



## Components of community rehabilitation programme for adults with chronic conditions: A systematic review



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### ABSTRACT

**Background:** Health services for individuals with chronic conditions often include a disease specific community rehabilitation programme to assist these individuals to maintain physical function and develop self-management skills. Nurses are often involved in the delivery of such programmes. Many individuals however live with more than one chronic condition and find it difficult to manage the rehabilitation demands for their different diagnoses.

**Objective:** To identify core programme components and clinically meaningful measures for a generic rehabilitation programme.

**Data sources:** Full text English language journal articles identified from CINAHL, MEDLINE (Ovid), AMED and PubMed, plus reference lists of included articles.

**Review method:** A systematic search of databases using keywords and MeSH terms for randomised controlled trials detailing a group based community programme for adults with chronic conditions. Study quality was appraised using the Cochrane Collaboration Tool for assessing risk of bias for randomised controlled trials. Data summarising characteristics of the studies such as participant numbers, programme components and the questionnaires, scales and measures were extracted and tabulated. An additional search of wider literature was undertaken to identify the minimal clinically important difference for each questionnaire, scale or measure used within the included studies.

**Results:** Fifteen good quality studies were identified. At baseline, there were 3856 participants (age range 42–84 years), with 642 participants lost to follow-up. Programmes were led by health professionals and/or lay leaders. Programme duration ranged from four to 12 weeks and included educational components targeting symptom management, and development of self-efficacy. Only three programmes included a supervised exercise component. Although many of the 64 outcomes measured across the programmes demonstrated statistically significant results, only three measures demonstrated clinically meaningful change for study participants and these measures were used in only two studies.

**Conclusions and recommendations:** The findings suggest community rehabilitation programmes for individuals with chronic conditions be a minimum of 4–6 weeks to cover necessary education for management of symptoms, be led by a health professional/s in combination with lay leaders, and include development of self-management skills. We recommend consideration be given to health literacy level of the programme, and that because of the known positive benefit of exercise on physical functioning, quality of life and in slowing progression of chronic conditions, an exercise time should be included. Lastly, we recommend that reporting and interpreting effect sizes of interventions within studies would facilitate more useful choice of outcome measures to be able to demonstrate clinically meaningful change.

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### What is already known about the topic?

- Community rehabilitation programmes are a core element of health services for people with chronic conditions.
- Many individuals live with more than one chronic condition and find it difficult to manage the rehabilitation demands for their different diagnoses.

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## What this paper adds

- This review identified that the usual components of community rehabilitation programmes are education on symptoms, symptom management, and strategies to develop self-management skills.
- Consideration should be given to including exercise within the programmes, so that attendees can develop self-efficacy to include health enhancing exercise in their lives.
- Reporting of the clinically meaningful change of an outcome measure would facilitate clinicians to interpret study outcomes in light of what would be considered meaningful to patients.

## 1. Introduction

A chronic condition is a disease of long duration and slow progression, with the number of affected individuals increasing substantially worldwide (World Health Organisation, 2014). Presence of chronic conditions are linked with decreased function (Bayliss et al., 2004) and quality of life (Fortin et al., 2004). Management of the impact of chronic conditions on the lives of individuals and healthcare systems has for some time been directed at provision of rehabilitation and self-management support in a community setting (Clarke et al., 2017; Epping-Jordan et al., 2004; Wagner, 1998). The aim of community rehabilitation programmes is to assist individuals living with chronic conditions to understand their symptoms, and to find ways to work around these, to achieve maximal functional potential (World Health Organisation, 2011b). An essential aspect of the provision of rehabilitation is self-management support, which involves encouraging informed lifestyle choices, risk-factor modification and development of self-efficacy (Adams, 2010). Self-efficacy, according to Bandura (1986; Bandura, 1997), alludes to an individual's attitude towards their ability to execute behaviours essential in producing specific performance achievements. From this stance therefore, individuals would need to develop their skills to problem solve, make decisions and set goals independent of healthcare professionals. The ability to make decisions and set goals independently fits with the Theory of Self-Determination (Deci and Ryan, 2008). Hence, self-management interventions should include scaffolded education, development of strategies to improve competence with problem solving, and regular assessment of progress (Lorig and Holman, 2003; Michie et al., 2011b). The goal of self-management support and rehabilitation is thus to assist the individual to improve their confidence, awareness and autonomy in regards to managing their own health condition/s (Adams et al., 2004).

Despite the reported effectiveness of community-based interventions/rehabilitation programmes in assisting people to regain and/or maintain physical function and independence (World Health Organisation, 2011a), programmes often have very low referral and attendance rates (Levack et al., 2012; Pack et al., 2015). For example, in Canterbury, New Zealand, only 585 out of an estimated 40,600 individuals with COPD attended, and of those referred, only 31% completed the programme (Willsman et al., 2016). Reasons for non-attendance and non-completion are many, varied and well documented (Clark et al., 2013; Willsman et al., 2016). In addition, due to rehabilitation programmes usually being disease specific, this makes it difficult for people with more than one chronic condition to manage the rehabilitation demands for their different diagnoses (Valderas et al., 2009). There are however some programmes catering for people living with multiple chronic conditions, however formal training is required for their delivery and they are licensed (for example Self-management Resource Centre programs (Self-management Resource Centre, 2019)), making them costly for the health system to sustain over the longer term. The aim of this

study therefore was to identify components of rehabilitation programmes reported in the literature so that these can be included into a generic community rehabilitation programme for people with chronic conditions. A second aim was to identify clinically meaningful measures that could be used in such a programme.

## 2. Methods

### 2.1. Search strategy

A full search of the CINAHL, MEDLINE (Ovid), AMED and PubMed databases was undertaken from inception to April 2018 combining the keyword “program\$” with MeSH terms of “primary care”, “education”, “community rehabilitation”, “physical activity”, “self-management”, “diabetes”, “cardiac disease”, “pulmonary disease”, “arthritis”, “stroke”, “neurological disease” and “chronic disease”.

### 2.2. Eligibility criteria

Randomised controlled trials (RCTs) published in English from 2000 onwards that described a community group based programme for adults with archetypal chronic conditions (for example, cardiovascular, respiratory and musculoskeletal conditions) were included. Studies were excluded if they described mail, telephone or internet based programmes, were located in an inpatient hospital setting, or had an exclusive focus on participants with mental illness, chronic pain, infectious diseases such as HIV/AIDS, or cancer. The reference list of included studies were searched for other potentially relevant articles.

### 2.3. Quality appraisal

Articles were critically appraised independently by two researchers, using the Cochrane Collaboration tool for assessing risk of bias in RCTs (The Cochrane Collaboration, 2011), chosen for its effectiveness in critically appraising RCTs (Zeng et al., 2014). The Cochrane Collaboration (2011) provide criteria for judging risk of bias in a study across six domains. These are selection, performance, detection, attrition, reporting, and other bias. The Cochrane Collaboration provide guiding questions and examples for each domain to facilitate the reader to make an assessment and judgement about bias (available at <http://handbook-5-1.cochrane.org/>).

For this review, a low risk of bias in the domains of selection bias (random sequence generation), detection bias (blinding of outcome assessment), attrition bias (incomplete outcome data), and reporting bias (selective outcome reporting) were considered as key for a study to be included in this review. Because participants would have been aware if they were in the usual care group or attending a rehabilitation programme, performance bias (blinding of participants) was classified as a less important domain. Other areas for bias, including allocation concealment (part of selection bias) were not considered as key domains. All quality appraisals were crossed checked by another researcher, with discrepancies in scoring for risk of bias discussed and resolved by the whole research team.

### 2.4. Data extraction and analysis

Information pertaining to condition, programme name, programme leader, country, location, participant characteristics, programme description, enrolment method, programme components and which scales, questionnaires or measurement tools were used was extracted and tabulated. Two studies (Smeulders et al., 2009, 2010) reported on the same population and intervention; therefore, the information was extracted from both studies to provide a complete picture of the overall research by these authors.

Once we had compiled a list of the scales, questionnaires and measurement tools used across the included studies, we grouped them by 1) disease specific and symptom measures, 2) measures of self-efficacy, quality of life and functional capacity, and 3) self-management behaviours. We identified whether the included study reported and/or discussed the clinically relevant change for each of their measures. We then undertook an additional search of wider literature (via google) to identify information about

clinically relevant change for the questionnaire, scale or measure, what the clinically relevant or meaningful change was for each of the scales, questionnaires or measures, and if studies about clinically relevant change had used a similar population to the population of the included studies.

Within the literature, a number of terms are used interchangeably for the idea of clinically relevant changes in outcomes, for example “minimal clinically important difference (MCID), clinically meaningful

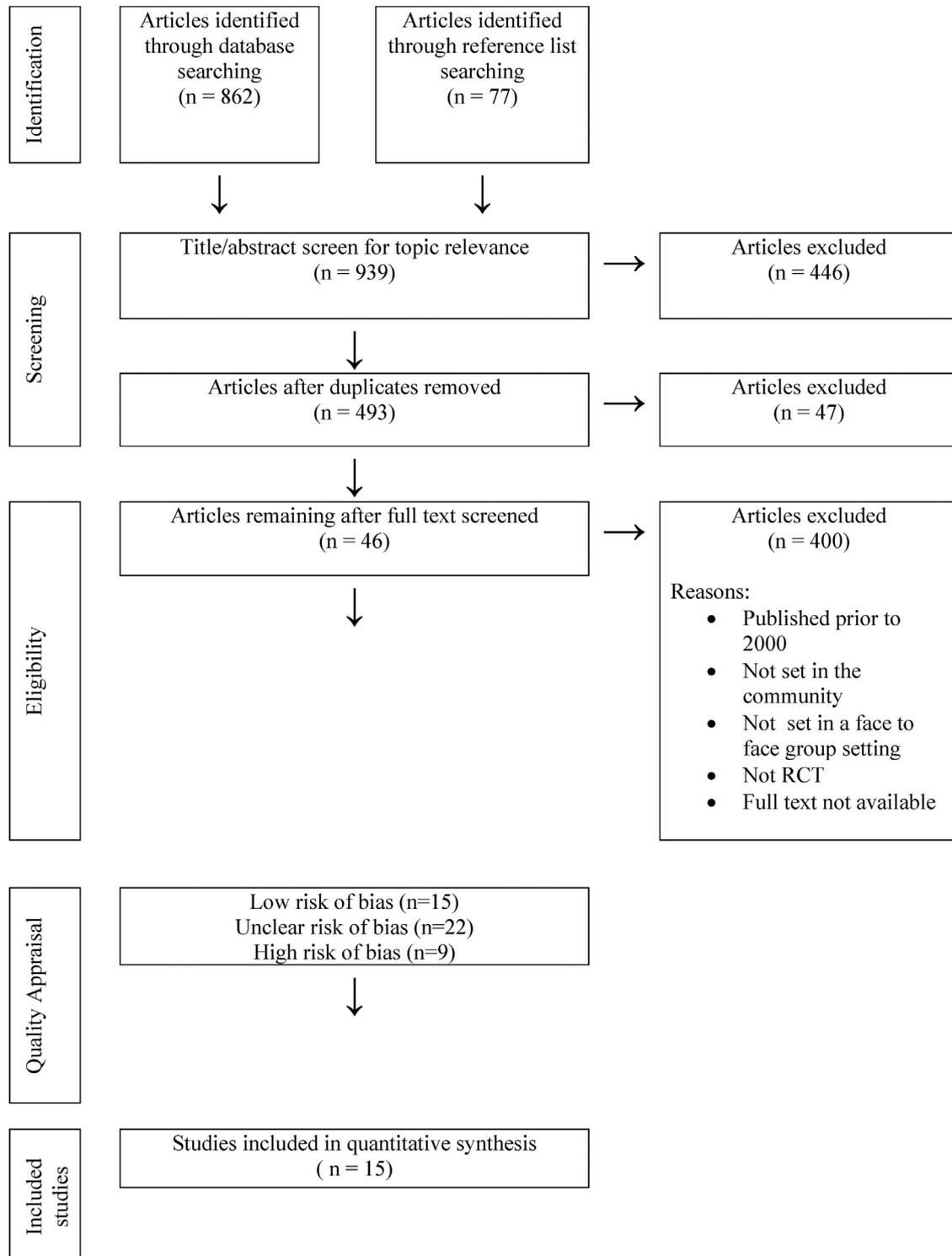


Fig. 1. Summary of process of data through the systematic review.

differences (CMD) and minimally important changes (MIC)" (Page, 2014). In this report we chose to use the term minimal clinically important difference (MCID). MCID facilitates a way for clinicians' to interpret whether or not a study's statistically significant outcome/s is/ are clinically relevant for a particular population group (Copay et al., 2007; Page, 2014).

### 3. Results

The search yielded 939 articles with 46 studies meeting the inclusion criteria (Fig. 1). Quality appraisal resulted in 15 low, 22 unclear and 9 high risk of bias studies. We included only the 15 studies with low risk of bias in the review (Table 1).

#### 3.1. Description of studies

The studies included participants with arthritis (2 studies), diabetes (3), lung disease (3), heart disease (2), and stroke (1). Three studies included individuals with various or multiple chronic conditions. Studies took place in England (3 studies), the Netherlands (3) and Ireland (3), with two studies in the United States, and one study in each of Germany, China, and Australia. The programmes were held in either community or hospital outpatient settings. At baseline, there were a total of 3856 participants. The age range across all studies was 42–84 years. Recruitment was primarily undertaken via health professional referrals, local advertisements or personal invitations. The majority of programmes were led by health professionals, with two programmes led by a combination of health professional and peer or layperson, and three being solely peer or lay led. A total of 642 participants were reported lost to follow up. Most of the studies provided adequate reasons for this, although three studies failed to do so. The most common reasons reported were illness, death and loss of interest. Other reasons were transportation problems, physical and cognitive issues in completing the programme and/or the outcome measures, or missing data.

#### 3.2. Programmes

Programme durations ranged from four to twelve weeks with an average of 7.3 weeks. Session durations ranged from one to three hours (average of 2.4 h). One study did not report on session duration. Eight of the programmes were based on Stanford's

self-management programmes or a derivative or adaptation of these programmes. Other programmes included disease specific programmes for people with stroke (Stroke-specific Self-Management Programme (SSMP)), rheumatoid arthritis (educational-behavioural joint protection programme), COPD (Structured Education Pulmonary Rehabilitation Programme (SEPRP)), heart disease (cardiac rehabilitation programme) and diabetes (Prevention of diabetes self-management program (PREDIAS); Diabetes Prevention Programme (DPP)) (Table 2).

Programme content covered education about disease, its accompanying symptoms and medical management, and core self-management skills. Core self-management skills education encompassed communication with health professionals, and development of self-management skills including self-efficacy, decision-making skills and problem solving, action planning, goal setting, and monitoring of health status. Exercise itself (as opposed to education about the importance of exercise) was a core component of three studies, and this included aerobic and strengthening exercises. Two studies included self-relaxation training (Table 3).

#### 3.3. Questionnaires, scales and measures

There were 64 questionnaires, scales or measures used across the included studies, and some were used in more than one study (Table 4). Six studies gave indications of clinical effectiveness either via providing effect size or confidence intervals for the outcomes of interest (Cadilhac et al., 2011; Casey et al., 2013; Fu et al., 2003; Garvey et al., 2015; Griffiths et al., 2005; Smeulders et al., 2010). However, Smeulders et al. (2010) only reported on sections of outcome measures, poorly stating to which section it belonged to and hence making it difficult to comment on clinical significance of the reported effect size. Interpretation was limited in Griffiths et al. (2005) as well due to a lack of reporting on the calculation method when outlining effect size. Fu et al. (2003) on the other hand calculated effect size but reported only on selected sections of the CDSMP questionnaire, and hence created difficulty to compare overall effectiveness of the programme. Only two studies included sufficient information about minimal clinically important difference (MCID) and this was for three measures. Hammond and Freeman (2001) found a clinically significant change in pain scores, measured using the Visual Analogue Scale

**Table 1**  
Summary of quality appraisal of the included studies.

	Author	Random sequence bias	Allocation concealment	Blinding participants	Blinding researchers	Blinding outcome assessment	Incomplete outcome data	Selective reporting	Other bias
1	Cadilhac et al. (2011)	+	+	-	+	+	+	+	?
2	Casey et al. (2013)	+	?	-	+	+	+	+	-
3	Finnerty et al. (2001)	+	?	?	+	+	+	+	?
4	Fu et al. (2003)	+	-	-	-	+	+	+	-
5	Garvey et al. (2015)	+	+	?	?	+	+	+	-
6	Griffiths et al. (2005)	+	+	?	+	+	+	+	?
7	Hammond and Freeman (2001)	+	+	?	+	+	+	+	-
8	Heuis et al. (2005)	+	?	?	+	+	+	+	+
9	Janssen et al. (2012)	+	+	?	?	+	+	+	?
10	Kulzer et al. (2009)	+	?	?	?	+	+	+	?
11	Lavery et al. (2011)	+	+	?	+	+	+	+	?
12	Lorig et al. (2009)	+	?	-	?	+	+	+	+
13	Ma et al. (2013)	+	?	-	+	+	+	+	-
14	Smeulders et al. (2009) Smeulders et al. (2010)	+	+	-	?	+	+	+	-

Key: + Low risk of bias; ? Unclear risk of bias; - High risk of bias.

Bolding denotes risk of bias domains deemed of most importance for this review.

**Table 2**  
Summary of included studies by condition, programme name, programme leader, country, location, participants, programme description, and enrolment method.

Condition/ Programme Name/ Leader	Country/Location	Participants	Programme description	Enrolment method
Cadilhac et al., 2011 Stroke	Australia	Total randomised: 143	<b>I:</b> SSMP - Stroke education on disease & symptoms, interactive teaching and development of core self-management skills*; 8 weeks; hours/week not stated	March 2008 and April 2009. Recruitment included advertising in local newspapers, promotion through divisions of general practice, local peer support group newsletters, and letters of invitation to discharged survivors at 1 of 7 participating hospitals. Potential participants were invited to make direct telephone contact
Stroke Self-Management Programme (SSMP)	Community	Lost to follow up: 52 <b>I:</b> <i>M</i> = 21, <i>F</i> = 27 Average age: 68 (SD 12)	<b>I:</b> Generic - Stanford chronic condition self-management programme, education on disease & symptoms, interactive teaching and development of core self-management skills*; 6 weeks; hours/week not stated	
Health professionals and lay leaders skilled in stroke and trained by the National Stroke Foundation		<b>I:</b> <i>M</i> = 18, <i>F</i> = 29 Average age: 71 (SD 12)  <b>C:</b> <i>M</i> = 19, <i>F</i> = 29 Average age: 69 (SD 11)	<b>C:</b> Usual care - information and education provided by hospital team and local general practices	
Casey et al., 2013 Chronic obstructive pulmonary disease	Ireland	Total randomised: 350	8 weeks; 2 hours/week. Plus support: phone call at 4 weeks and 1 hour group session a 12-14 weeks	Via general practices, enrolment method not stated
Structured Education Pulmonary Rehab Programme (SEPRP)	General practices	Lost to follow up: 73 <b>I:</b> <i>M</i> = 117, <i>F</i> = 61 Average age: 68.8 (SD 10.2)	<b>I:</b> Education on disease & symptoms, medications, interactive teaching and development of core self-management skills*, and an exercise programme <b>C:</b> General practice visit	
Nurse and physiotherapist		<b>C:</b> <i>M</i> = 106, <i>F</i> = 66 Average age: 68.4 (SD 10.3)		
Finnerty et al., 2001 Chronic Lung Disease	England	Total randomised: 100	6 weeks	Participants were known to the Respiratory team at the hospital due to having long-standing lung disease.
Programme name not stated	Outpatient clinic	Lost to follow up: 45	2 sessions per week	

Table 2 (Continued)

Condition/ Programme Name/ Leader	Country/Location	Participants	Programme description	Enrolment method
Physiotherapist, dietician, occupational therapist		<b>I:</b> $M = 25, F = 11$ Average age: 70.4 (SD 8)  <b>C:</b> $M = 19, F = 10$ Average age 68.4 (SD 10.4)	<b>I:</b> 1 hour exercise & 2 hours education/ advice on disease, symptoms, diet, relaxation & breathing techniques. Plus invite to attend monthly local "Breathe Easy" club and drop in exercise sessions at weeks 8, 9 and 10. Information pack with tailored schedule and action plan <b>C:</b> Routine 3 monthly outpatient visits, invitation to education sessions, Information pack with tailored schedule and action plan	
<b>Fu et al., 2003</b> Chronic Condition	China	Total randomised: 954	7 weeks 2/2.5 hours/ week	June 1999 - Feb 2000, public service announcements in mass media, posters at community senior centres, referrals from flyers in community clinics, interpersonal persuasion
Chronic Disease Self-Management Programme (CDSMP) - adapted  Lay leaders	Senior centres, community hospitals and patients' homes	Lost to follow up: 175  <b>I:</b> $M = 115, F = 315$ Average age: 64.2 (SD 9.8)  <b>C:</b> $M = 108, F = 241$ Average age: 63.8 (SD 10.3)	<b>I:</b> Education on disease, symptoms, & core self- management skills* plus copy of "Living a healthy life with a chronic condition" <b>C:</b> Waitlist (intervention programme 6 months later)	
<b>Garvey et al., 2015</b> Multi-morbidity (2+ long-term conditions & minimum 4 repeat medications)  OPTIMAL (based on Bandura's Theory of Self-Efficacy)	Ireland  Three primary care centres in local communities	Total randomised: 50  Lost to follow up: 6  <b>I:</b> $M = 9, F = 17$ Median age: 65 (Range: 50-83)	6 weeks 3 hours  <b>I:</b> Education & goal setting sessions on fatigue management, healthy eating, maintaining physical activity & mental health, managing medications, and	Identified opportunistically during visits to family practitioner and other primary care clinicians

Table 2 (Continued)

Condition/ Programme Name/ Leader	Country/Location	Participants	Programme description	Enrolment method
Occupational therapists, incorporating elements of peer support, and physiotherapist and pharmacist		<b>C:</b> $M = 9, F = 15$ Median age: 67.5 (Range: 42–84)	communicating effectively with health professionals. Plus a resource booklet of educational information. <b>C:</b> Wait list control	
<b>Griffiths et al., 2005</b> Bangladeshi adults with diabetes, arthritis, respiratory or cardiovascular disease	England	Total randomised: 476  Lost to follow up: 37 <b>I:</b> $M = 105, F = 133$ Average age: 48.9 (SD 9.9)	6 weeks 3 hours/week  <b>I:</b> Education on disease, symptoms, mood, fatigue, healthy eating, medication, exercise & action plans, & core self- management skills*	Recruited by writing to individuals listed on disease registers of 10 general practices in the area
Chronic Disease Self -Management Programme (CDSMP) - adapted Lay leaders		<b>C:</b> $M = 99, F = 139$ Average age: 48 (SD 9.5)	<b>C:</b> Waitlist	
<b>Hammond &amp; Freeman, 2001</b> Rheumatoid Arthritis	England	Total randomised: 127	4 weeks 2 hours/week (week 3&4 2.5 hours)	Individuals diagnosed with rheumatoid arthritis were recruited through two hospitals. Following assessment from an occupational therapist were sent a letter inviting them to participate.
Programme name not stated	Hospital outpatients	Lost to follow up: 12 <b>I:</b> $M = 12, F = 53$ Average age: 49.5 (SD 11.4)	<b>I:</b> The joint protection programme: Part 1- Education on disease, symptoms, joint protection & energy conservation, demonstration of hand-joint protection methods & a homework task to identify problems activities & find solutions using principles taught. Part 2 – discussion of homework task, repetition of principles, demonstration of hand-joint protection, group practice of protection methods & trying assistive kitchen devices. Contracting and	

Table 2 (Continued)

Condition/ Programme Name/ Leader	Country/Location	Participants	Programme description	Enrolment method
Nurse, medical doctor, occupational therapist & physiotherapist		<b>C:</b> $M = 18, F = 44$ Average age: 51.6 (SD 9.7)	goal setting in workbook. <b>C:</b> The standard programme: Education on disease & symptoms, & short talks by various healthcare professionals about possible treatment options for rheumatoid arthritis. Some demonstration and practise of exercise, joint protection and relaxation	
<b>Heuts et al., 2005</b>				
Osteoarthritis of the hip or knee	Netherlands	Total randomised: 297	6 sessions (actual weeks not stated presume ran consecutively) 2 hours/week	GP referral and by local advertisements
Programme name not stated - based on Stanford Arthritis Self-management programme	Primary healthcare setting	Lost to follow up : 24	<b>I:</b> Education on disease, symptoms and medication, self-diagnostic & core self-management skills*, & self-relaxation training. Plus osteoarthritis self-management handbook and booklet.	
Physiotherapist		<b>I:</b> $M = 54, F = 78$ Average age: 51 (SD 5.0) <b>C:</b> $M = 56, F = 85$ Average age: 52.2 (SD 5.1)	<b>C:</b> Usual care as prescribed by doctor or consultant	
<b>Janssen et al., 2012</b>				
Ischaemic coronary heart disease	Netherlands	Total randomised: 210	1 hour individual motivational counselling and goal setting session 5 group sessions (weeks 3, 5, 7, 9, 11), 2 hours 2 follow up sessions (weeks 15, 19), 2 hours	Individuals who had been diagnosed and had attended a major cardiac rehabilitation centre were invited to participate (by their physiotherapist) following completion of a 3-month cardiac rehabilitation programme.
A self-regulation programme (not named) Health psychologist	Rehabilitation centre	Lost to follow up: 34 <b>I:</b> $M = 80, F = 22$ Average age: 56.6 (SD 9.2)	<b>I:</b> Self-regulation programme on maintenance of lifestyle change. Individual motivation and goal setting session. Group sessions	

Table 2 (Continued)

Condition/ Programme Name/ Leader	Country/Location	Participants	Programme description	Enrolment method
		C: $M = 81, F = 15$ ** Average age: 58.8 (SD 9.3)	structured around the self- regulatory phases of goal pursuit. C: Received an individual 1-hour individual interview with a health psychologist during week 1, where encouraged to set a goal. No motivational interviewing techniques used, plus standard care.	
<b>Kulzer et al., 2009</b> Diabetes	Germany	Total: 182	12 group sessions (first 8 sessions offered weekly, last four sessions offered bimonthly) 1.5 hours/ session I: PREDIAS based on self- management theory. Exercise book containing diabetes prevention information (eating diaries, exercise log book) C: Written information about diabetes prevention	Individuals with elevated diabetes risk based on a high score (>10) on Diabetes Risk Score or according to primary care physician assessment
PREDIAS Diabetes educators or psychologists	Community	Lost to follow up: 17  $M = 104, F = 78$ Average age: 56.3 (SD 10.1) NB: Intervention and control group numbers not stated.		
<b>Lavery et al., 2011</b> Bronchiectasis	Ireland	Total: 64	8 weeks 2.5 hours/week	Specialised bronchiectasis clinic, general medical clinics, specialist nurse clinics, physiotherapy appointments, and hospital admissions
Expert Patient Programme (EPP) – adapted to be disease specific for people with bronchiectasis	Regional respiratory centre	Lost to follow up: 5  I: $M = 14, F = 18$ Average age: 60 (SD 9)	I: Education on disease & symptoms, core self- management skills* (2 weeks disease specific & 6 weeks standardised EPP) plus usual care & patient booklet "Living well with Bronchiectasis".	

Table 2 (Continued)

Condition/ Programme Name/ Leader	Country/Location	Participants	Programme description	Enrolment method
Physiotherapist & nurse		<b>C:</b> <i>M</i> = 15, <i>F</i> = 17 Average age: 60 (SD 8)	<b>C:</b> Usual care (3 monthly reviews at specialist respiratory clinic to monitor spirometry, inflammatory blood markers, sputum microbiologic assessment with inhaled therapy, antibiotics or hospital treatment if required)	
<b>Lorig et al., 2009</b>				
Type 2 Diabetes	United States	Total: 345	6 weeks 2.5 hours/week	Self-referral – Study advertised in community via word of mouth, announcements in churches, clinics and mass media. Physicians or clinics referred 6% of participants.
Diabetes Self-Management Programme (DSMP) for English speakers	19 programmes in community settings such as churches and senior centres	Did not complete 6 or 12 month follow-up questionnaires: 110 <b>I:</b> <i>M</i> = 70, <i>F</i> = 116 Average age: 67.7 (SD11.9)	<b>I:</b> Education on disease self-management, symptoms and care, medication, core self-management skills*. Interactive with emphasis on action planning and problem solving, goal setting and reinforcement of goal enhancing participants' self-efficacy.	
Lay leaders		<b>C:</b> <i>M</i> = 54, <i>F</i> = 105 Average age: 65.4 (SD 11.4)	<b>C:</b> Usual care then at 6 months offered DSMP	
<b>Ma et al., 2013</b>				
Overweight or obese adults with pre diabetes and/or metabolic syndrome	United States A primary care clinic	Total: 241  <b>I:</b> <i>M</i> = 41, <i>F</i> = 38 Average age: 54.6 (SD 11.0)	Coach led, first 1-3 months - 12 weeks, 1.5.- 2hours/week. Then next 4-15 months - every 2-4 weeks, variable length of time <b>I:</b> Coach led, adapted 12 session DPP Group Lifestyle Balance intervention curriculum (group discussion, review of progress, identification of	Recruited from a large primary care clinic. Enrolment method not stated.

Table 2 (Continued)

Condition/ Programme Name/ Leader	Country/Location	Participants	Programme description	Enrolment method
Diabetes Prevention Programme (DPP) adapted		<b>I:</b> $M = 44, F = 37$ Average age: 51.8 (9.9)	personal barriers and solutions, action planning, goal setting, food tastings, 30–45 minute guided physical activity) plus usual care. Use of web portal for weight and physical activity goal setting and self-monitoring, weight scale and pedometer. Monthly motivational email messages plus monthly personalised feedback messages based on self-monitoring records. Ability to submit questions and receive answers. <b>I:</b> Self-directed home based DVD plus usual care. Use of web portal for weight and physical activity goal setting and self-monitoring, weight scale and pedometer. Bi-weekly reminder email messages about self-monitoring and monthly motivational messages. Ability to submit questions and receive answers. <b>C:</b> Usual care	
Coach-led (registered dietician & contracted fitness instructor) or self-directed via DVD		<b>C:</b> $M = 44, F = 38$ Average age: 52.5 (SD 10.6)		
<b>Smeulders et al., 2009,2010</b> Congestive Heart Failure (CHF)	Netherlands	Total: 317	6 weeks 2.5 hours/week	2010 -Visited heart failure and/or cardiology outpatient clinics of the participating hospitals between July 2004 and November 2005, had a diagnosis of (CHF), could speak Dutch 2009 - Outpatients received written information about the study if they had a CHF diagnosis for at least 6 months and were literate in Dutch
Chronic Disease Self-Management Programme (CDSMP)	Hospital outpatients	Lost to follow up: 52 <b>I:</b> $M = 89, F = 42$ Average age: 66.6 (SD 11)	<b>I:</b> Education on disease and symptoms, core self-management* skills plus usual care	

**Table 2** (Continued)

Condition/ Programme Name/ Leader	Country/Location	Participants	Programme description	Enrolment method
Nurse & lay leader		C: M = 141, F = 45 Average age: 66.8 (SD 10.1)	C: Usual care (regular outpatient check-ups)	

Abbreviations: I, Intervention; C, Control; M, Male; F, Female; SD, Standard deviation.

\* Core self-management skills: Problem solving, decision making, resource utilisation, forming of a patient/health care provider partnership, and taking action. Skills are taught interactively to facilitate participants' development of a new range of skills, and to facilitate more effective management of the daily impact of the condition on their lives. NB: Information about programmes is often located in supporting articles and not those directly included in this review.

\*\*The reporting of number of people in control group (M = 81; F = 15) do not reflect the totals provided (n = 97).

(VAS) (Wolfe and Michaud, 2007) from baseline to six months, with continued improvements up to 12 months. A clinically significant change in the 6 Minute Walk Test (Wise and Brown, 2005) from baseline to three and six months was found in the study by Finnerty et al. (2001). Additionally, Finnerty et al. (2001) also showed a large clinically significant change in the St George Respiratory Questionnaire (SGRQ) (Jones, 2002) at three months, but this change was not maintained at six months.

**4. Discussion**

The aim of this review was to identify core programme components for inclusion in a generic community rehabilitation programme and to identify clinically meaningful measures that could be used in such a programme. Programmes were delivered by lay leaders, health professionals or a combination. Health professionals have knowledge of health conditions but Barlow et al. (2009) have suggested that peer leaders with a common background to programme attendees would have a better understanding of attendees' contexts, and be better than health professionals in identifying strategies to overcome barriers to self-management. None of the included studies in this review discussed the health literacy level of the educational components of the

programme. Health literacy is defined as an individual's capacity to seek, understand and act on health information (Adams, 2010). It also includes the level of complexity of healthcare information, and more broadly encompasses the communication ability of health professionals and accessibility of the healthcare system itself (Pourselami et al., 2016). Personal health literacy is an essential component for making appropriate health decisions and lay leaders could be better placed than healthcare professionals to put health information into lay terms. If an individual also has a low level of literacy itself, this could lead to poor understanding of educational materials and contribute to less than effective self-management skills (Pourselami et al., 2016; van der Heide et al., 2018). Therefore to support the shift in health service delivery to focus on rehabilitation and self-management in a primary care setting (Boutwell et al., 2009), we suggest that the literacy level of health programmes needs to be considered, and that a peer or lay leader together with a health professional may be the most useful approach to deliver a rehabilitation programme.

The duration of the programmes of the included studies ranged from four to twelve weeks. However, as most of the studies incorporated an education component of at least four weeks, it could be suggested that four weeks is the time frame required to cover necessary educational elements. The most prevalent programme

**Table 3**  
Summary of programme components.

Programme components	Cadilhac et al., 2011	Casey et al., 2013	Finnerty et al., 2001	Fu et al., 2003	Garvey et al., 2015	Griffiths et al., 2005	Hammond and Freeman, 2001	Heuts et al., 2005	Janssen et al., 2012	Kulzer et al., 2009	Lavery et al., 2011	Lorig et al., 2009	Ma et al., 2013	Smeulders et al., 2009, 2010
Education about disease, symptom & medication management	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Core self-management skills*	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓
Exercise programme**		✓	✓										✓	
Self-relaxation training***								✓	✓					

\* Core self-management skills: Problem solving, decision making, resource utilisation, forming of a patient/health care provider partnership, and taking action (Lorig and Holman, 2003). Skills are taught interactively to facilitate participants' development of a new range of skills, so they can more effectively manage their daily lives.

\*\* Exercise programme: Casey – Information from online supplementary material (Data supplement 2) – Eight physiotherapy led exercise sessions, 10 exercise stations tailored to participants needs, 3 x sets of 8–10 repetitions (for maximum 3 min). Prescription and progression of intensity calculated on BORG scale level 4, i.e. experienced a moderate level of breathlessness and once a participant could perform 3 sets of 8–10 repetitions easily in one go then the exercise was progressed by increasing the weight or the number of repetitions. Home exercise programme (pursed breathing, positions of ease, warm up 5 min walk at 1–2 on BORG scale, Stretch Walk 20 min. (overall) each day at 4 on Borg scale; exercises 3 sets of 8 repetitions of each arm and leg exercise). Finnerty – Six physiotherapy led exercise visits, 10 min warm up, 25 min aerobic activity, 10 min cool down period. The aerobic activity included diagonal arm raises, arm abduction into elevation and reverse, and arm abduction, forward flexion, and reverse; treadmill or static bicycle exercise; step-ups with three step heights; and straight leg raises. In addition, subjects were asked to exercise once or twice daily a minimum of five times a week, using a walking programme with nine levels, the maximum level being 10 min of rest and then 10 min of walking. Ma – 30–45 minutes of guided physical activity (timed walk and circuit training).

\*\*\* Self-relaxation training: Heuts – Three sessions, led by two physiotherapists, for pain control and overall wellbeing (method/content not explained). Janssen – a 2-h practical session on progressive relaxation (led by a physical therapist) (method used not explained).

**Table 4**  
Summary of questionnaires, scales and measures used in individual studies.

Questionnaires, scales and measures	Cadilhac et al., 2011	Casey et al., 2013	Finnerty et al., 2001	Fu et al., 2003	Garvey et al., 2015	Griffiths et al., 2005	Hammond and Freeman, 2001	Heuts et al., 2005	Janssen et al., 2012	Kulzer et al., 2009	Lavery et al., 2011	Lorig et al., 2009	Ma et al., 2013	Smeulders et al., 2009, 2010
1 Disease specific and symptoms														
Breathlessness (using 5 point Likert or visual numeric scales)				✓✓		✓✓								
Centre for Epidemiologic Studies Depression Scale (CES-D)										✓				
Chronic Respiratory Disease Questionnaire (CRQ)		✓✓												
Disease severity (5 point Likert scale) & stiffness (minutes)							✓							
Energy/Fatigue scale				✓										
European League Against Rheumatism (EULAR 28)							✓							
Fatigue (using visual numeric or 5 point Likert scale)				✓✓		✓✓						✓✓		
Grip strength (Jamar dynamometer)							✓✓							
Hospital Anxiety and Depression Scale (HADS)					✓✓	✓✓								✓✓
Irritability, Depression, Anxiety Scale (IDA)	✓													
Joint Alignment and Motion Scale							✓							
Joint Protection Behaviour Assessment							✓							
Kansas City Cardiomyopathy Questionnaire (KCCQ)														✓
Pain (using visual analogue or numeric, or 5 point Likert scale)				✓✓		✓✓	✓✓✓	✓✓						
Patient Health Questionnaire (PHQ-9)												✓✓		
Personal Health Questionnaire Depression Scale (PHQ-8)				✓										
Rheumatoid Attitudes Index							✓							
St George Respiratory Questionnaire			✓✓✓✓								✓✓			
State-Trait Anxiety Inventory										✓				
Symptom Checklist-90 (Dutch version)														
The Western Ontario & McMaster Universities Arthritis Index								✓✓	✓					
2 Self-efficacy, quality of life and functional capacity														
Adapted Illness Intrusiveness Ratings				✓										
Arthritis Impact Measurement Scale (AIMS2)							✓							
Assessment of Quality of Life Scale	✓													
Canadian Occupational Performance Measure (COPM)					✓✓									
EuroQoL – five dimensions questionnaire (EQ-5D)		✓✓			✓✓	✓✓								
Frenchay Activities Index (FAI)					✓									
Goal Attainment Scaling (GAS)					✓									
Health Distress (Lorig et al 1996)				✓								✓		
Health Education Impact Questionnaire (HeiQ)	✓				✓									
Incremental Shuttle Walk Test		✓✓												
Kansas City Cardiomyopathy Questionnaire (KCCQ)														✓✓
Medical Outcome Study Short Form - 36 (SF-36)								✓✓						
Nottingham Extended Activities of Daily Living (NEADL)					✓✓									
Patient Activation Measure (PAM)												✓✓		
Patient Specific Functional Status (PSFS)								✓						
Pearlin Self-Mastery Scale														✓
Perceived Autonomy (VAS range 0-100)														✓
RAND 36-item health Survey (RAND-36)														✓✓
Self-efficacy scales														✓
Arthritis Self-efficacy Scale							✓	✓						
Cardiac Self-efficacy Questionnaire														✓
General Self-efficacy Scale (GSES)														✓
Chronic Disease Self-efficacy Scales (10 sub-scales)											✓			
Self-efficacy for Managing Chronic Disease (6 item scale)		✓		✓	✓	✓					✓			
Self-efficacy for Managing Diabetes (8 item scale)											✓			
St George Respiratory Questionnaire			✓✓✓✓								✓✓			
Stanford HAQ 8-Item Disability Scale				✓										✓
Self-rated Health				✓							✓	✓		



64 measures used across the included studies, this information does not necessarily match the population of interest of the studies included in this review. Therefore to assist clinicians in decision making about interventions, it would be useful for research to expand on current knowledge about MCID (Copay et al., 2007).

A strength of this review was that it included a large total number of participants across the studies and only RCTs with low risk of bias. However, exclusion of other types of studies could potentially have limited the pool of information to inform the aim of the review. For example, information about participant perceptions of the usefulness of content in rehabilitation programmes, and a Delphi type study exploring healthcare professionals' ideas about content of such programmes, would further inform development of a generic rehabilitation programme for people with chronic conditions.

## 5. Conclusion and recommendations

In conclusion, the findings of this review show that rehabilitation programmes for individuals with chronic conditions i) need to be 4–8 weeks in length, ii) should include education on symptom management and iii) should include time to develop and embed self-management skills. Based on rehabilitation literature, we suggest programmes would be best led by health professional/s together with lay or peer leaders, and should include exercise, so that exercise self-efficacy can be developed over the course of the programme. We suggest also that research on rehabilitation programmes should incorporate outcome measures that show clinically relevant change or report interpretable effect sizes. Lastly, providing patients with information about a programme at a suitable level of (health) literacy may be a useful strategy for referral and retention into programmes.

## Declaration of contribution of authors

HM and AW conceived the study and supervised DC, CN, NK, AL and SD. DC, CN, NK, AL and SD undertook initial database search, data extraction and analysis, and write up of manuscript. AW undertook follow up database search, data extraction and analysis, and together with HM wrote final draft of the manuscript. All authors approved the final version of the manuscript. The authors declare no conflicts of interest.

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## Declaration of conflicting interest

The authors declare that there is no conflict of interest.

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