS, Hodgkin JE. National Pulmonary Rehabilitation survey update J Cardipulmonaryrehabil 1995; 15: 406–411 (USA)	Descriptive survey; 55-item questionnaire sent to programme leads to describe services. Most outpatient (94%) 27% also included in patients rehabilitation hospitals/fitness centres etc The survey tool is not described in any detail. Topic areas included staffing, content, charges and reimbursement, programme sites/facility types, entrance requirements, referrals and equipment. Responses rate not given. 283 responses from 44 states. Recruitment through 3 networks questionnaire distributed between June 1992–April 1993), distributed to CCR, AACPR, CSPR)	PR teams consisted of: dietitian (83.4%, 236/283) physician (78.9%, 221/283) RRT (72.9%, 204/283) RN (68.4%, 188/283) social worker (58.2%, 142/283) physical therapist (49.5%, 140/283) occupational therapist (48.5%, 137/283) CRT (44.8%, 127/283) exercise physiologist (44.9%, 126/283) pharmacist (34.8%, 98/283) psychologist (23%, 65/283) chaplain (18.7%, 30/283) licenced practical nurse - LPN (7.8%, 22/283) nurse practitioner (3.9%, 11/283)	Physician referrals required for 88% of programmes 49% also accepted self-referrals, 45% referred by primary care physician Spirogram performed 80% at beginning of the programme, EKG 67%, ABG (testing) 65%, chest xray (57%), exercise stress test (55%), lung volumes (49%), diffusing capacity (48%), chemistry panel (44%), 6- minute walk test (39%), pulmonary EST (37%), 12 min walk test (31%), ABG with exercise (25%), psychological test (7%) Programmes met for a mean 2 h per day for 9 weeks with a mean programme length of 45 h. An individual program is used by 22% of respondents, group format only by 3% and combination by the remainder 75%	The education style was not described. Lecture topics (only topic titles were given) that are routine components of PR programmes were: Aerobic exercise (99%, 274/283) Breath retraining (99%, 274/283) Activities of daily living/energy conservation (50.2%, 255/283) Early warning signs of infection (93.6%, 265/283) Relaxation/panic control (93.6%, 265/283) Nutrition (93.3%, 264/283) Inhaler training (92.2%, 261/283) Oral medications (92.2%, 261/283) Upper extremity exercise (92.2%, 261/283) Stretching and flexibility (91.9%, 259/283) Oxygen therapy (87.6%, 248/283) Indoor and outdoor pollution (82%, 232/283) Smoking cessation (88.9%, 229/283) Postural drainage and chest physiotherapy (80%, 215/283) Travel for the lung patient (74.6%, 211/283) Medical test (74.3%, 210/283) Sexuality (68.2%, 193/283) Educational manual used in 92% of the programs 41% used educational videotapes, 30% used slides and 29% used audiotape programs An individual-only format was used by 22% of the programmes and 211 used a format which combines individual and group activities 75%	Descriptive study only	PR was mostly conducted in a hospital setting to rehabilitate predominantly COPD outpatients. Most PR programmes accepted those who smoked (83%, 225/283). 88% reported physician referrals were required but 49% could accept self-referrals. A number of assessments made at the beginning of the programme (not stated if this is part of the screening process). A wide range of staff involved in the teams. Physicians had a varying role. The topic list included a significant number of exercise topics included in the list. 147/283 stated that smoking cessation was offered

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Appendix 4 (continued)

Full reference (country)	Study details (design, setting, sample size and population/participants)	Staffing (lead and facilitators; i.e. healthcare professional, lay)	Screening for entry to PR/ baseline and description of the overall programme	Education sessions (details of individual education sessions, materials used, structure - group/one-to-one set ups, family/carer participation)	Outcome measures	Findings
3. Blackstock FC, Webster KE, McDonald CF, Hill CJ. Comparable improvements achieved in chronic obstructive pulmonary disease through pulmonary rehabilitation with and without a structured educational intervention: a randomised controlled trial. <i>Respirology</i> (2014) 19:193–202 (Australia)	Randomised controlled trial; large metropolitan tertiary hospital. Participants randomised to either 8 weeks twice weekly group exercise training plus education or exercise training alone. COPD patients referred for outpatient PR were invited to participate. 141 were allocated to the intervention arm, and 126 in the control arm of the study.	Team members who delivered components of the PR intervention included: Respiratory physician Respiratory scientist Pharmacist Respiratory nurse Physiotherapist Occupational therapist Exercise physiologist Dietician Social worker Speech therapist	Screening for entry to PR/ baseline and description of the overall programme baseline assessment included screening for nutritional and psychological abnormalities.	The education programme consisting of sixteen 45-min sessions. The content and format were consistent with international position statements/recommendations. Group education sessions minimized didactic delivery, delivery included facilitated. Group discussions with MDT. Lung disease and COPD management - Respiratory physician Respiratory function tests - Respiratory scientist Medications Pharmacist - Home oxygen therapy Respiratory physician Self-management including exacerbations - Respiratory nurse Managing breathlessness - Physiotherapist Energy conservation - Occupational therapist Exercise and physical activity - Exercise physiologist Stress and anxiety - Occupational therapist Nutrition and health eating - dietician Sexuality and intimacy - Respiratory nurse Community resources - Social worker Swallowing and COPD - Speech therapist Swallow screening - Speech therapist Continence and COPD - Physiotherapist Airway clearance - Physiotherapist Individual action plans were produced and reviewed at each session and included short term changes over 1–2 week periods. An illustrated education booklet, compiled by MDT with patient feedback, was issued to participants. Content was reviewed by a senior respiratory physician, and language and structure were edited by a reading language specialist to achieve a good health literacy Carers or support people were welcome to accompany participants to all sessions	Primary outcomes included: disease-specific HRQoL evaluated with the self-reported Chronic Respiratory Disease Questionnaire (CRQ), CRQ measures health related quality of life in patients with respiratory disease. There are 20 questions scored on a 7-point Likert-type scale for four domains: dyspnea, fatigue, emotional function and mastery. Secondary outcomes included dyspnea, assessed with the Medical Research Council dyspnoea scale, functional activity with the grocery shelving task, general HRQoL using the Assessment of Quality of Life tool and self-efficacy with the General Self-Efficacy Scale-12. health-care usage was measured as respiratory-related hospital admissions.	There were no significant differences between the groups for any Chronic Respiratory Disease Questionnaire domain scores or 6-min walk distance There were no clinically important differences between the groups in any outcomes, reinforcing the belief that exercise is the key component for improving functional capacity and HRQoL in a pulmonary rehabilitation programme. The heIQ was used for phase 2 participants in an attempt to detect differences between the groups related to the education intervention – no significant differences between the groups. A limitation of this study is the completion rate with only 60% of those randomised completing the intervention protocol and 26% of participants not attending any follow-up assessment.

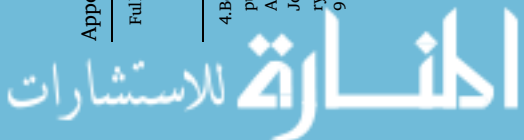
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Appendix 4 (continued)

Full reference (country)	Study details (design, setting, sample size and population/participants)	Staffing (lead and facilitators; i.e. healthcare professional, lay)	Screening for entry to PR/ baseline and description of the overall programme	Education sessions (details of individual education sessions, materials used, structure - group/one-to-one set ups, family/carer participation)	Outcome measures	Findings
4. Borkgren M.W. Diversity in pulmonary rehabilitation: A geographic survey study. <i>Journal of Cardiopulmonary Rehabilitation</i> (1989), 9:63-71 (USA)	Descriptive survey; Convenience sample of 31 pulmonary rehabilitation programmes A 26 item survey was mailed to 31 programme coordinators to describe services. Limited detail about the survey tool, open and closed questions and covered three key areas; programme organisation, methods of implementing daily programme activities and programme administration 16/31 (51.6%) response rate. 8 had outpatient programs 8 had inpatient and outpatient programs.	Staff involved in PR included: respiratory therapist (93.8%, 15/16) dietician (75.0%, 12/16) social worker (68.8%, 11/16) nurse (43.8%, 7/16) physical Therapist (37.5%, 6/16) occupational Therapist (31.3%, 5/16) pharmacist (25.0%, 4/16) exercise Physiologist (12.5%, 2/16) psychologist (6.3%, 1/16) All were MDT and had a physician medical director	Pre-testing/screening processes are not described.	Program length varied from 2 weeks - to 4-6 months and were mostly structured for three visits per week. Time devoted to education 9.13 ± 7.05 h, range 2-30 h The following topic areas were covered: Respiratory anatomy and physiology (pathophysiology of COPD) - (100%, 16/16) Breathing strategies (diaphragmatic/pursed lips breathing)- (100%, 16/16) Medication - (94%, 15/16) Relaxation techniques - (94%, 15/16) Complications of COPD (congestive heart failure, infection)- (87.9%, 14/16) Bronchial hygiene techniques - (87%, 14/16) Biofeedback - (25%, 4/16) Following topics addressed in 1-3 programs Travel, nutrition, sexuality, energy conservation in activities of daily living, diagnostics. Multiple media were used including published materials (American Lung association brochures) in 86.9% (14/16) programs and videotapes in 94% (15/16) (Pulmonary self care: a program for patients encyclopedia britannica educational corporation, Chicago, 1980). 75% (12/16) institutions developed their own materials and 25% (4/16) used audiotapes (e.g better breathing today, health communication services, La Jolla, CA 1985). One program used a pre/post program quiz In 82.9% (10/16) programmes patients were seen individually. 4 programs had sessions in groups of 2-5 patients, for the remainder patients [2] seen in groups of 6-10	Descriptive study	16/31 programs responded (51.6%) response rate to look at similarities and differences in mid- west PR programmes. 82.9% (10/16) programmes seen patients individually. All programs were MDT, range in the topics delivered between institution. Limited survey tool
5. Burkow T.M. et al. Comprehensive pulmonary rehabilitation in home-based online groups: a mixed method pilot study in COPD. BMC research notes (2015). (Norway)	Mixed methods pilot study; One outpatient rehabilitation clinic at a university hospital 10 patients with a clinical diagnosis of COPD, age above 40 participated in a 9-week Internet-enabled home pulmonary Rehabilitation programme. Ten patients were recruited and allocated into two rehabilitation groups. The Regional Committee for Medical and Health Research Ethics (REC North) approved the study.	A multidisciplinary team consisting of a specialist, nurse, physiotherapist, nutritionist and social worker provided the online group education sessions.	Potential participants living in a location without potential access to a broadband network were excluded from participation The user's TV was connected to a small computer with an Internet connection, and a camera and a headset were used during videoconferencing. The participants used a keypad on a remote control to enter user data and answer multiple-choice questions in the health diary. The home programme was a modified version based on the outpatient pulmonary rehabilitation programme. It included weekly group education and exercise sessions, as well as individual consultations, for 9 weeks at home.	The education sessions were held once a week, lasting 60 min, with a lecture and discussion format. For some topics, the patients were requested to watch one or more online videos before the sessions. Educational topic sessions included: Proper use of medications Breathing strategies, anxiety and panic control, relaxation techniques and stress management Energy conservation Pathophysiology of lung disease Benefits and maintenance of physical activity Prevention and early treatment of respiratory exacerbations Nutrition Social security rights Maintaining the benefits of educational and exercise training The education was delivered as a group education session in lecture and discussion format. Carers/families could be involved but this needed to be agreed in advance and the person needed to be visible on camera.	The patients were assessed at baseline, and assessed and interviewed shortly after the intervention. Technology usability was assessed using interviews and the System Usability Scale (SUS) A semi-structured interview guide for telephone interviews were used with opened and closed questions was developed. The primary themes of the interview guide were user perceptions of the delivery mode and components of the programme. St Georges Respiratory Questionnaire (SQOR) was assessed pre and post PR	Comprehensive multidisciplinary pulmonary rehabilitation delivered in home-based online groups may be feasible for patients with COPD. The mode of delivery and components of the programme appeared to be acceptable, with high usability SUS scores. The programme provided an environment for learning both from healthcare personnel and from peers, for undertaking PR as well as for social support. Further work is needed.

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Appendix 4 (continued)

Full reference (country)	Study details (design, setting, sample size and population/participants)	Staffing (lead and facilitators; i.e. healthcare professional, lay)	Screening for entry to PR/ baseline and description of the overall programme	Education sessions (details of individual education sessions, materials used, structure - group/one-to-one set ups, family/carer participation)	Outcome measures	Findings
6. McDonnell, T. J., Concanon, D., Connor, M. C., O'Driscoll, M. F., O'Shea, F. D. Efficacy of pulmonary rehabilitation in an Irish population. <i>Irish Medical Journal</i> 94, 46–48 (2001). (Ireland)	Quasi experimental study Based in a hospital and outpatient setting 170 patients with COPD (mean FEV ₁ 43.1 17.0% pred.) were participated in the 8 week PR programme.	A multidisciplinary team consisting of a physician, a physiotherapist, a respiratory nurse, a dietician, a pharmacist, an occupational therapist and a social worker.	The first week of this programme consisted of an inpatient stay of 5 days and 4 nights, followed by twice weekly attendances of 2 h each.	The education was delivered by the MDT. The patient education consisted of the following: breathing techniques effective chest clearance and an exercise circuit (instruction supported with educational video) Relaxation methods – group session inhaler technique, nebuliser use and oxygen was reviewed by the respiratory nurse; Dietary requirements – reviewed by dietician Medication use and side effects - discussed with pharmacist; activities of daily living (ADLs) – reviewed occupational therapist. Group educational sessions took place in the form of 1 h lectures by each of the team members and each patient received a comprehensive manual containing the educational material.	Assessment at baseline, 8 and 52 weeks. Pulmonary function testing; exercise tolerance (shuttle walk test) and an endurance test (treadmill test); quality of life (CRDQ), the St. Georges Hospital Questionnaire (SGHQ) and the Breathing Problems Questionnaire (BPQ); and perceived dyspnoea on the Borg scale.	106/129 patients included at 8 weeks and 78/129 were included at assessment at 52 weeks. Significant improvements (between baseline and wk 8) in exercise tolerance, (shuttle p < 0.001, treadmill p < 0.001), QoL, (BPQ p < 0.001, CRDQ p < 0.001, SGHQ p < 0.001) and dyspnoea (p < 0.001) were demonstrated after 8 weeks and maintained at 52 weeks. These results suggest that pulmonary rehabilitation can increase exercise tolerance and improve QoL in patients with COPD.
7. Cosgrove D., MacMahon J., Bourbeau J., Bradley J.M. & O'Neill B. Facilitating education in pulmonary rehabilitation using the Living Well with COPD programme for pulmonary rehabilitation: A process evaluation. <i>BMC Pulmonary Medicine</i> (2013). (Northern Ireland)	Quasi experimental study Process evaluation; three Health and Social Care Trusts in Northern Ireland Evaluation of the Living Well with COPD: a plan of action for life – self management programme adapted for use with PR. Health professionals who were involved in the delivery of education sessions in pulmonary rehabilitation based in hospital and community settings were invited to participate. 57 patients with COPD were recruited from the pulmonary rehabilitation assessment clinics at each participating site.	A total of 25 health professionals were involved in the delivery of education in this study. A range of disciplines were involved: nurses, physiotherapists, occupational therapists, a doctor and a pharmacist. The mean number of health professionals who delivered education sessions in each site was 3 health professionals (SD: 1; range: 2–5). The disciplines of the health professionals who delivered the education varied between sites depending on the skill mix available.	The programme was adapted for use in UK pulmonary rehabilitation using focus groups to determine the topics of interest and style of delivery. They preferred practical group-based education sessions delivered using visual aids and models and supplemented by written information. The number of education sessions from eight to six and the length of the education sessions from 1 to 1½ hours to 30–45 min.	The key topics included: disease education, management of breathlessness, exacerbation management, medications, psychosocial issues and welfare and benefits. Session 1 Management of Breathlessness Session 2 Energy Conservation Session 3 Overview of the Action Plan and Management of an Exacerbation Session 4 COPD Medication and appropriate use of Inhalation Devices Session 5 Management of Stress, Anxiety and Depression Session 6 Continuing Exercise and Self-Management Strategies Gaps and differences in the programme warranted the development of new materials/content and the adaptation of existing materials/content. Experts and health professionals in their respective fields advised, collaborated on and reviewed individual sessions and/or specific information. All modifications and reformatting were reviewed in collaboration with the authors of the LWVW COPD programme who approved all final materials Each of the modified education sessions was delivered to a lay population to establish length of time, ease of use and comprehension. It was delivered using a range of educational materials and resources for both health professionals (introductory guide, health professional manuals [n = 6], posters [n = 25] and cue cards [n = 6]), and patients (information booklet, key messages [n = 5] and written action plan) Terminology was reviewed and localised to improve readability and applicability of information. Cue cards were developed to display during the exercise classes to help integrate key self-management skills (for example, pursued	Understanding COPD (UCOPD) questionnaire which assesses their satisfaction with the education component of pulmonary rehabilitation Changes in patients' knowledge and self-efficacy to manage their condition were measured using the UCOPD questionnaire and the Bristol COPD Knowledge questionnaire (BGKQ) pre- and post-pulmonary rehabilitation Health professionals' feedback on how they used the content and materials and their views on using programme to deliver key information and self management strategies relevant to patients were gathered using written feedback questionnaires.	monstrated that the adapted LWVW COPD programme for pulmonary rehabilitation can be used to deliver high quality PR education sessions

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Appendix 4 (continued)

Full reference (country)	Staffing (lead and facilitators; i.e. healthcare professional, lay)	Screening for entry to PR/ baseline and description of the overall programme	Education sessions (details of individual education sessions, materials used, structure - group/one-to-one set ups, family/carer participation)	Outcome measures	Findings
8. Crisafulli E. et al. Learning impact of education during pulmonary rehabilitation program. An observational short-term cohort study. <i>Monaldi Archives for Chest Disease - Pulmonary Series</i> (2010). <i>Monaldi Arch Chest Dis</i> 2010; 73: 2, 64–71 (Italy)	physician, respiratory therapist, nurse and psychologist	6 × 1 h educational sessions Patients were grouped to attend each lesson in the morning at the same time and following training activities, but they were left free to choosing if they wanted to participate in each lesson. Sessions were led by different “health educators” (physician, respiratory therapist, nurse and psychologist) on the topics.	lip breathing and pacing). Key message summary sheets were developed for patients to summarise each education session to help increase information uptake and memory recall. A written action plan for COPD was developed based on the original IWWCOPD programme. The six sessions included the following topics: Anatomy and physiology of pulmonary system, early recognition of symptoms and signs of exacerbation (physician), role of muscle training and chest physiotherapy in pulmonary diseases (respiratory therapist), domiciliary use of inhalers (nurse and respiratory therapist), management of mood disturbances (psychologist). Any other specific information and/or educational material (i.e. leaflets) on other topics were encouraged and proposed to each patient according to his/her individual needs;	Anthropometric and demographic characteristics were collected at baseline including 6MWD, Medical Research Council (MRC) scale and St. George's Respiratory Questionnaire-GRQ. Lung function in terms of dynamic volumes (forced expiratory capacity in the 1st second-FEV ₁ , and FEV ₁ to forced vital capacity-FVC ratio). A specific questionnaire (ESQ) completed by participants to assess knowledge and the learning impact in three areas: <i>Symptoms-therapy, Aids, Mood</i> . validated in Italian language were recorded as general PR outcomes.	Similar improvement in PR outcomes was recorded in both groups, ESQ total and partial scores significantly increased in ‘Completers’ only ($p < 0.001$). ESQ-Aids score improved to a greater extent in ‘Completers’ than in ‘Control’ ($+0.60 \pm 1.03$ vs $+0.27 \pm 1.27$ point respectively, $p = 0.036$). A higher proportion of ‘Completers’ improved above the median change of both ESQ total and aids scores ($p < 0.05$). Attending educational sessions produces a specific short-term learning effect during rehabilitation of COPD patients. Not RCT, or on intention to treat basis Eighty-two percent of the 218 responding programs discussed with patients prognostic information. Only 33% of programs asked patients if they had advance directives. Thirty-three percent of programs provided some form of advance directive education, and 42% distributed directive educational material, usually through informal and unstructured methods. Larger programs were more likely to present information about patient prognosis. Most programmes (86%) stated that they would initiate educational sessions on
9. Hefner J.E., Fahy B. & B-arbieri C. Advance directive education during pulmonary rehabilitation. <i>Chest</i> (1996). (USA)	Not described	Not described	Of the 218 responding programs, 82% discussed with patients information relating to the prognosis and natural history of their lung diseases, including issues around complications. The 73 programs that collected information on advance directives did so through group sessions directed by social workers, the outpatient admissions, classes on advance directives, or hospital databases. Educational sessions on LW or DPAHC were presented by 33% of programs (n = 73). Living wills (LW) and durable power of attorney for health care (DPAHC) Only 8% of the 218 programs provided details that they discussed advance directive education in structured sessions for all participants. Forty-two percent (n = 92) of programmes stated that they distributed some form of written materials on living wills and durable power of attorney for healthcare. Forty-one of these programs also stated that they included topics covering patient rights including communication, patient autonomy, right-to-die, ventilators, DNRs and funerals. 77% agreed that PR was an appropriate site to introduce	Descriptive study	(continued on next page)



Appendix 4 (continued)

Full reference (country)	Study details (design, setting, sample size and population/participants)	Staffing (lead and facilitators; i.e. healthcare professional, lay)	Screening for entry to PR/ baseline and description of the overall programme	Education sessions (details of individual education sessions, materials used, structure - group/one-to-one set ups, family/carer participation)	Outcome measures	Findings
10. Hickey, S. et al. The effect of structured education on inhaler technique. <i>Practice Nursing</i> 28, 196–206 (2017). (UK)	Cluster randomised controlled trial The study compared whether a structured education session would be more effective than an informal discussion in teaching inhaler technique and reducing inhaler misuse 136 participants in total were recruited to undertake PR at 4 different sites (ABCD) and the control and intervention was run at each site except site D which only had the intervention. The participants were randomised primarily on the geographical location of their usual residence.		The study inclusion criteria was anybody undertaking the PR course whose regular treatment required any form of inhaled medication delivered by a pMDI or DPI.	Most responding programmes (86%) stated that they would include educational sessions on advance directives if they had appropriate teaching materials. Most (67%) of the PR programmes did not introduce their patients to topics pertaining to advance directives. Only 9 of the 218 (4%) surveyed programs provided patients with instructional booklets combined with blank copies of LW and DPAHC forms. Participants randomised to usual care received their normal pulmonary rehabilitation inhaler technique training. The PR group (both participants and non-participants) received a brief summary of all the different pMDI, DPI and spacer devices available on local prescribing formulary. Their correct use was then demonstrated by the researchers. Following the education, the group was split into three or four smaller groups where more specific individualised training took place. Participants were asked to demonstrate inhaler technique using placebo inhalers. Any specific errors were highlighted and corrected enabling the researchers to confirm that the individual had demonstrated good inhaler technique. The intervention arm received identical inhaler training used in control but with the addition of a 10 min PowerPoint presentation. The purpose of the presentation was to explain why each inhaler use step is important with the evidence to support each step. The presentation consisted of 11 slides: Worldwide evidence for poor inhaler technique Effect of age on technique Most common errors Significance of inspiratory flow Inspiratory flow and how it affects drug deposition Poor teaching of inhaler technique by healthcare professionals Issues with education retention Choosing the correct device Correct use of a pMDI Correct use of a DPI Conclusion and recommendations Participants in the intervention arm were also given a leaflet entitled 'Information to use your inhaler device'. Following completion of all of the assessments participants and non-participants in the control arm were also given a copy of the information leaflet used in the intervention.	Placebo inhalers was used to check inhaler technique. AIM was used for all pMDI and DPI assessments	115 participants attended the education sessions with 98% (control) and 100% (intervention) achieving the standards for good inhaler technique. No difference was found in the prevalence of good technique post training or at final assessment between the two groups In older patients a more structured approach to teaching inhaler technique is no more effective than usual care.

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Appendix 4 (continued)

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11. Marquese A. et al. Family-based psychosocial support and education as part of pulmonary rehabilitation in COPD: A randomised controlled trial. <i>Chest</i> (2015). (Portugal)	physiotherapist, gerontologist, psychologist, nurse, and clinician	12 weeks of PR composed of exercise training and psychosocial support and education, conducted in primary care centres Family members assigned to the family-based PR participated in the psychosocial support and education component together with patients. Family members randomised to conventional PR did not attend the sessions with patients, apart from baseline and post-intervention assessment appointments.	<p>Educational sessions were designed based on a comprehensive literature review on COPD rehabilitation, family needs etc. Education aimed to provide information about COPD, increase the family skills set to adjust to and manage the disease, and promote adherence to therapy and healthy lifestyles. Psychosocial support was included to help manage the emotional demands of living with COPD, promote communication within and outwith the family. Weekly sessions, lasting approx. 90 min, were conducted and facilitated by the multidisciplinary team. Several didactic methods were used during the sessions, such as group discussions, home tasks, role playing, and brainstorming.</p> <p>The sessions consisted of the following: Week 1: information about COPD/impact on family life - Brief overview of COPD (eg. symptoms, progression and treatments) Period of questions identification, exploration, and normalisation of the impact of COPD on family life Week 2: management of respiratory symptoms - Identification and training of breathing control and airway clearance techniques Discussion of practical strategies to prevent and manage exacerbations Week 3: family identity and development - Work on family cohesion, exploring the family identity (eg, participants had to create their "family identity card," which symbolized the specific values of each family) Week 4: medication and oxygen therapy - Information about medication and oxygen therapy Discussion of the importance of treatment compliance Training of inhalation techniques Week 5: management of stress and anxiety - Discussion of the possible causes of stress and the effects of stress in family life Ways to manage stress (eg. relaxation techniques) Week 6: healthy lifestyles-physical activity - Discussion of the benefits of physical activity in the whole family Work on strategies to increase/maintain physical activity habits Week 7: healthy lifestyles-nutrition and sleep - Identification of the most common nutritional mistakes Discussion of ways to address nutritional mistakes, emphasising the importance of a healthy diet Description of sleep problems and suggestion of solutions Discussion of the impact of COPD on sexual relationships Week 8: emotions management/community resources - Exploration and normalisation of emotions Training of a practical technique to manage emotions, the "Six thinking hats" Identification of available resources for families, as well as the appropriate timing to contact these resources Week 9: fall prevention/communication of feelings, needs</p>	<p>Crisis Oriented Personal Scales (F-COPES) Psychosocial Adjustment To Illness Scale-Self Report (PAIS-SR). St. George's Respiratory Questionnaire</p>	<p>The main findings indicate that integrating the family member in PR contributed to improve the coping strategies of the family to manage the disease, with further improvement in family members' sexual functioning and psychologic distress Patients (P = 0.048) and family members (P = 0.004) in the intervention group had significantly greater improvements in family coping compared to the control group. Family members of the family-based PR had significantly greater improvements in sexual relationships (P = 0.026) and in psychologic distress (P = 0.033) compared with the control group. Patients from both groups had significant improvements in exercise tolerance, functional balance, knee extensors strength, and health-related quality of life after intervention (P < 0.001). 12 dyads did not complete the intervention and were excluded.</p>

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Appendix 4 (continued)

Full reference (country)	Study details (design, setting, sample size and population/participants)	Staffing (lead and facilitators; i.e. healthcare professional, lay)	Screening for entry to PR/ baseline and description of the overall programme	Education sessions (details of individual education sessions, materials used, structure - group/one-to-one set ups, family/carer participation)	Outcome measures	Findings
12. O'Neill B, Elborn J.S., MacMahon J. & Bradley J.M. Pulmonary rehabilitation and follow-on services: A Northern Ireland and survey. Chronic Respiratory Disease (Northern Ireland)	Descriptive survey. A survey was sent to PR sites, local council centres providing respiratory exercise programmes and patient support groups. The purpose was to identify the different components of the patient pathway in Northern Ireland and 23 PR sites were identified and 13 support groups	Staff involved in PR included: physiotherapist, nurse (87%, 20/23) technical instructor (30%, 7/23) physiotherapy assistant (13%, 3/23) rehabilitation worker (13% 3/23),	Duration and frequency varied 65% ran 6 week programme, 35% running an 8 week programme. Out of 24 topics, 14 were provided in more than 60% of the sites.	<p>Some of these topics were supplemented by the provision of written material in some sites</p> <p>Anatomy and pathophysiology (100%, 23/23)</p> <p>Pharmacology (100%, 23/23)</p> <p>Dyspnea management (100%, 23/23)</p> <p>Symptom management (100%, 23/23)</p> <p>Chest clearance techniques (100%, 23/23)</p> <p>Energy conservation/pacing (100%, 23/23)</p> <p>Relaxation (100%, 23/23)</p> <p>Exacerbation management (100%, 23/23)</p> <p>Inhalers and nebulizers (100%, 23/23)</p> <p>Benefits of exercise (96%, 22/23)</p> <p>Anxiety management (83%, 19/23)</p> <p>Identifying and changing beliefs about exercise and health behaviors (61%, 14/23)</p> <p>Nutrition advice (87%, 20/23)</p> <p>Some of the topics were supplemented with written materials at some sites</p> <p>Education delivered by the physiotherapist (100%, 23/23), the nurse (100%, 23/23) and dietician (68%, 16/23), pharmacist (60%, 14/23), occupational therapist (56%, 13/23); other personnel were less frequently involved.</p> <p>74% of programmes invited carers/partners/spouses to attend the exercise session, only 1 programme stated that carers/spouses attended the exercise session.</p>	All (100%) programs used at least one type of exercise test, breathlessness scale, and a quality of life scale; however, there was a lack of consistency between tools used.	The PR in Northern Ireland meets the guidelines for structure and format for the educational component of PR used.

(continued on next page)



Appendix 4 (continued)

Full reference (country)	Study details (design, setting, sample size and population/participants)	Staffing (lead and facilitators; i.e. healthcare professional, lay)	Screening for entry to PR/ baseline and description of the overall programme	Education sessions (details of individual education sessions, materials used, structure - group/one-to-one set ups, family/carer participation)	Outcome measures	Findings
13. Scherer Y.K., Schmieider L.E. & Shimmel S. The effects of education alone and in combination with pulmonary rehabilitation on self-efficacy in patients with COPD <i>Rehabilitation Nursing</i> , 23 [2], 71-77 USA	pre- and post-test trial design. This study investigated the effects of a PR programme with education and exercise compared to education alone. Subjects had a diagnosis of COPD and had been referred to the pulmonary rehabilitation program. 37 subjects were included in the study, 22 participants self-selected to the education alone arm.	87% included a nurse OT and dietitian - (83%, 38/46) Physician - (83%, 38/46) Social worker - (83%, 38/46) 46 nurse assistant - (15%, 7/46)	The pulmonary rehabilitation program consisted of 1-h classes conducted by a clinical nurse specialist (CNS) three times a week for 12 weeks. The educational (alone) classes consisted of 2-h sessions offered once a week over a 4-week period.	Intervention – education alone Methods designed to increase self-efficacy-namely, fostering performance accomplishments, providing vicarious experiences, using verbal persuasion, and decreasing emotional and physical arousal. Breath retraining and the importance of exercise also key elements. Pulmonary rehabilitation group-The program included an educational component that focused on such topics as the pathophysiology of COPD, nutrition, self-care instruction, and stress management.	CSES used to assess COPD patients' level of confidence regarding their ability to manage or avoid breathing difficulty while participating in certain activities pre and post-test, and 6 months after intervention	Patients' self-efficacy scores significantly improved after the pulmonary rehabilitation program and remained significantly improved 6 months later. Education alone was also effective in significantly improving self-efficacy scores, but patients' scores 6 months later were not significantly better than pre-program scores. This study indicates that a rehabilitation program that combines education and exercise training is more effective in improving long-term self-efficacy in patients with COPD.
14. Wadell K. et al. Hospital-based pulmonary rehabilitation in patients with COPD in Sweden-A national survey. <i>Respiratory Medicine</i> (2013). (Sweden)	Descriptive survey; This study investigated the availability and content of hospital-based PR services in Sweden. A web based questionnaire with 32 questions covering six areas: caregiver and patient characteristics, extent and content of the PR, evaluation of PR, waiting lists and collaboration with patient organizations. 71 hospitals in Sweden (70 responded).	Most programmes offered group sessions twice weekly for between 5 weeks-6 months. Education was included 76% of programmes, mostly in a group setting. Other than exercise component the following was offered (n = 46) Nutritional counselling/treatment (85%, 39/46) Assistive device testing (78%, 36/46) Psychosocial counselling (76%, 35/46) Energy conservation technique (74%, 34/46) Smoking cessation (70%, 32/46) Relaxation technique (50%, 23/46) ADL training (35%, 16/46) Education (26%, 12/46)	46/70 (66%) respondents offered PR in their hospital, all offered it for stable COPD. 19/70 (41%) offered PR after exacerbation. Smokers were allowed entry in all sites. Most programmes offered group sessions twice weekly for between 5 weeks-6 months. Education was included 76% of programmes, mostly in a group setting. Other than exercise component the following was offered (n = 46) Nutritional counselling/treatment (85%, 39/46) Assistive device testing (78%, 36/46) Psychosocial counselling (76%, 35/46) Energy conservation technique (74%, 34/46) Smoking cessation (70%, 32/46) Relaxation technique (50%, 23/46) ADL training (35%, 16/46) Education (26%, 12/46)	Lung anatomy and physiology (76%, 35/46) COPD disease (76%, 35/46) Energy conservation technique (76%, 35/46) Effect of exercise and physical activity (74%, 34/46) Effects of medication (74%, 34/46) Nutrition (74%, 34/46) Inhalation techniques (72%, 3/46) Self-management (65%, 30/46) Signs of infections (59%, 27/46) Leisure activities (53%, 25/46) Relaxation (50%, 23/46) Strategy for changing behavior (48%, 22/46) Family role (41%, 19/46) Oxygen therapy (35%, 16/46) Sleep (30%, 14/46) Travel (24%, 11/46) Air pollution (indoor and outdoor) (15%, 7/46) Sexuality (9%, 4/46) Advanced health care planning (0%, 0/46) End life decision (0%, 0/46) Other components: Nutritional counselling/treatment (85%, 39/46) Assistive device testing (78%, 36/46) Psychosocial counselling (76%, 35/46) Energy conservation technique (74%, 34/46) Smoking cessation (70%, 32/46) Relaxation technique (50%, 23/46) ADL training (35%, 16/46) Education (26%, 12/46)	Descriptive study only	51% of the education was given as lectures, 32% as group discussions and 27% as individual one-to-one sessions.



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