Understanding the reasons for non participation in self-manegement intervemtions amongst aptienrs with chronic conditions: addressing and increasing opportunities for patients with advanced chronic obstructive pulmonary disease to access self-management

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Understanding the reasons for non-participation in self-management interventions amongst patients with chronic conditions: addressing and increasing opportunities for patients with advanced chronic obstructive pulmonary disease to access self-management

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A thesis submitted in partial fulfillment of the requirements of the Degree of Doctor of Philosophy

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24 September 2014
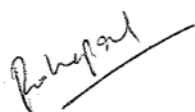
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Details of collaboration and publications:

Sohanpal, R., Seale, C., Taylor, S.J.C. Learning to manage COPD: a qualitative study of reasons for attending and not attending a COPD-specific self-management programme. *Chronic Respiratory Disease.* 2012;9: 163-174.

Collaborations

Dr Helen Cameron-Tucker in the Menzies Research Institute, Hobart, Tasmania, Dr Hilary Pinnock, will be willing to collaborate on any future projects that involve the use of the 'CENTREd' Model.

Dr Alethea Cooper will be willing to collaborate on a future study that involves adaptation of the cardiac rehabilitation questionnaire for COPD.

Ms Jayne Din will be happy to be a patient advisor in future projects depending on prior commitments.

Acknowledgements

Abstract

Background

In chronic obstructive pulmonary disease (COPD), understanding the problem of poor patient participation in evidence-based self-management (SM) and pulmonary rehabilitation (PR) programmes (together referred to as SM support programmes) is critical. This thesis aimed to improve understanding of poor patient participation and retention in these programmes; how participation might be improved; and how might patients be better supported with their SM.

Methods

Using the Medical Research Council guidance on complex interventions this thesis (1) quantified the 'actual' patient participation and completion rates; (2) explained, using theory, the factors that influenced participation in studies of SM support including the programmes among chronic disease and COPD patients; and (3) explored patient and expert stakeholders' perspectives on the reasons for non-participation in SM support programmes, how participation might be improved, how might patients be supported with their SM.

Results

(1) Among 56 studies, high study participation rates and completion rates were seen however, the incomplete reporting of participant flow confused the problem of participation. (2) Among 31 studies, participation among patients with chronic disease including COPD was shown to be influenced by their 'attitude' and 'perceived social influence/subjective norms'; 'illness' and 'intervention perceptions'. (3) From 38 interviewees, besides patients' beliefs, non-participation was also influenced by resignation and denial of the illness; health systems; and programme organisational factors. Professionals building relationships and supporting patients with their SM alongside programme organisational improvements might encourage patient participation in SM and the programmes.

Conclusions

Patient participation is a complex behaviour, besides socio-behavioural factors, participation behaviour can by influenced by a mix of several health system and programme organisational factors. Changing the behaviour of health professionals and indeed the wider health system, towards normalising a patient partnership approach, with implementation of SM support in

routine care might help more patients to consider participation in their care and improve patient participation in COPD SM support programmes.

Glossary

Definitions used in this thesis

Uptake/Participation/Non-participation: patient taking part in a self-management (SM) intervention or in studies of SM interventions or not taking part;

Attendance: number of sessions in a SM programme actually attended (e.g. 2 of 7 sessions);

Non-attendance: no sessions of the programme attended;

Completion: attendance at all sessions of a SM programme (or at sufficient to reach a pre-determined "effective dose" of the intervention);

Drop-out/Non-completion: patient who withdraws from the programme or leaves the study.

List of abbreviations

AIDS	Acquired Immuno Deficiency Syndrome
AIA	Assigned to Intervention Arm
AMI	Acute Myocardial Infarction
ASE	Attitude-Social influence-Self-efficacy
ATS	American Thoracic Society
BLF	British Lung Foundation
BMI	Body Mass Index
BTS	British Thoracic Society
CABG	Coronary Artery Bypass Graft
CASP	Critical Appraisal Skills Programme
CCGs	Clinical Commissioning Groups
CCT	Controlled Clinical Trial
CDSMP	Chronic Disease Self-management Programme
CHD	Coronary Heart Disease
COPD	Chronic Obstructive Pulmonary Disease
CONSORT	Consolidated Standards of Reporting Trials
CR	Cardiac Rehabilitation
CR	Conceptual review
CS-SRM	Common Sense-Self Regulation Model
DALY	Disability Adjusted Life Years
DH	Department of Health
DSME	Diabetes Self-Management Education services
DMC	the Diabetes Management Centre
EPP	Expert Patient Programme
EPP CIC	Expert Patient Programme Community Interest Company
ERS	European Respiratory Society
FEV_1	Forced Expiratory Volume in 1 second
FVC	Forced Vital Capacity
GOLD	the Global initiative for chronic Obstructive Lung Disease
GP	General Practitioner
HAPA	Health Action Process Approach
HbA1c	Glycated Haemoglobin

HAART	Highly Active Anti-Retroviral Therapy
HCP/s	Health Care Professional/s
HCU	Health Care Use/ Health Care Utilisation
HIV	Human Immuno-deficiency Virus
HSU	Health Service Use/ Health Services Utilisation
HE	Health Education
ICF	International Classification of Functioning, Disability and Health
ICR	Intervention Completion Rate
IDR	Intervention Dropout Rate
IPQ	Illness Perception Questionnaire
IPQ-R	Revised Illness Perception Questionnaire
IDU	Injection Drug User
LTC	Long Term Condition
MeSH	Medical Subject Heading
MI	Myocardial Infarction
MRC	Medical Research Council
N/n	Number
NCF	Necessity-Concerns Framework
NHS	National Health Service
NICE	National Institute of Health and Clinical Excellence
PAM	Patient Activation Measure
PBC	Perceived Behavioural Control
PCT	Primary Care Trust
PR	Pulmonary rehabilitation
QOF	Quality and Outcomes Framework
RCT	Randomised Controlled Trial
SM	Self-management
SCT	Social Cognitive Theory
SCR	Study Completion Rate
SDR	Study Dropout Rate
SoC	Stage of Change Theory
SPR	Study Participation Rate
SRM	Self-Regulation Model

TPB	Theory of Planned Behaviour
UK	United Kingdom
US/USA	United States/United States of America
WHO	World Health Organisation
WISE	Whole System Informing Self-management Engagement

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Chapter I. Uptake of self-management programmes by patients with chronic obstructive pulmonary disease

Chapter I presents the:

- Background section as follows
  - a brief description of COPD; burden of COPD on the individual, society and health services;
  - the national and international guidelines on the non-pharmacological treatment/management of COPD with a particular focus on self-management (SM) interventions including pulmonary rehabilitation;
  - the definition and description of SM, the distinction and relationship between SM and the terms used synonymously with SM, the different methods of SM delivery to patients with COPD and role of SM in COPD is explained;
  - the existing evidence of benefit from studies of SM in COPD and existing participation and completion rates in studies of COPD SM is presented; and
  - the description of the current availability or delivery of SM for COPD in clinical practice
- Summary of the rationale for this study.
- Aims and objectives of the study.
- Structure of the thesis.

1.1 Background

1.1.1 Chronic obstructive pulmonary disease

"Chronic Obstructive Pulmonary Disease (COPD) is a preventable and treatable disease with some significant extrapulmonary effects that may contribute to the severity in individual patients. Its pulmonary component is characterized by airflow limitation that is not fully reversible. The airflow limitation is usually progressive and associated with an abnormal inflammatory response of the lung to noxious particles or gases".[15]

The chronic airflow limitation characteristic of COPD is caused by a mixture of small airway disease (obstructive bronchiolitis) and parenchymal destruction (emphysema), the relative contributions of which vary from person to person. COPD is characterised by chronic and progressive dyspnoea, cough and sputum production. Chronic cough and sputum production may precede airflow limitation by many years. Conversely, significant airflow limitation may develop without chronic cough and sputum production. COPD is also associated with periodic exacerbations of symptoms. An exacerbation being defined as *"an event in the natural course of the disease characterized by a change in the patient's baseline dyspnoea, cough, and/or sputum that is beyond normal day-to-day variations, is acute in onset, and may warrant a change in regular medication in a patient with underlying COPD".*[15]

1.1.1.1 Aetiology and pathology

The main cause of COPD in high and middle income countries is tobacco smoking including second-hand smoke or passive exposure http://www.who.int/respiratory/copd/causes/en/index.html (accessed 5-1-14) Other factors associated with COPD are occupational exposure, alpha-1 antitrypsin deficiency (the most well documented genetic risk factor), indoor air pollution from biomass cooking, seen mostly in the developing countries, and childhood respiratory infections.[15,16] The risk of developing COPD is also inversely related to socio-economic status.[15]

The pathologic changes occur in the proximal airways, peripheral airways, lung parenchyma and pulmonary vessels of patients.[15] The changes include chronic inflammation with increased numbers of specific inflammatory cell types and structural changes which increase with severity and persist on smoking cessation. In COPD patients the inflammatory response appears to be an amplification of the normal inflammatory response of the respiratory tract to

irritants such as cigarette smoke. Lung inflammation is further amplified by oxidative stress and an excess of proteinases in the lung.[15]

Spirometry is vital for the clinical diagnosis of COPD and provides a useful description of its severity based on the pathological changes in COPD;[15] this method of measurement is the most widely available reproducible test of lung function. The presence of a post-bronchodilator Forced Expiratory Volume in 1 second (FEV_1)/Forced Vital Capacity (FVC) <0.70 confirms the presence of persistent airflow limitation and thus of COPD.[17]

1.1.1.2 Prevalence

COPD is a public health problem worldwide.[18] According to the World Health Organisation, an estimated 65 million people have moderate to severe COPD http://www.who.int/respiratory/copd/burden/en/index.html (accessed 4-1-13).

COPD represents a global health burden and will change from ranked 12 as cause of disability adjusted-life years (DALY) lost to ranked fifth by the year 2020.[19] One DALY can be one lost year of "healthy life"

 http://www.who.int/healthinfo/global_burden_disease/metrics_daly/en/ (accessed 18-1-13).

COPD is projected to rank third among all causes of death by 2020.[20] The 2010 data from the Global Burden of Disease, Injuries and Risk factors Study showed that the UK, in comparison to the European Union countries, in all ages, had significantly higher rates of years of life lost from several diseases with COPD being the fourth cause of years of life lost behind ischaemic heart disease, lung cancer and stroke.[21] In the UK, research by the British Lung Foundation (BLF) showed that an estimated 3.7 million people are suffering with COPD, yet only 900,000 are currently diagnosed, receiving treatment and care and an estimated 2.8 million are unaware that they have the condition.[22] Patients' might dismiss a cardinal symptom, breathlessness, and perceive it to be a sign of getting old or perceive it as smoker's cough, http://www.lunguk.org/media-and-campaigning/media-centre/latestpressreleases/British-Lung-Foundation-victory?dm_i=FWX,H6XI,3L2RQO,1EGV0,1 (accessed 1-1-2011).

The Quality and Outcomes Framework (QOF) data from UK general practice, estimates COPD prevalence to be 1.4%, but this proportion could be much higher.[16]

Normally, COPD was more common in men, but because of the increased uptake of smoking among women in high income countries and exposure to indoor air pollution

in low income countries, the disease now affects men and women equally http://www.who.int/respiratory/copd/burden/en/index.html (accessed 4-1-13).

1.1.1.3 Impact of COPD on patients, society and the National Health Service (NHS)

COPD is the fifth biggest killer in the UK.[23] The numbers of deaths from COPD increase with age as the condition is progressive and deteriorates over time. Persons living with COPD may suffer from both physical and psychological limitations.[24,25] These are at an increased risk of comorbidities such as cerebrovascular and cardiovascular disease, and suffer from neurological and musculoskeletal symptoms[26] which can disrupt their daily functioning. The physical limitations imposed by COPD may result in patients' avoiding social participation and social isolation can negatively influence activities of daily living.[25]

Mental health problems are three times more common amongst patients with COPD in comparison to the general population.[27] Psychological limitations such as depression, anxiety (seen higher in women[28]), and panic disorder are commonly seen amongst patients living with COPD.[29-31] In a review[31] of mental health in COPD and chronic heart failure, the prevalence figures in COPD for depression ranged from 8-80% and for anxiety the range was 6-74%. In a COPD patient suffering from anxiety and panic disorder, the sensation of breathlessness is more acute and may be out of proportion to disease severity.[29] As a result, these patients' experience problems with activities of daily living and rely on others for their care.[29] Psychological factors including fear, frustration, regret and social isolation add to the emotional burden of COPD.[32] Depression may prevent adherence to medications, a healthy dietary regime, exercise and smoking cessation all potentially worsening the course of the illness;[24] Psychological distress also affects mood, motivation, health care utilisation and survival.[30] Many patients with COPD accept that they are helpless – *"a perception that whatever [they] do will make no difference in the future."*[32] Help-seeking by patients with severe symptoms can be affected by loss of self-esteem, hope, and fear about the future.[33]

COPD patients with anxiety and depressive symptoms are at an increased risk of acute exacerbations.[31] Consequences of an acute exacerbation include deterioration in: lung function; peripheral muscle function; exercise capacity activity level; and quality of life.[19,30] The frequency of exacerbations accelerates the disease process.[26] A patient with COPD

suffers from about two to three exacerbations a year and the recovery time from an exacerbation can take up to three months.[26]

The burden of COPD on society includes lost taxes, increased state benefits and lost productivity. A global survey in 2011 of people aged 45-67 years was carried out to reveal the impact of COPD on the individual, health service use and economies.[34] The survey revealed that the COPD costs the economy nearly €1.7 billion (UK £1.5billion, US $2.4 billion). The annual lost productivity costs, due to early retirement, amounts to €500million.[34]

COPD is the most costly respiratory disease in Europe, estimated at €38.7 billion annually.[35] In the UK, COPD is responsible for over 30,000 deaths, 1.4 million GP consultations, a million hospital bed days and costs the NHS over £800 million each year[36] more than half of which is related to hospital care.[22] About one in eight emergency hospital admissions maybe due to COPD;[19] It is the second most common cause of emergency admission;[22] and the fifth most common cause for hospital readmissions.[37] In England and Wales, COPD direct costs per patient was £819.42 and indirect costs was £819.66 in 2000/01;[38] the cost of an exacerbation per patient by severity was £7.94 for mild, £23.43 for mild/moderate, £139.74 for moderate and £1446.48 for severe disease.[38] According to a BLF report, in 2007, an estimated annual cost of treating a patient with mild disease was reported to be £149 and £1307 for a person with severe COPD.[22]

1.1.1.4 Non-pharmacological management of COPD

COPD cannot be cured but can be treated or managed.[30] Effective COPD management includes focusing on four key areas:

1) assess and monitor disease;

2) reduce risk factors;

3) manage stable COPD; and

4) manage exacerbations

http://www.who.int/respiratory/copd/management/en/ (accessed 30-11-2012).[39]

The goals of effective COPD management include:

- Prevent disease progression
- Relieve symptoms

- Improve exercise tolerance
- Improve health status
- Prevent and treat complications
- Prevent and treat exacerbations
- Reduce mortality

1.1.1.4.1. Guidelines and recommendations given by experts on COPD non-pharmacological management

The effective management of COPD includes both pharmacological and non-pharmacological interventions.[34] The non-pharmacological management complements pharmacological treatment and enhances patient outcomes.[40] This study will place emphasis on two non-pharmacological interventions namely, self-management (SM) interventions and pulmonary rehabilitation (PR).

Table 1.1 presents a summary of the various non-pharmacological interventions recommended by global health guidelines including the UK (i.e. based on best available research evidence).

Table 1.1 Summary of national and international guidelines recommended for COPD non-pharmacological management

Name of organisation	Guidance
WHO http://www.who.int/respiratory/copd/management/en/ (accessed 30-11-2012)	Health education, Exercise training programmes, and Oxygen therapy (for stable COPD) Non-invasive positive pressure ventilation (for exacerbation management)
GOLD 2011 [39]	Smoking cessation, PR, Physical activity, and Vaccinations (for all respiratory disease patients)
GOLD 2013 [17]	Smoking cessation (essential), Physical activity (recommended), Flu or pneumococcal vaccinations
ATS/ERS 2006 [41]	PR to consider provision of SM education instead of didactic education
BTS 2013 [42]	Educational talk within PR to include SM
NICE 2010 [43]	Smoking cessation, Oxygen therapy, Non-invasive ventilation, PR with education and multidisciplinary management comprising of education and SM (for stable COPD) Non-invasive ventilation; oxygen therapy; and Physiotherapy (for exacerbation management)
NICE 2012 [44]	Home care by outreach nursing for COPD patients, Complex patient education programmes (comprising of

	SM action plans with limited education and/or a disease management programme)

PR to be delivered to patients who have recently experienced an exacerbation |
| Consultation strategy document for COPD services 2010 [23] | 'Self-care'; Chronic disease management approach, moderate exercise, and standardisation of tools to support implementation of SM plans, and provision of SM support |
| Outcome strategy for COPD and asthma in England 2011 [45] | Holistic focus with a call to action from the health and social care system. Recommendations included effective proactive disease management, partnership between HCPs and patients to be partners in their care; patients should be able to self-manage their condition and have a voice in their treatment and where it is delivered. The management plan for patients with chronic disease was also suggested for COPD management and SM i.e. risk profiling, integrated care and self-care. Provision of SM support was also suggested right across the COPD patient pathway. |

Key:
WHO – World Health Organisation; GOLD – Global Initiative for Chronic Obstructive Lung Disease; ATS – American Thoracic Society; ERS – European Respiratory Society; BTS – British Thoracic Society; NICE – National Institute of Health and Clinical Excellence; PR - Pulmonary rehabilitation; SM – Self-management; HCPs – health care professionals

Besides health policy guidelines, several workshops have also been convened by experts to discuss the place of SM and PR in COPD management. A common theme among these workshops was: delivery of PR that includes SM education,[41,46](Professor Mike Morgan, personal communication 5Dec2012) for patients with more severe problems,[46] or those who had suffered an acute exacerbation,[30] patients that have capacity to understand(Professor Mike Morgan, personal communication 5Dec2012), or taking account of their level of health literacy[41] to help improve exercise adherence which could lead to positive health behaviour change following completion of PR.[41] In addition, provision of SM programmes for patients with less severe problems and disease management by HCPs was suggested for patients with more severe problems.[46] The delivery of SM education within PR was reported as an element of the integrated model which was considered synonymous or interchangeable to the disease management or chronic care model.[47]

Improving SM or ensuring patients with long term conditions including COPD are better able to self-manage their condition is the scope of the abovementioned policy guidelines, experts' recommendations and a major focus of the NHS strategy.[48,49] However, within some policy guidelines the term 'education' has been used synonymously with 'SM education'; and, 'SM' has been incorporated within an 'educational package'[41,43,44]. The terms 'SM' and 'self-care support' have been used interchangeably[49]. More recently in the research literature the term 'SM programme' was used synonymously to 'disease management'[50] which we debated in a recent article[51] and called for a universally common definition of SM improve communication between researchers, clinicians and policy makers alike. The lack of clarity between these terminologies and how they might function at the expert/policy level could create further confusion or lack of understanding at the practice level among health care professionals. This might prevent referral or delivery of these types of non-pharmacological management to patients thus affecting patient SM and health outcomes. Thus, the next section defines each of these terminologies, clarifies their function and shows the relationship between these terms.

1.1.1.4.2 Self-management (SM)

This section defines and describes SM and its derivatives and how they might be interrelated. Next, the role of SM in COPD is explained; from published research existing evidence of SM benefit in COPD is reported, existing patient participation and completion rates in SM and PR programmes, and existing reasons given for participation and completion in these programmes is presented. The section concludes with the current service provision of SM in COPD.

1.1.1.4.2.1 Definition, function and relationship between SM and its derivatives
a) Definition of SM

There is neither one nor a universally accepted definition for the term 'self-management'. For the purpose of the study the definition given by Barlow[52] has been adopted where SM refers to an *"individual's ability to manage symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition."*
Efficacious SM encompasses ability to monitor one's condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. This definition has also been adopted by the DH.
http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_4890904 (accessed 28-12-12).

The US Institute of Medicine http://www.iom.edu/ (accessed 28-12-12) has defined SM as *"the tasks that individuals must undertake to live with one or more chronic conditions. These tasks include having the confidence to deal with medical management, role management and emotional management of their conditions."*

The Australian National chronic disease strategy defined SM as *"active participation by people in their own health"*.[53]

One study[54] explored the meaning of SM from patients living with a chronic illness and patients revealed that *"SM is a dynamic, active process of learning, trialing and exploring the boundaries created by illness."* Patients perceived SM of a chronic illness as more than just *'doing'* but was enmeshed with a sense of *'being'* and *'becoming'*; Patients had to constantly plan, pace, and manage daily life based on recognising the physical and psychological

responses to their illness. Another study[55] also reported that an individual's ability to manage their health and condition was a result of internal factors; additionally, external factors such as, political, economic and social factors that create social determinants of health can also affect SM.

b) Aim of SM

The aim of SM, reported by the NICE guidance in 2010[43] was very similar to its recommendations for COPD management, to prevent exacerbations by lifestyle adaptation through acquisition of skills to treat exacerbations from SM education and/or SM plans.

c) Description of SM

Effective SM of chronic illness is complex and requires significant participation by both patients and their families; the SM components include:[56,57]

- engaging in activities that promote physical and psychological health;
- interacting with health care providers and adherence to treatment recommendations;
- monitoring health status and making associated care decisions and
- managing the impact of the illness on physical, psychological and social functioning.

Achieving effective SM would involve the adoption of core SM skills such as[58]:

- problem-solving;
- action planning;
- decision-making;
- act of finding and utilising resources and
- forming partnerships with health care providers

The effects of SM are achieved through operationalisation of the self-efficacy theory,[59] *"beliefs in one's capabilities to organize and execute the courses of actions required to produce given attainments"*, a major component of the Social Cognitive Theory (SCT).[58] The latter feature is unique to SM interventions that set it apart from health promotion and patient education interventions. The self-efficacy enhancing components, incorporated within the structured teaching processes of a SM programme, include performance mastery, modelling, interpretation of symptoms, and social persuasion[58]. Specifically:

- performance mastery or skills mastery is action planning e.g. action plan to begin exercise;

- modelling can take place in several ways such as, provision of materials (written, video) suited to the population they are developed for, peers with a similar chronic condition and people, can act as models for each other e.g. observation of breathing technique;

- interpretation of physiologic symptoms is aimed at people to help them form alternative explanations for their symptoms as these might occur due to several reasons and this could result in managing symptoms in different ways e.g. how to respond when anxious due to breathlessness; and

- social persuasion is an important element suggesting that if people around you are performing a behaviour or not, then people are more likely to follow e.g. peer support.

d) The various derivatives of SM and the relationship between them

The various derivatives of SM include self-care, self-care support, SM support, education, SM education, and disease management. The relationship between these terms is illustrated in Figure 1.1.

Figure 1.1 Illustration of relationship between SM support and disease management interventions

Self-care support

Disease management programme/Integrated care model

Self-management support

Pulmonary rehabilitation

Self-management education programme

Self-management plan

Education

Other support needed e.g. clinical information systems
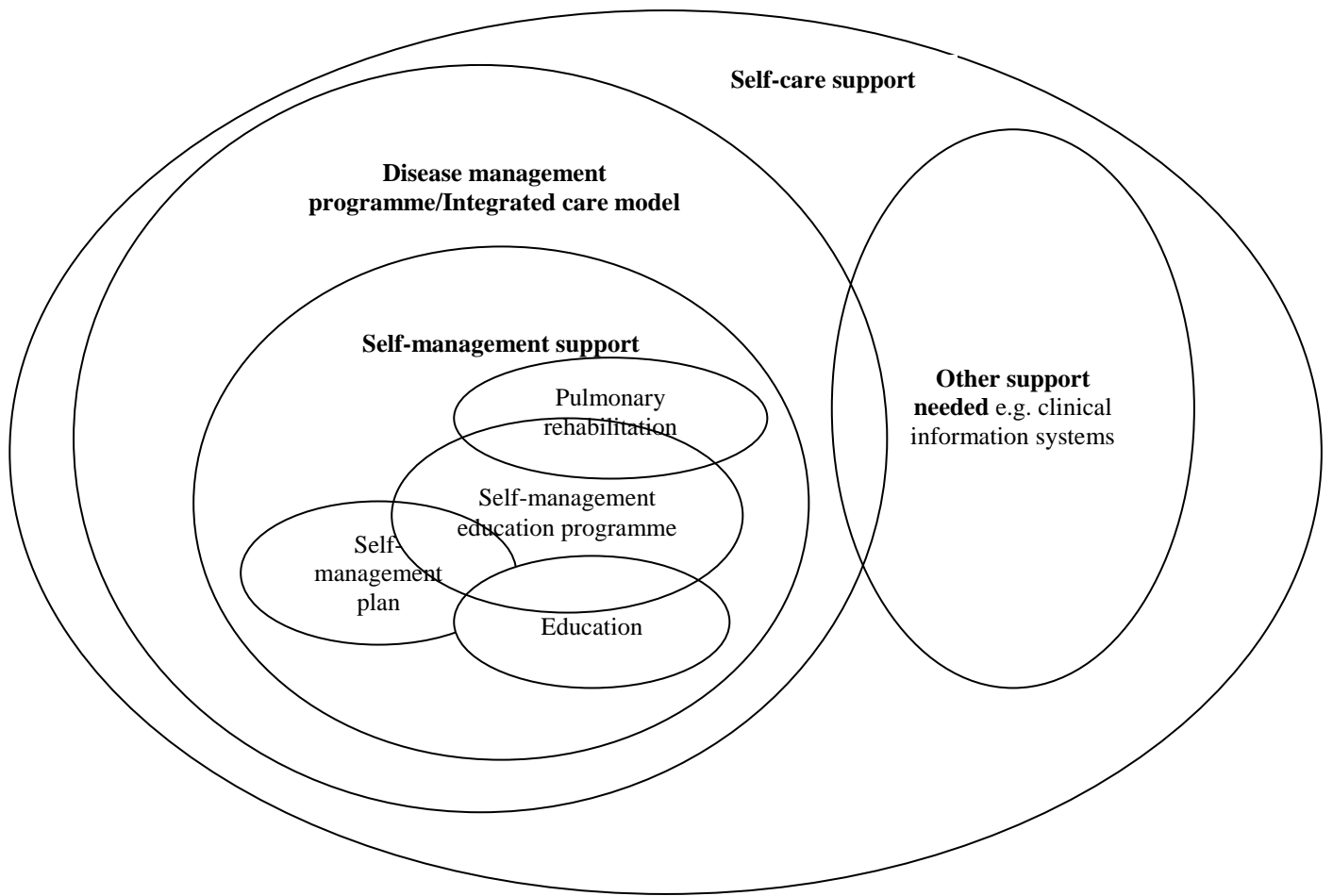
Difference between the terms 'self-management' and 'self-care' and the relationship between them

The DH[60] has defined self-care as *"the actions people take for themselves, their children and their families to stay fit and maintain good physical and mental health; meet social and psychological needs; prevent illness or accidents; care for minor ailments and long-term conditions; and maintain health and wellbeing after an acute illness or discharge from hospital."* Another definition has been given by Barlow,[52] *"care taken by individuals towards their own health and wellbeing: it comprises the actions they take to lead a healthy lifestyle; to meet their social, emotional and psychological needs; to care for their long-term condition and to prevent further illness or accidents".* Parsons[61] in the context of understanding experiences of SM and expectations from older people in their report defined SM as *"those actions individuals and others take to mitigate the effects of a long term condition and to maintain the best possible quality of life."*; and referred to self-care as a *"wider set of behaviours which both the healthy and the not so healthy take to prevent the onset of illness or disability, and, again to maintain quality of life."*

Based on the above definitions of SM and self-care, SM is one activity among various other activities within self-care that an individual living with a chronic condition can utilise to better manage their condition. However, self-care can be performed by individuals who are healthy, at risk or ill and include activities/behaviours such as, self-diagnosis, SM, self-medication and self-monitoring.[62]

Self-care support

Self-care support has been defined as *"increasing the capacity, confidence and efficacy of the individual for self-care by providing a range of options".*[63] Roger's[64] in their study encompassed the Expert Patient Programme (EPP), through which an individual with chronic disease can undertake to manage their illness such as, negotiating the way through the health service, utilise skills, information, technology and resources, and mobilise and draw on social networks, within self-care support. However, based on the above definition of self-care the EPP fits more within the remit of SM and SM support as the EPP is only aimed at individuals with chronic disease.

The definitions also clarify that perhaps the terms 'self-care support/self-management' grouped together and illustrated at the bottom of the risk pyramid model in the DH

Supporting people with long term conditions report [49] and aimed particularly at 70-80% of people living with chronic disease might not be appropriate.

SM support

SM support has been defined as *"the systematic provision of education and supportive interventions by health care staff to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support."[65]*

According to the COPD consultation document,[23] provision of SM support is about helping people manage work and leisure activities and developing strategies to deal with the psychological consequences of illness.

Provision of SM support forms one component of the chronic care model – a disease management model;[66] The model is a guide for health systems to improve the health of people with chronic conditions by making changes to the health system organisations, to improve delivery of patient care alongside empowering patients to manage their health through the provision of SM support.[23,66]

Effective SM support is more than telling patients what to do; patients' central role in managing their health needs to be emphasised and acknowledged by health care providers. The goal of SM support has been reported as changing patient behaviour by increasing their self-efficacy and knowledge to achieve health and functional outcomes.[67] Patients and professionals need to work in collaboration and form partnerships to identify and define problems, set priorities, establish goals, create treatment plans and solve problems simultaneously; and resources in the community need to be in place to provide ongoing support to patients. http://improvingchroniccare.org/index.php?p=Self-Management_Support&s=22 (accessed 4-1-13)[60,62]

For professionals, to encourage effective partnerships with a patient (or to deliver SM support), it would require other components of disease management to work together for example, provision of training for professionals to provide the right clinical and behavioural support (decision support); delegation of tasks to other team members (delivery system design) e.g. nurses allocated more time to deliver SM support;[43] assessment of patient needs; delivery of information from evidence based guidelines (clinical information systems) to patients using computers or telephone; and changes at the organisational level (health care organisation) where appropriate e.g. at personnel level.[68]

Delivery of SM support within a clinical consultation setting could include delivery of SM plans and outside of a patient-professional clinical consultation context could include delivery of effective programmes that provide education, emotional support and strategies for living with a chronic illness among patients though, provision of SM support cannot begin and end with attendance in one class or programme. The two key programmes that support and enable patients with COPD to better self-manage their condition include SM and PR programmes.

(1) SM programmes

SM programmes have been promoted as one of the most important, non-pharmacological way of helping people with intractable chronic conditions;[69] The programmes are group-based programmes either tailored to a specific disease (e.g. COPD, asthma, diabetes) or multiple chronic conditions via a *generic* programme (the Expert Patients Programme (EPP)). In the UK, the EPP, is the anglicised version of the Chronic Disease Self-management Programme developed by Lorig and colleagues in Stanford, USA.[70] The EPP comprises six weekly sessions, each lasting two and a half hours and is led by trained and accredited lay tutors who themselves have chronic illnesses.[70]

Pilot generic SM programmes were delivered by several primary care trusts (dissolved now into clinical commissioning groups (CCGs)) across England in 2002-2004 to persons living with a long term condition (LTC).[71] In 2005, the national evaluation[71] of the EPP revealed recruitment difficulties for the group-based programmes including lack of engagement in these programmes from the participating trusts[1.] The generic SM programmes faced criticism for not recruiting people of lower socio-economic or with low health literacy which was perhaps due to the programme commissioners foreseeing this group as difficult to recruit.[73] However, the critics reported that people who had participated in the programmes may already have been good self-managers in comparison to people who did not participate in the programmes thus affecting outcomes.

The evaluations of the generic SM programmes reported that effect on health status was weak.[74] A Cochrane review[75] of 17 studies of lay-led SM interventions reported that many of

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[1] Note: The responsibility of the primary care trusts shifted to a GP consortia in 2012/2013. The consortia took the role of commissioning in 2012/2013 and makes funding allocations for 2013/2014. The GP consortia has taken full financial responsibility from April 201372. Department of Health. Equity and Excellence. Liberating the NHS. London: 2010 2010. Report No.

the studies used volunteer patients, overall the patients were predominantly female (70%) and were quite well at baseline.

Nonetheless, the national evaluation identified some patients' desire for disease-specific EPP.[71] Another study[76] suggested that impact of lay-led programmes may be enhanced by including specific disease management advice delivered by a health professional and complementing lay tutoring. This led to wide interest in the development and delivery of disease-specific SM programmes e.g. in asthma, COPD and diabetes.

A SM programme has been defined (by experts in the field around SM for chronic pain http://www.ihse.qmul.ac.uk/chs/pctu/current_projects/copers/index.html (accessed 4-1-13) as:

Structured programmes with the broad goal of improving participants' health status or quality of life. They are:

1. always aimed at, and delivered to, patients, and at patients where there is scope for improvement in managing their own health. (Carers may be involved but the programmes are principally directed at patients).

2. always structured. (Individual elements are organised and delivered in a particular way).

3. always include a taught or self-taught component that aims to increase participants' skills and knowledge and to enable participants to deploy these enhanced skills in aspects of their lives beyond the intervention.

In addition:

A. Self-management programmes are often multi-faceted.

B. They may be directed at some or all of the following,

Managing the Illness:

- Taking medications
- Changing diet and exercise
- Managing symptoms of pain, fatigue, insomnia, shortness of breath, etc.
- Interacting with the medical/social care system
- Managing daily activities and roles
- Maintaining roles as spouse, parent, worker, etc.
- Managing the emotions
- Managing anger, fear, depression, isolation, etc.

C. They may include some or all of the following components:

- Psychological training, aimed at increasing awareness, changing attitudes and beliefs.
- Physical training, including exercise, biofeedback, diet etc.

Programmes that only involve exercise training do not constitute as SM programmes.

While, Burtin[77] proposed a narrow aim of SM programmes focusing mainly on exacerbation management, more holistic aims have been provided such as, to provide people with the knowledge and skills that are needed to manage their risk factors, monitor their disease, make effective use of services and manage the impact of disease on their lives[53] thereby, reducing the burden of chronic illness on individuals and the community.[78]; to teach skills needed to perform a specific medical regimen, guide health behaviour change, and provide emotional support for patients to control their disease and function better.[79] The latter author has illustrated (Figure 1.2)[80] the behaviour change process caused by enhancement of self-efficacy, knowledge gained, and learnt skills within a SM programme.

Figure 1.2 Causal model of behaviour change
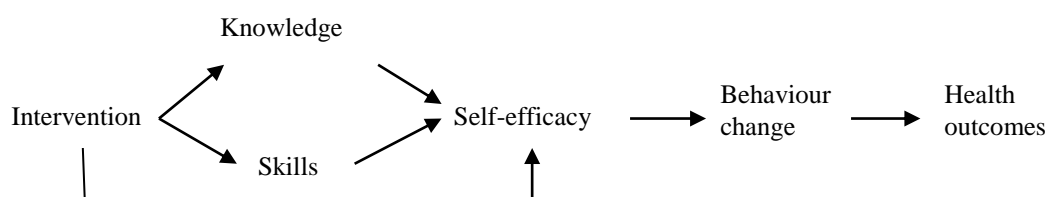
Some studies have reported that knowledge and skills might not be enough to cause behaviour change as SM is dependent upon other variables such as, health beliefs, decision-making ability, quality of communication with clinician[32,67] and sense of power and control.[81] Development of knowledge and skills can be influenced by psychological factors such as intrinsic motivation, depression, panic, anxiety, fear, frustration, regret and a feeling of helplessness; lack of social support,[32] and health literacy.[82] These factors may prevent patients wanting to engage in complex SM strategies[32] e.g. exercise.

Difference between the terms 'education' and 'SM education programmes'

One study has defined the term 'education' as *"provision of information to patients about their condition and what to do, so that knowledge may lead to changes in health behaviour that will in turn improve health and other outcomes".*[83]

Several research studies[84,85] have evaluated SM education programmes (or ~~also be~~ referred to as SM programmes) among COPD patients. Blackstock's[86] review of disease-specific health education for COPD differentiated the 13 included studies into studies of SM education and didactical education. The former was defined as *"education focusing on changing health behaviours through knowledge, goal setting and development of action plans"* and the latter was defined as *"education given in a passive lecture format, with opportunity to interact, but no focus on health behaviour change."* A similar distinction between education and SM programmes has been reported in other studies.[46,81,87] Effing in a recent study[46] recognised that different meanings of SM programmes have been assigned by several health guidelines (acknowledged in the beginning of this section) and reported that as 'SM' is aimed mainly at behavioural change and 'education' is normally interpreted as transmission of knowledge which mostly will not lead to behavioural change, it would be advisable to either use the term 'SM' or 'SM training' instead of 'SM education' in the future.

(2) PR programmes

Provision of SM education and/or support within PR has been recommended by policy guidelines[41] experts (Professor Mike Morgan, personal communication 5Dec2012) and as the role of PR is to assist patient SM,[42] PR has been referred to as a SM support intervention/programme throughout the study.

In the UK, The IMPRESS (Improving and Integrating Respiratory Services in the NHS)[88] group have defined features of a successful rehabilitation programme.

"Such a programme:

- is an individually tailored, multi-disciplinary intervention for symptomatic patients that is integrated into their overall care.

- aims to reduce symptoms, improve functional performance, increase participation and reduce health care costs.

- contains effective, individually prescribed, physical exercise training together with lifestyle and self-management advice

- addresses the social and psychological impacts of the disease on the patients and those close to them

- monitors progress with appropriate individual outcome measures and programme quality control"

The IMPRESS statement further distinguishes between *"encouragement to the individual to remain active"* (SM programmes) *"and the deliberate supervised therapeutic process of restoring function through the process of formal rehabilitation"* (PR programme). IMPRESS states that *"PR must include individually prescribed lower limb physical training with twice weekly supervised sessions at least and that supervised sessions should be augmented by further daily home based sessions. The typical duration of a PR session is 6 to 12 weeks."*

(3) SM plans

A SM plan has been defined as *"a plan (either written or verbal) designed with the primary purpose of patient self-management of COPD exacerbations".*[43]

Delivery of SM plans have been coupled with limited education and/or part of disease management and in PR in the above mentioned recommended by the policy guidelines.

Disease management programmes

Disease management has been defined as a *"system of coordinated health care interventions and communications for populations with conditions in which patient self-care is significant".*[89] Another study[90] has defined these programmes as, *"a group of coherent interventions designed to prevent or manage one or more chronic conditions using a systematic, multidisciplinary approach and potentially employing multiple treatment modalities. The goal of disease management is to identify persons at risk for one or more chronic conditions, to promote self management by patients and to address the illnesses or conditions with maximum clinical outcome, effectiveness and efficiency regardless of treatment setting(s) or typical reimbursement patterns."*

1.1.1.4.3 Role of SM in COPD

Chronic conditions cannot be treated or cured but need prolonged SM by patients.[81] Patients have to be responsible for the daily management of their condition which affects both their physical and psychological health; and participation in managing one's own condition is often a reality and a necessity rather than a choice.[81]

Central to COPD management includes adherence to medication, early recognition of symptoms and prompt access to early treatment in the event of an exacerbation,[91] reducing frequency of exacerbations, preventing hospitalisations and improving quality of life.[32] Furthermore, management includes adopting breathing techniques, exercising, attending

nutritional programmes and stress management.[91] This necessitates the patient understanding their disease and management. However, several studies[24,82] have reported that patients with COPD do not understand their disease and/or management. A recent qualitative study[82] showed patients with severe COPD had limited knowledge of COPD, and performed limited SM skills. Another study[92] explored the needs of patients with advanced COPD belonging to three GP practices where smoking rates were higher than the national average and found that patients had poor understanding about their condition, and some patients did not know the condition was known as COPD.

Specifically, with regard to management, patients with COPD would like: to avoid getting breathless,[67] more information on how to control or manage breathlessness, exacerbations,[24,93] to learn about medications,[93] treatment options[94] and new methods and interventions to improve outcomes.[67] Additionally, patients would like to know what to expect from the condition now and in the future,[93] and more information on nutrition, diet and healthy weight.[95] Besides management of the clinical aspect of the disease, patients with COPD would like: information about the services available which they can understand easily; to be empowered to makes decisions about their care and be supported in decision-making; to be treated as a whole person and be enabled so they can take part in activities of daily living.[23] Patients with COPD consider activities relating to personal care and housework important[96] and have a strong desire to engage in social activities and be independent.[97]

One way to achieve the above could be through patient self-managing which could include making decisions about their health and engaging in behaviours that affect their health in a positive manner;[98] this would require support from HCPs (right support at the right time).[23,46] for example, provision of information on SM strategies.[95] These strategies may provide patients with valuable skills to help manage their condition and which may have the potential to have a lasting effect beyond completion of delivery of the intervention.[99] However, SM strategies are complex behaviour change strategies and require significant effort and commitment from patients.[32] In COPD, these strategies among several, include smoking cessation, learning and implementing breathing and coughing techniques, adhering to exercise programmes, using inhaled medication regularly and self-initiating use of corticosteroids or antibiotics at the onset of an exacerbation through following set action plans, deploying effective coping and behavioural skills learnt from SM education[32,67] and health outcomes would be dependent upon the degree of effective SM

http://improvingchroniccare.org/index.php?p=Self-Management_Support&s=22 (accessed 4-1-13).

One barrier to adoption of SM skills could be due to poor communication between patient and professional.[67] Communication style may influence patients' motivations and commitments towards making health-related goals and plans resulting in behaviour change.[67] Another barrier could be lack of referral to programmes that implement SM strategies such as, PR programmes.[82]

1.1.1.4.4 Evidence of SM benefit in COPD

The evidence presented below is from studies of COPD SM programmes, disease management programmes including SM support, SM action plans and PR programmes.

The most popular way to enable SM among patients with chronic conditions including COPD has been mainly through delivery of group-based PR and SM programmes.[53,100]

The disease-specific SM programmes have tended to produce more positive outcomes than the generic programmes;[74] this is certainly true for asthma (i.e. improvement in health outcomes including improvement in health care use, days lost from work and quality of life,[86] and diabetes (i.e. improvement of glycaemic control).[101] Patients with chronic disease with effective SM skills make better use of HCPs time, make daily decisions about medications, self-monitoring and exercise and hence play a central role in determining the course of their disease. However, this does not seem to apply to patients with COPD.[87] This may be because of the evidence of benefit for SM in COPD is patchy.

Blackstock's review[86] reported that studies of SM education had the potential to improve quality of life of patients with COPD and improve health care utilisation in comparison to studies of only didactical COPD education and concluded that future research should concentrate on SM educational programmes with underlying Social Cognitive Theory (SCT) health behaviour theory.[59] Effing's review[84] of COPD self-management education suggested that SM education may reduce hospital admissions but because of heterogeneity (in populations, outcome measures, follow up times and interventions) among the included studies definite conclusions on effectiveness could not be made. One recommendation by the review was also that future SM programmes should be designed using theoretical model of behaviour change such as the SCT. The heterogeneity in Effing's review was mentioned in an editorial by Bourbeau[87] who suggested that heterogeneity may affect implementation of SM in clinical practice and further explained, that the studies in the review instead of focusing on

the complex sequence of effects that result in behaviour change, placed focus on measuring patients unscheduled visits to the hospital, with expectations to see a reduction in health care utilisation within a short period of time and this was unrealistic. Furthermore, the same study suggested that studies need to assess behaviour change as behavioural change will increase the likelihood of obtaining better patient outcomes and a reduction in health care utilisation.

Our recent pilot study[85] evaluated a COPD-specific SM programme underlying with the self-efficacy theory, a major component of the SCT. Patient measures included behaviour change measures such as, self-efficacy scales around managing disease, SM behaviour scales for exercise and communicating with clinicians. The study results suggested that patients who received the intervention were more likely to exercise and have improved quality of life. Despite the positive results, one limitation of the study was poor patient recruitment (23%) from primary care and 35% of patients amongst those registered to attend the programme did not attend any sessions of the programme (0 out of 7 sessions). Subsequently, the low participation rate prevented a further evaluation of the programme in a larger RCT as patient numbers would have to increase drastically to see the programme effect.

Meanwhile, the evidence of benefit from studies of PR programmes is well established and has been widely reported.[40] PR improves exercise capacity, improves breathlessness, quality of life and reduces health care use.[40] Recent health policy guidelines, experts and a review[77] on effectiveness of rehabilitation strategies to counteract consequences of patients suffering acute exacerbations in the field of COPD management, have suggested that the incorporation of SM within PR would be advantageous for patients as, SM skills could help with exacerbation management while, PR could help to prevent new exacerbations from occurring. However, considerable published reports exist around the problem of poor patient participation and high attrition in studies of PR programmes (discussed further in the next section).

Regarding effectiveness of disease management in COPD, a review by Adams[102] with 32 studies saw significant reduction in healthcare use (admissions and unscheduled visits) by COPD patients specifically, in trials that implemented interventions with two or more components of the chronic care model. On the whole, the review, because of lack of published evidence on chronic care interventions in COPD management, concluded that more rigorous conducted trials with multi-component chronic care interventions were needed.

The evidence from individual studies of disease management in COPD has been positive[103] and recently more negative.[104,105] A study of disease management by Rice[103] showed that education, an action plan and monthly phone calls by a case manager to patients who had recently suffered an acute exacerbation, was effective in reducing the number of COPD-related hospitalisations and unscheduled care.

Two recent studies[104,105] of disease management directed at patients with severe COPD presented negative findings; the aim of both studies was to demonstrate a reduction in time to hospital admission for acute exacerbations. In Fan's study[105] patients' received SM educational sessions, in a prescriptive and instructional format, based on the Precede-Proceed model[89] of health programme planning and evaluation with a focus on exacerbation management and an action plan from a case manager. This study had to be terminated early because of an excess of patient deaths in the intervention group, however, the cause of mortality could not be determined. Bucknall's[104] intervention comprised of SM (empowering patient mainly through didactic teaching sessions) and case management, with a focus on exacerbation management by activation of an action plan through self-regulation - a model of disease management; this meant being observant and making judgements based on observation and reacting appropriately to achieve a goal.[106] The intervention was not effective and only 42% of patients who received the intervention were able to respond appropriately to signs and symptoms of an exacerbation.

A review[107] of SM action plans with limited education (1.5 hours or less) for COPD concluded that action plans and limited education were helpful for patients to recognise and respond to exacerbations by taking appropriate medication. However, to see improvement in quality of life and reduction in health care use, the delivery of action plans and education on its own were not enough and should be delivered to patients as part of ongoing SM or a disease management programme.

1.1.1.4.5 Patient participation in studies of SM support programmes

Examination of the evidence on proportions currently reported for patient participation and completion in COPD SM programmes showed that the proportions varied in studies and were unclear whether the proportion referred to the study or the intervention.

Regarding participation and attrition in COPD SM programmes, besides our study[85] that showed poor patient participation and poor programme non-attendance (35%), in Effing's review,[84] an overall participation rate was not reported, data was provided on the total number of patients who completed the studies (86%) and only one study in the review reported a dropout rate of 30.4%. In addition, patients' in the included studies were identified from a variety of different sources, some studies did not report how patients were identified or invited, or the number of patients approached the proportion who were eligible. A study[86] has reported that it is unreasonable to expect more than 85% of COPD patients to complete a SM intervention.

Regarding participation and attrition in PR, studies have reported that about 34% of participants attend after being referred to PR;[108] uptake figures of 33%-39% have been reported from outpatient clinics[109] though, it was not clear whether the figures were based on patient referrals or patient assessments; between 20% and 40% of eligible patients do not complete PR programmes;[110] one study[111] reported a programme dropout rate of 39% and 23% in the intervention and control group respectively; one review[112] examined what prevents people with COPD to attend PR and reported proportions for PR non-attendance (8.3% to 49.6% amongst referrals) and non-completion (9.7% to 31.8%) from a mix of both qualitative and quantitative studies; and a recent study[113] examined attendance and completion rates of an integrated PR service in clinical practice and also found low uptake (54% from PR assessment) of programme and completion (40% from those referred).

Due to the varied reports of uptake and retention in studies of PR and limited reports of uptake and retention in the case of COPD SM, the study will examine the current evidence in a systematic review (Chapter III) to see if a problem of poor patient participation and retention in the studies of these programmes does exist before determining ways to address the problem.

Some explanations from both qualitative and quantitative studies have been given for patient non-participation and non-completion in PR and COPD SM programmes.

From the literature, factors that influence non-attendance and non-completion in PR programmes included: socio-demographic factors such as, current smokers;[25,114,115] stigma;[115] practical or physical barriers such as, transport difficulties including longer travel time to get to the programme; organisational factors for instance, length of programme; and clinical factors such as, previous hospital admissions or higher MRC dyspnoea scale score. Specifically, the reason given for PR non-attendance was health system organisational factors

such as, inadequate local service provision, difficult referral process,[116] health care professionals' not knowing the benefits of PR.[30]

Reasons given for PR non-completion included, socio-demographic factors such as, higher age;[25] clinical factors such as, being less ill,[117] lower quadriceps strength, high smoking pack years, depression, high MRC score,[118] and lack of physical performance;[119] and also participants' personal reasons for instance, personal beliefs such as, lack of perceived benefit, lack of motivation and expectations not being met,[111] termination of group programme, loss of supervision and not being able to achieve goals.[120]

Studies have also reported on factors that influence PR adherence and they were: an individual's perceived benefit from programme adherence in relation to their illness beliefs;[110,120] presence of supervision; development of an exercise routine;[120] and group and family support.[120,121]

Only our study of a COPD SM programme explored reasons for patient attendance and non-attendance by patients with moderate to severe COPD from the perspectives of patient and lay tutors who delivered the programme and the reasons comprised a mix of socio-demographic, personal and health factors.[122]

Due to the limited evidence on patient reasons for non-participation and non-completion in studies of PR and COPD SM programmes, the latter will be explored further from perspectives of COPD patient stakeholders (Chapter V) and experts comprising lay and HCPs (Chapter VI).

A study has suggested that non-adherence with PR may indicate non-adherence with other SM strategies.[123] In addition, two recent reviews[112,121] concluded that patient demographics and/or clinical factors may not be enough to understand the problem of patient participation and retention in interventions that promote SM. As a result, Chapter IV of this study will synthesise qualitative evidence and apply behavioural/psychological theories (identified in Chapter II) to findings of existing primary studies to further understand participation behaviour of COPD patients in studies of SM support programmes.

1.1.1.4.6 Current service provision of SM support in COPD

Even though delivery of PR and SM education/advice for COPD management has been reported as a priority,[24] studies have reported that patients with COPD have limited access to

PR programmes in practice[124] which could be due to local PR centres closing down owing to poor programme uptake by patients (Dr Anne Kennedy, personal communication 26May2012) or perhaps because of limited availability of PR.

Despite the NICE guidance,[43] about referral/offer of PR to patients with MRC score $\geq 3^2$ there are several reports of poor PR referral. A recent study[125] attempted to identify characteristics of patients who had a first hospital admission (in a North London district teaching hospital) with a COPD exacerbation and found that only 17% of patients were considered for PR even though, 59% of patients were eligible for referral. A survey[93] in primary care (Lambeth and Southwark GP practices) on palliative needs of patients with advanced COPD detected that more than 50% of patients had not been referred to PR. Another survey[16] examined differences by ethnicity in COPD prevalence, severity and management of COPD in East London and found that only 18.5% of patients (Whites 19.3%, south Asians 16.7% and Blacks 12.6%) with COPD were offered PR.

In the UK, the variability in PR availability has been acknowledged whereby, in some cases patients have to be referred to a respiratory specialist unit to attend PR and others might be able to access PR from primary care
http://www.cks.nhs.uk/chronic_obstructive_pulmonary_disease/management/scenario_stable _copd/assessment/assessment_of_severity/medical_research_council_dyspnoea_scale#-474714 (accessed 13-1-11).

The poor service provision of PR also exists in other developed countries. A study[124] that surveyed PR providers (Canada, Australia and UK) reported that only 1-2% of eligible patients were able to access or receive PR programmes and the reasons were attributed to patient factors, inadequate referrals from primary care and lack of infrastructure for provision of PR. The lack of patient referral and lack of supply of PR programmes[82] to eligible patients with COPD would be more likely to have worse outcomes[30] which is matter of huge clinical concern.[112]

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[2] Medical Research Council (MRC) Dyspnoea Scale: Grade 1- Not troubled by breathlessness except during strenuous exercise; Grade 2- Short of breath when hurrying or walking up a slight hill; Grade 3- Walks slower than contemporaries on the level because of breathlessness, or has to stop for breath when walking at own pace; Grade 4- Stops for breath after walking about 100 m or after a few minutes on the level; and Grade 5- Too breathless to leave the house, or breathless when dressing or undressing
http://www.cks.nhs.uk/chronic_obstructive_pulmonary_disease/management/scenario_stable_copd/assessment/ assessment_of_severity/medical_research_council_dyspnoea_scale (accessed 13-1-13)

Regarding provision of SM education/advice for COPD management recommended by policy guidelines, the generic SM programme or the EPP was suggested as one mainstay way to reduce the burden of LTCs (comprising of 70-80% of population) including COPD for patients at low risk[63] thus reducing the burden of cost on the health services. Following pilot delivery of the EPP and its evaluation, the UK government pledged to treble the investment in the EPP and established the Expert Patients Programme Community Interest Company (EPP CIC) www.expertpatients.co.uk (accessed 24-1-13) in 2007 to increase delivery of SM programmes from 10,000 to 100,000 in England. The EPP CIC delivered several generic or disease-specific (asthma, arthritis, diabetes, epilepsy, heart disease, COPD and multiple sclerosis) programmes to patients in the community following its commissioning by several NHS PCTs/CCGs and/or organisations (e.g. research organisations). The EPP CIC also offers online programmes to patients who cannot access programmes in the community as a result of their condition (e.g. mobility issues) which can include patients with COPD. Though, there is much anecdotal evidence that there is poor patient participation and high dropout in COPD SM programmes (COPD SM programme tutor, personal communication 8Jun2011) including in ongoing research studies (Co-Creating health respiratory nurse, personal communication 9Sep2011).

Furthermore, delivery of SM plans (either in written or verbal format) in clinical practice within overall management of COPD have been introduced for patients with COPD http://www.cks.nhs.uk/chronic_obstructive_pulmonary_disease/management/scenario_stable _copd/self_management_plan#-472499 (accessed 13-1-11); the plan needs to be personalised to help patients recognise early signs of an exacerbation and respond appropriately and contact their doctor if no improvement takes place. However, it was difficult to estimate the proportion of GP practices that offer SM plans to COPD patients because the NHS QOF do not require practices to report the delivery of SM plans to patients.

The QOF, does, however, (as part of ongoing management) include a COPD indicator that records *"The percentage of patients with COPD with a record of FEV_1 in the previous 15 months (COPD 10)",* to help GPs identify potential patients who could benefit from PR. There are no COPD indicators that require direct recording of percentage of PR referrals from practices;[126] though, this might change in 2013/2014 as the QOF Advisory Committee meeting[127] for COPD indicators made recommendations on piloting two new indictors for COPD recording,

(1) *"The percentage of patients with COPD and Medical Research Council (MRC) Dyspnoea Scale ≥3 at any time in the preceding 15 months;"*

(2) *"With a subsequent record of an offer of referral to a pulmonary rehabilitation programme."*

So, the implementation of SM support in practice for COPD management, despite the guidelines recommendations, is poor/ patchy and needs improvement to enable patients with COPD to self-manage their condition and gain health benefits. How patients can be better supported with SM will be covered in Chapter V and VI. In addition, a novel way to provide SM support to COPD patients in a non-group setting which will be described and discussed in Chapter VII.

1.1.2 In summary the rationale for this study

Chronic conditions are health problems that *require ongoing management over a period of years or decades*.[128] The increasing prevalence of chronic or LTCs) worldwide is placing considerable pressure on governments, health systems and the broader community.[53] In the United Kingdom (UK), around 80% of general practitioner (GP) consultations take place with patients with chronic diseases, and these patients also account for 60% of hospital bed days.[129] One of the policy goals for managing LTCs in the UK is to reduce GP consultations and episodes in hospitals, whilst promoting the health and wellbeing of patients.[129] The new National Health Service (NHS) mandate,[48] calls for supporting and empowering people with LTCs to help patients manage their condition to reduce hospital admissions.

A huge proportion of healthcare costs in the UK are attributed to COPD.[24] COPD, is preventable[130] and the widely acknowledged risk factor for COPD, mostly in high income countries, is exposure to tobacco smoke[20,130] while, in middle to low income countries, it is exposure to air pollution and occupational dust and chemicals.[17] Once established, it is a progressive and irreversible manageable condition characterised by breathlessness, cough and sputum production.[15] The progression of COPD, if smoking related, can be slowed down or arrested if exposure to cigarette smoke ceases.[131] A UK survey in 2006 including 11,000 COPD patients found that more than 36% were current smokers, compared to 22% of the general population http://www.emphysema-copd.co.uk (accessed Dec 2009). COPD leads to 30,000 deaths, 1.4 million GP consultations, a million hospital bed days, and costs the NHS over £800 million, each year.[36]

Patients with COPD suffer from both physical and psychological limitations; and commonly have several comorbidities which add complexity to their management. Thus, services and treatments need to be integrated and tailored to the needs of each patient.[30]

Non-pharmacological treatments complement pharmacological treatments in COPD and enhance outcomes.[40] The non-pharmacological treatments recommended in the government consultation document[24] for COPD care included, smoking cessation, oxygen, pulmonary rehabilitation (PR), cognitive behavioural therapy, and self-management (SM) advice, SM education programmes to support self-care and personalised action plans.

The focus of this doctoral study is on two non-pharmacological interventions, COPD SM programmes and PR deemed necessary for COPD management. As PR includes a SM component and enables patient SM,[47] these programmes will be referred together as SM support interventions/programmes throughout this study. The goal of SM support programmes is to bring about behaviour change in patients by increasing their self-efficacy skills and knowledge to achieve health and functional outcomes.[67]

In the literature,[19,112] the problem of poor participation and retention in COPD SM support programmes is well documented, more for well evidence-based PR programmes in comparison to COPD SM programmes (with some evidence of benefit); however, the problem of poor uptake and dropout in both these types of programmes, is widely and well acknowledged in practice (personal communication, Camden Primary Care Trust).

A Cochrane review[84] (comprising of 14 studies) of COPD SM education suggested that the intervention may reduce hospital admissions but concrete conclusions could not be made owing to the heterogeneity among the included studies in study populations, interventions, follow up times, and outcome measures. Only one study in the review reported a dropout rate: 30.4%, however it was unclear whether the proportion reported was for the study or intervention. Moreover, patients were identified from a variety of different sources, some studies did not report how patients were identified or invited, or the number of patients approached the proportion who were eligible.

In 2009 we conducted a pilot mixed-methods study[85] that evaluated delivery of a COPD-specific SM programme for patients with moderate to severe COPD. We showed that, on what was effectively an intention to treat analysis, the intervention had the potential to improve the quality of life of patients in the intervention group and the potential to be a cost-effective intervention. However, despite the positive findings patient recruitment in the study was only 23% of those eligible and invited to take part. About 35% of intervention arm

patients who had registered to attend the intervention did not attend any of the seven sessions of the programme. Thus, a decision by the pilot study team was made not to conduct a larger randomised controlled trial (RCT) until the challenge of patient recruitment was addressed and improved (this PhD arose in response to these findings).

Some studies have explored patients reasons for non-attendance and/or non-completion in studies of PR programmes[112] but only our pilot study[122] explored reasons for high and poor attendance in the COPD SM programme from the perspective of both the recipients and the lay tutors who had delivered the programme.

The delivery of PR and SM programmes to eligible COPD patients who are in need, and would benefit from SM support, remains a priority for the government, HCPs, charities and patients.[19,24] Therefore, to ensure good uptake so that the majority of COPD patients receive these interventions and not just a particular few, there was need for further research aimed at understanding non-participation in SM support programmes for COPD and how participation could be improved.

1.1.3 Aims and objectives

Research aims

1) To identify existing rates of participation and completion of interventions that support SM amongst people with COPD.

2) To gain a better understanding of the factors relating to the uptake and completion of interventions that support SM, amongst patients with chronic disease, particularly COPD.

3) To refine an existing COPD SM programme and/or adopt a new delivery method or deliver a new SM support intervention that will help to increase both intervention uptake and programme completion by patients with moderate to severe COPD.

Research objectives comprise of three stages

Stage 1: To conduct a conceptual review to explore the meaning of patient participation in health care and health care interventions and identify behavioural theory that has explained patient participation in health care interventions including self-management interventions among patients with chronic disease; to conduct a mixed-methods review, the quantitative element will quantify existing participation and completion rates in SM support interventions and the qualitative element will identify and explain, using behavioural theory, factors that

influence participation and completion of SM support interventions among patients with COPD.

Stage 2: To conduct focus groups and interviews with patients with COPD of varied severity and with experts who develop and/or deliver SM interventions for COPD patients and who are involved in the management of COPD patients to explore:

    a. reasons for poor uptake and completion of SM support interventions by patients with COPD,

    b. what might be done to make COPD SM support interventions more appealing and applicable for patients with varying levels of COPD severity, including changes to programme content and different modes of delivery,

    c. whether different modes of SM delivery should be considered for patients with different degrees of airflow obstruction, and

    d. what might be the most suitable delivery method for patients with moderate to severe COPD to increase programme uptake and completion.

Stage 3: To describe a non-UK developed SM support intervention adapted for the UK.

1.1.4 Structure of the thesis

The structure of the thesis follows steps suggested by the new MRC guidance for developing and evaluating complex interventions.[132] The guidance has defined a complex intervention as an intervention with several interacting components (complexity could be the result of interacting components within the intervention, range and variable outcomes to be measured, delivery of intervention by range of people at various levels to different types of population, and/or flexibility available to tailor the intervention). Behaviour change interventions (e.g. to exercise, adhere to medications, attend a screening programme) are complex interventions which include several components.[133] One such behaviour change intervention is a self-management intervention (which for example, promotes exercise, healthy eating, medication adherence, conducting breathing techniques and smoking cessation).

This thesis includes three stages, described, discussed and presented in eight chapters including this chapter. The findings of each stage informed the development of the next stage which made the steps within each stage logical and feasible to carry out.

This **Chapter I** begins with the rationale for conducting the study and outlines the study's aims and objectives; the background sections describes COPD, its non-pharmacological management particularly SM support interventions; and introduces the problem of poor participation and retention reported for COPD SM support programmes in the literature.

Following the MRC guidance on *developing a complex intervention*:

Stage 1 of the study comprises of **Chapter II, III and IV** which examines the *existing evidence base* on patient participation and completion in SM support programmes and *utilises appropriate theory* to explain patient participation and completion in SM support programmes for COPD.

Specifically, **Chapter II** presents a conceptual review. The review, from relevant literature helped uncover the origins, concepts and definitions of patient participation and non-participation in health care and health care interventions; Theoretical concepts and models, particularly behavioural models, were explored to explain an individual's reasoning behind health service use and participation and non-participation in health care interventions particularly SM interventions.

Next, a mixed methods review is covered in **Chapter III** and **Chapter IV.** The quantitative element of the systematic review in Chapter III identifies existing participation and dropout

rates in studies of COPD SM support programmes and Chapter IV presents the qualitative synthesis that explored patient given reasons for participation and dropout in studies of COPD SM support programmes.

Stage 2 of the study comprises a primary qualitative study presented in **Chapter V** and **VI** where a *theoretical understanding* was further developed on the problem of poor patient participation and retention in COPD SM support programmes and how change (improvement in patient participation and retention) can be further achieved.

Particularly, patient reasons for non-participation and completion in SM support programmes, how participation may be improved and how patients with COPD, who cannot or do not want to participate or attend SM support programmes, can be better supported with their SM was explored from patient stakeholders in Chapter V and from lay and health care professionals in Chapter VI.

Stage 3 includes **Chapter VII** that describes a non-UK developed SM support intervention, new to the UK, to be delivered in a clinical setting.

Then, **Chapter VIII** presents the summary findings of chapter II, III, IV, V, and VI, discusses findings of the study and its implications for future research and clinical practice and presents overall conclusions.

Next, Chapter II describes the origin of patient participation in health care and in health policy guidelines; reviews the various meanings given to the term 'patient participation' in health care and explains the relationship between patient participation and self-care/self-management; and identifies literature that has used theory to explain patient participation in health care, health care interventions including SM interventions among patients with chronic disease including COPD.

Chapter II. Meanings of patient participation in health care and factors that influence participation in health care including self-management interventions - a conceptual review

Chapter II describes a conceptual review. The results of the review explore:

- the various meanings ascribed to patient participation in health care

- the relationship between participation and self-care/self-management

- a description of health behaviour models that have been utilised to explain health care seeking behaviour and participation in health care interventions particularly, self-management interventions among patients with chronic disease

- Theoretical factors that explained health care seeking behaviour and participation in health care interventions with particular reference to SM interventions among patients with chronic disease

Following this the chapter presents a discussion and conclusion.

2.1 Background

Before examining and attempting to understand the problem of poor participation from published studies of group-based SM and PR programmes for COPD patients (Chapters III and IV) it is important to understand the meaning of patient participation in health care, whether participating in health care is similar to participating in a SM intervention for a patient with chronic disease and what factors influence patient participation in health care and health care interventions.

Patient participation is receiving increasing attention in health care[134,135] and in healthcare activities[136] such as decision-making, self-medication, self-monitoring, patient education, goal setting or taking part in physical care,[137,138] which suggest that the concept of 'patient participation' could have different functions and meanings to simply 'taking part'. In addition, patient participation is being considered at every level of the NHS, in varying health care contexts, from making choices about the care patients receive, to making a contribution towards policy-making, to making decisions in clinical consultations, to making decisions about their health outside the clinical setting.[139] This could lead to varied definitions or interpretations of the concept of 'patient participation', amongst both patients and professionals.[138] Very few studies have previously reviewed the concept of 'patient participation' in health care - and those that have addressed the concept have been mainly limited to nursing practice.[135,138]

It is important to understand the reasoning behind an individual's decision to seek health care and participate in health care interventions. Theories help to provide conceptual understandings of things that are complex and cannot be pinned down e.g. why people interact in certain ways.[140] There is a vast amount of literature[141-144] that has examined, using social, psychosocial or health behaviour theories, health care seeking behaviour of healthy individuals or their participation behaviour in health promotion programmes e.g. screening. However, in comparison to healthy individuals, the factors that might influence patients with chronic disease to seek health care and/or participate in health care interventions, such as self-management (SM) interventions, have received little attention. Thus, the focus of this review was to examine studies that have utilised theory to understand health care seeking behaviour and participation behaviour in SM interventions amongst patients with chronic disease.

The aim of this review was to uncover the origins, concepts and definitions of patient participation and non-participation in health care. Theoretical concepts and models, particularly social, psychological or behavioural models, were explored to explain the reasoning behind health service use and participation or non-participation in health care interventions particularly SM interventions amongst patients with chronic disease.

The review questions were:

1) What do we mean by 'patient participation' and 'patient non-participation' in health care?

2) Can theory help to explain the factors that influence an individual with chronic disease to seek health care and participate in SM interventions?

In addition, the assessors at the nine month PhD review also asked me to critically analyse the relevant policy literature in this chapter specifically, to explore who and why it was decided that it is important for patients with chronic disease/COPD to participate in SM and SM support programmes in policy. As a result, policy literature/guidelines that explained patient participation in health care with a focus on chronic disease self-management was explored including key references denoted by the policy guidelines which in turn led to going back further to examine the origins of patient participation in health care. Before moving to the methods, this section describes the origin of patient participation in health care and origin of patient participation in health policy guidelines.

2.1.1 Origins of patient participation in health care

Since the 15th century, the medical model of disease and management focused on causes and symptoms and often treatment of the disease.[81] In the UK, in the early 19th century, while the wealthy utilised the health services, many other people were responsible for their own health because of necessity and relied on the limited resources of their community and is reflected in the saying *"None practice physic nor professeth midwifery but charitably one neighbour helpth another".*[145] This practice, was referred to as part of a 'dual system' of health care which was followed from ancient Greece, where care was provided both by professionals and by ordinary citizens using home remedies and folk medicine.[146] In the latter part of the 19th century the medical profession grew in power, the health services were more comprehensive and some freely available.[81] Around the same time and continuing in the early 20th century the *'public health movement'* resulted in the reduction of communicable disease because of improvements in housing, nutrition, education and social changes.[145] This occurred through

the participation of people with wealth or status or in a position of academic standing. The wider public were not heavily involved in this movement but they were the beneficiaries of reduced hours of work, clean water supply, efficient waste disposal and many other reforms.[145] Because of these environmental reforms and improvements the pattern of disease changed[81] whereby, recovery from acute illnesses was replaced by the emergence of chronic conditions e.g. heart disease.[81,145] As a result, sociologists stated that the medical profession was transforming health problems into technical issues, non-life threatening conditions were being treated, and thus, people's autonomy to manage their own health problems was being undermined, or they were being prevented from leading independent lives.[81] This change in the nature of health and illness, the shift from acute to chronic illness was one of the first contributing factors towards the rise of patient participation in health care.[145]

The limitations of modern medicine were another contributing factor in the rise of patient participation in health care. Self-help groups were originated by people who had lost trust in the medical profession[145] e.g. following the catastrophe of thalidomide where thousands of babies were born with malformed limbs because of side-effects from a new drug prescribed to pregnant mothers.[147] During the 20th century people became more knowledgeable about health, the wider influences on health were acknowledged, people were aware of available services, various forms of self-help were available, people became aware of disparities in clinical practice and their rights. This was a result of information being available outside of the formal health services (e.g. voluntary groups, books, leaflets, help-lines, internet)[81] and negative health stories in the media.[148]

Various mass movements in the United States during the 20th century led to change in society,[81] which encouraged people to participate in health care.[145] *'The human rights movement'* placed emphasis on the participation of lay individuals in health policy, self-determination and a reduction in the influence of professionals and technology.[149] There was a general trend towards encouraging people to accept more responsibility for their own health[81] and well-being, instead of relying on health services and also, for lay people to have a voice in policy making.[145] However, because there were consumers who still asked for prescriptions for minor complaints and the doctors who were willing to provide the prescriptions, it was argued that patients should at least be fully involved in the decision-making process.[145] The *'consumer movement'* of the 1960s established the consumers' right to safety, the right to be informed, the right to choose and the right to be heard.[137] Consumerism included mass movements around national issues such as the *'civil rights*

movement', *'the women's movement'*, and the *'welfare rights movement'*. These movements challenged basic assumptions about the way the country was governed and demanded changes in national policies. As a result of certain events that took place nationally and internationally people felt they needed to act for themselves rather than asking the state to act on their behalf. In a health care context, consumerism had its impact both at the group and to a lesser extent, at the individual level.[145] At a group level, for instance in occupational health and safety field, the community increased their skills and informed themselves of the health hazards that could affect their work or home or the general community. Communities no longer just had to accept whatever was handed down to them or done for them. The public had, 'the right to know, right to a safe workplace and the right to withdraw labour'.[147] However, consumerism was seen less at an individual level[145] which suggests this was because individuals feared confrontation or dismissal of their views, or that they might not get treated by their health professionals in an emergency. This perhaps arose from the historically accepted assumption that illness could be only diagnosed and treated by health professionals. Patients were regarded as passive recipients of care[135] i.e. *"to seek competent help and cooperate with the physician in order to get well"*.[81] A modern view of the patient role defined the patient as an active consumer.[135] It was believed that the relationship between patient and health care professional (HCP) should involve mutual participation, a model where both patient and professional have equal power, need each other and engage in activity that would be satisfactory to both parties.[81]

Consumerism into the NHS[135] led consumers to become more actively involved in the provision of health care.[145] Although the aims of the NHS policy were

(1) to accommodate the demands for national policies designed to share out scarce resources in a fair and rational way,

(2) participation in decision-making by those (professionals) actually working in the organisation and

(3) being responsive to the views of the users about services offered at point of delivery. McEwen[145] argued that these policies were conflicted because implementation of national policies required centralised control and effective participation by either staff, or consumers, required flexibility, local democracy and diffusion of control. So, within the system there was both the facility of the centralised power to create policy and the facility of the staff and recipients to reject it.

Within healthcare, the role of community participation was considered important in health matters where different interested parties had different opinions.[147] This form of participation was a way for people who had less or no scientific knowledge on a health matter to be involved in decision-making. The role for community participation in health was strengthened by the Alma Ata declaration *'Health for All'* (considered important by all governments).[147] The declaration was made to protect and promote the health of all people around the world because of the gross inequality in health amongst people seen both between, and within, countries. Among the 10 declarations made, one declaration was that, *"The people have the right and duty to participate individually and collectively in the planning and implementation of their health care".*[150] Another was, *"Primary health care is essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. It forms an integral part both of the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care"* [150]

During the 1980s, primary health care was considered broader than simply medical care. Provision of services were to be based on need, were to be culturally acceptable and included health promotion, housing and education and involving the community in the primary care process (nhshistory.net accessed 28-3-13). Changes in life style were needed, particularly in smoking, diet, exercise, alcohol consumption, sexual activity and behaviour on the roads. The adoption of the Alma Ata declarations was not immediately recognised in Europe, including in the UK (nhshistory.net accessed 28-3-13); people with the greatest need were not always prioritised and patient participation was rare. One explanation given was because the declarations posed a threat to the values and beliefs of professionals and professionals disregarded active participation as too irrelevant, too political or difficult[135] (nhshistory.net, accessed 28-3-13). Section 2.3.1 and 2.3.2 presents some perspectives of patients and professionals regarding patient participation in health care.

Due to the abovementioned reasons, patient and public participation in health care involved, the public taking control of their lives and becoming less reliant on health/professional services and technology. The public became aware of their rights and wanted to be involved in decision-making with clinicians. The role of being a passive recipient of care was shifted to an active consumer in their care.

This shift of taking responsibility for one's own care or participation in care was particularly emphasised or was considered important for people living with a chronic illness.[135] While, patient passivity during an acute illness was considered normal[135] participation in care by a patient with a chronic condition was recognised as a reality or was considered necessary and not seen as a choice;[81] It was acknowledged that treatment of patients with chronic disease may need a long-standing regime of SM and participation in self-help such as rehabilitation procedures were considered appropriate for this group of patients to lead a suitable lifestyle.[145] In addition to proposing SM as a way of giving patients control over their condition, a different concern, increasing health care costs was the reason for encouraging self-care including self-management among chronic disease patients.[151,152] These two drivers led to the emergence of the self-care/SM initiatives in government policy documents for patients living with a long term condition (LTC) (see section 2.1.2).

The focus on SM for patients with chronic disease originated within the context of another mass movement of the 1960s and 1970s called the *'self-care movement'.*[152,153] Two studies[146,154] have explained the shift of 'self-care' from sitting within the field of social work and outside of policy and medicine in the 1970s, to becoming a key component of chronic disease management in policy and in the medicine field whereby the concept of patient 'self-care' and 'activated patient' became intertwined.[146]

Historically, the trend of self-care, along with other mass movements, was also a result of social, economic and technological changes, changed illness patterns and also because of the increased workload faced by primary care which was being inappropriately utilised (e.g. most visits to doctor were for minor complaints).[146] The self-care movement sat outside, and was not given importance to the field of medicine and policy and promoted individual self-reliance and not worrying about what professionals cannot do.[146] In DeFriese's study,[154] 'self-care' was referred to as *"actions taken by laypersons in their own health interest without formal medical supervision."* or *"the practices of individuals and families through which the forms or symptoms of illness are detected and treated, other diseases are prevented*

and positive health behaviour is generally promoted." The latter terminology is similar to the self-care definition presented in Chapter I (section 1.1.1.4.2.1). In the 1970s, the HCPs who were not involved in, or privy to, the role of 'self-care' saw self-care as making laypersons as independent as possible of conventional medical care. They believed several training programmes were designed to train laypersons in the performance of tasks normally considered to be those of the medical or allied health care professions and they felt the message of these programmes appeared counter-medical. However, the rising health care costs and recognition of limitations of modern medicine led professionals to change their view and they started to believe that people's health status would improve from making lifestyle changes involving changing or adopting health behaviours. Thus, educational efforts to bring about lifestyle changes became important.[154] There was also an emphasis on partnerships and communications between patients and professionals but at the same time there was emphasis on increasing the relative degree of control amongst consumers and patients in matters related to health – but mainly in the case of minor ailments; they saw 'self-care' as care 'until the doctor comes'.[154] While, some professionals were fearful of the concept of 'self-care' it was some professionals themselves who soon developed self-care educational programmes.[154] During the 1980s self-care became absorbed into the US health care system and self-care programmes delivered were classified as health service delivery organisations. The self-care concept was denoted as medical self-help/self-care in clinical medicine, nursing and allied health literature, with a focus mainly on disease management and maintenance of functional status.[154]

Defriese[154] in their study, when talking about self-care programmes, was referring to one self-care programme namely, 'The Course of Activated Patients'.[146] The programme originated in Herndon, Virginia in 1970 and was delivered to people with the skills to enable them to take a more 'active' role in their own health and that of their families.[146] According to Senhert,[146] the course differed from traditional health education lectures as it complemented health promotion activities, taught self-care/self-help methods and emphasised greater energy, independence, and increased fitness. The course was complementary to professional care but also advocated that professional care might not be necessary. 'The course facilitators helped people to look at health not as an absence of disease but as a way to achieve the energy needed to set and then meet life goals. The end result of the course was termed 'health activation'. This involved the use of positive health habits and self-regulation to achieve greater harmony between the body and its external and internal

environments.' The course was adopted by HCPs for their communities in several American states because of its benefits e.g. improved patient-provider relationship. Senhert[146] believed the course would be utilised in the future by health maintenance organisations, fee-for-service groups and by private industries where methods were being examined to reduce increasing health care costs.

During the 1990s, in the UK, attempts to reduce the burden of health care costs on health services associated with the increasing prevalence of chronic disease led to policy initiatives such as the promotion of self-care, and the adoption and delivery of SM programmes, a component of self-care, aimed at patients with LTCs so patients would become responsible, participate or take an active role towards their health. This is discussed in the next section.

2.1.2 Origins of patient participation in UK health policy

This section describes the origin of patient participation in health care, the type of patient and public involvement in health care within UK health care policies, including involvement by patients with chronic disease in the form of self-care and/or SM. Box 2.1 briefly describes development of policy.

Box 2.1 Brief description of policy development

According to Liddiard and Ritvo[2] policy development is dependent upon organisational interests, financial constraints, professional domains, client needs, government structures and national ideologies. The different perspectives for policy development include:
1) Development in response to commonly recognised problems e.g. community mental health services
2) Development with population needs in mind resulting in the development and delivery of programmes to meet those needs e.g. mobile food programmes
3) Via geographic analysis – what are the needs of a specific state, local authority etc e.g. water conservation efforts

Other views include:
1) Policies develop as a result of collective sense of the most efficient and effective path to goal achievement. In this model it is assumed that decision-makers know most relevant facts, understand and subscribe to social values, and select the most appropriate policies to implement these aspirations
2) Policy is an outcome of an elite group action. Decisions reflect those who are in, or possess, power
3) Extending (number 2 view) another model appears – which is developing policy by compromise. Here policy includes a strategy to balance diverse views. Compromise is a form of decision-making that allows policies to develop almost without attention to related events. The authors suggested that the third view might lead governments to consider health promotion and disease prevention efforts here and reported that self-care fell within the second and the third view.

In line with McEwen's[145] views, the aims of the NHS policy during the 1970s and 1980s included being responsive to the opinions of service users about services at point of delivery.

Government policy documents show that prior to the 1990s the role or extent of patient and public involvement was limited to encouraging individuals to give their views on services to improve the care and delivery of health services within the NHS.

For instance: In 1974, the UK government, following re-organisation of the NHS (established in 1948), had set up Community Health Councils to protect the rights of patients and public and gave importance to their views to improve health care in the NHS http://www.achcew.org/index.html (accessed 28-3-13). The Councils tried to support individual patients and complainants; monitored local hospital and community (but not primary care) services; and provided a citizen's perspective on service changes.[139]

In 1989, patient choice in service delivery was central in the *Working for Patients* document.[155] This document was a result of reforms in the NHS (to manage the growth in health care costs from the mid-1970s and to make the NHS more efficient) where in addition to being responsive to the needs of users, another change suggested was creation of a market whereby health authorities would identify patients' needs and contract for services; services would be provided by hospital and community units and these services would compete to obtain contracts to provide the services (nhshitory.net accessed 28-3-13). However, Geoffrey Rivett (nhs.history.net accessed 28-3-13) commented that this model was more suited to elective surgery but less appropriate for elderly people and for psychiatric services as the needs of the elderly or those needing psychiatric support were different and these needs could not be fulfilled by hospitals or community units. During this period, self-care was not included in policy when the health of individuals was on the policy agenda. Liddiard and Ritvo's[2] argument to introduce 'self-care' within health policy was centred on the elderly for whom the medical model was no longer appropriate. They believed self-care included environmental, cultural, biological, social and economic factors and introducing and supporting the elderly to self-care would prevent their exclusion from society.

The tragedy at the Bristol Royal Infirmary, where about one-third more than expected infants had died after open-heart surgery between1984-1995 in a paediatric cardiac unit led to the Bristol enquiry report in 1998 which laid out several recommendations for improvements in the care of patients. http://www.bristol-inquiry.org.uk/final_report/report/sec1_chap_4_8.htm (accessed 21-8-12). One recommendation was that a new NHS culture should emerge which should include patient involvement, wherever possible, in decisions about their treatment and

care; another was that public involvement in the NHS must be embedded in the structures such that their views must be heard and taken into account wherever decisions regarding the provision of healthcare were made.

During the late 1990s, in addition to being responsive to the needs of the consumers, the focus of the UK government was on building partnerships between the Government, local organisations and individuals. The strategy was to increase involvement of: patients in decisions about their own care; users in the NHS and development of health services; the public in the NHS and their health generally;[156] and to reduce inequalities in health (by reducing 300,000 deaths from accidents and in four conditions namely, heart disease, stroke, cancer and mental health)

http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4007059 (accessed 21-8-12) and.[156]

One action to reduce inequalities in health suggested in The White Paper: *'Saving Lives: Our Healthier Nation'* published with *'Reducing Health Inequalities: an Action Report'*[156] was the 'Health Citizens' programme. This programme initiated a shift in responsibility where people were encouraged to develop key skills e.g. first aid skills, links to NHS Direct (a health advice and information service) were made perhaps for people to perform self-care. An element within this programme was the 'Expert Patients Programme' (EPP) aimed at patients living with LTCs. The EPP or the SM programme was about promoting patients to take responsibility for their health and to help them take control over the management of their condition.[156] The EPP initiative was conceived as part of a government commitment to place patients 'at the heart of healthcare'. The initiative had the potential to meet three elements of chronic disease management:

      1) involvement of patients in their own care

      2) minimising unnecessary visits and admissions to health care providers/facilities

      3) providing care in the least intensive care setting

This EPP policy initiative was further justified in *"The Expert Patient: A new approach to chronic disease management in the 21st century".*[153] The report first stressed that the patient-centred NHS must recognise the increasing burden of chronic disease (such as cancer, heart disease, stroke, arthritis, mental illness, diabetes mellitus and asthma), seen from second half of the 20th century and beginning of the 21st century, because people are living longer into their seventies, eighties and beyond and so, *"When acute disease was the primary cause of illness, patients were generally inexperienced and passive recipients of medical care. Now*

that chronic disease has become the principal medical problem, the patient must become a co-partner in the process." Secondly, health and social services had failed to recognise that patients already played a role in self-managing their condition. Patients were ineffectively managed; some common experiences of patients included: lack of involvement in decisions; no-one to talk to about anxieties and concerns; tests and/or treatments not clearly explained; insufficient information for family/friends; and insufficient information about recovery. Thirdly, the report quoted views of HCPs about their chronic disease patients, "…my patient understands her disease better than I do. They are, in fact, "experts" in their own right for they have acquired the life skills to cope with a chronic condition and have the potential to be confident partners with professionals in their care." Hence, the EPP was seen as a systematic approach whereby patients could be supported to manage their LTC. Furthermore, the policy stated that the concept of SM was used in the 1960s and 1970s in the context of the *'self care movement'*, described above, when the concept 'self-care' was outside of the medical profession and health policy but now both concepts are ingrained in heath policy and should be integrated in health services.

Rogers,[157] from a sociological perspective, has explained that the SM/EPP mentioned in UK health policy is actually different to the 'self-care' within the self-care movement and which they referred to as the *'social movement'*. Rogers mentioned that during the social movement in the 1980s and 90s, the health voluntary bodies in England had some influence over health policy and these bodies had started to align themselves with the views of the social movements. Particularly, some support groups for chronic conditions, such as Arthritis Care, were running SM programmes – and a new role was found for lay people in the changing policy climate. However, Rogers pointed out that the policy vision for chronic disease management had gone farther than the need for chronic disease patients to adopt desirable behaviours to manage their condition or take responsibility for their health, to a type of patient that needs to be fashioned – the 'empowered' or 'expert' self-caring individual. They claimed that the policies that focused on what patients should do to maintain their health for LTC management, instead became what sort of person the patient should become - there was an expectation that an ideal self-managing individual would include being 'activated', 'empowered' ' co-producer', 'expert' or 'autonomous' and this was different than the older self-care/self-help traditions. Rogers further continued that another reason for the adoption of SM in policy was because the *'Wanless report'*[158] had presented three scenarios, 'Solid

Progress', 'Slow Uptake', 'Fully Engaged', regarding future resource requirements to preserve high quality services in the NHS and the 'Fully Engaged' scenario was the least expensive option modelled and it appeared to present better health outcomes.

The chronic disease self-management programme (CDSMP), on which the EPP was based, was a result of Kate Lorig's work in Stanford, California in the field of arthritis (Arthritis Self-Management Programme, ASMP) for 20 years.[153] The CDSMP was utilised by several voluntary patient bodies to design a version of the SM programme applicable for various conditions. In England e.g. the 'Challenging Arthritis' course was developed. The *'Expert Patient'* report[52,153] based on Barlow's review (the report referred to an unpublished review – I was unable to locate) on effectiveness of SM programmes amongst chronic conditions, concluded that the programmes were beneficial, patients experienced reduced severity of symptoms, pain, improved life control and activity and improved resourcefulness and satisfaction. However, Barlow's published review[52] (not referred to in the report) recognised the heterogeneity amongst the included studies in the review and reported that SM approaches were effective in increasing patient knowledge, symptom management, use of SM behaviours, self-efficacy and improvement in mood, particularly depression, in comparison to standard care i.e. no SM intervention. But these improvements were not seen in all conditions, e.g. all studies did not assess psychological well-being and all programmes did not show improvement in all outcomes. Despite these results Barlow's Arthritis SM programme (1998) was utilised to develop the generic EPP. The EPP was developed by the Expert Patient Task Force which comprised both professional and lay members. The report recommended the pilot delivery and evaluation of the EPP between 2001 and 2004 and the wider delivery and its integration within health services between 2004 and 2007.

Perhaps the limited evidence of effectiveness in most chronic conditions, despite being rolled out by the Government, led to the criticism of the expert patient policy and the EPP by several authors.[73,159] [64] One critique was that the EPP had taken a narrow view by focusing on changing the behaviour of individuals with chronic disease using one psychological theory, the self-efficacy theory[59] i.e. through increasing confidence of patients, and has ignored or failed to recognise that self-efficacy is also dependent upon the social and historical context of the individual.[73,159] Wilson[159] stressed that an individual's past life experiences and positive perceptions of these experiences play a major part in self-efficacy, while Lindsay and Vrijhoef[73] reported that an individual's perceptions of their world and the function of illness

in that world can shed light on health-related behaviours. In addition, Wilson[159] reported that the terms 'expert' or 'active' and 'patient' are a contradiction; the expert patient cannot be seen in the same light as professionals because the knowledge and understanding that an expert patient has is from their experience of the illness and not education.

The Government in 2004 gathered evidence on benefits from patient and public involvement in health decision-making in the *'Health in Partnership'* report[160] and reported that patient and public involvement is necessary to improve patient experience of the health service. The report was the result of patients' and professionals' perspectives on 12 funded projects with a condition that patients and public had to be involved in the design and execution of projects. Out of the 12 projects:

- six projects focussed on patient and carer involvement in decisions about their own treatment and care e.g. a qualitative study exploring patient participation in decision-making
- four addressed public involvement in service planning and delivery e.g. a survey examining decisions about service development from young people with chronic illness or physical disability
- two were principally concerned with education and training issues e.g. shared decision-making and risk communication in general practice by delivering training programme and evaluating clinical consultations

Shared decision-making in the report was defined as, *"The process of involving patients in clinical decisions. The ethos is one where professionals (should) work to define problems with sufficient clarity and openness so that patients can comprehend the uncertainties that surround most decisions in medicine and therefore appreciate that choices have to be made between competing options."*

The findings from the projects were divided into perspectives of patient involvement and public involvement.

a) The value of patient involvement from patients' perspectives of decisions about their care was: being treated as equal partners, being listened to, and being informed, however, for the latter to take place in a clinical consultation there was need for privacy and time. The report

mentioned that not many patients had experienced shared decision-making but patients had different expectations of what level of responsibility they wanted to accept. Patients looked for information and guidance from HCPs, the sharing of information or communication and how it was received could affect how much patients would share during a consultation.

The report highlighted that one source of information outside of the consultation setting for a patient was the EPP, but also reported about the programme in a negative tone, particularly, 'the EPP exploited and acknowledged that patients might know more about their condition more so than their HCPs'. The report argued that patients do not have knowledge about their health and health care options and this limits their judgement on decisions made about their health.

Furthermore, the results of the report suggested that shared decision-making was further hampered because of lack of training and skills among both professionals and patients. A patient's level of participation in shared decision-making would vary according to their situation and context e.g. women may be more likely to involve themselves in decision-making about family planning than about ear nose and throat cancers; and patients may find it difficult to get involved in decision-making if they have not done it before. Thus, a solution offered in the report was that shared decision-making should be promoted through professional training and patient empowerment.

b) The value of patient involvement from the professionals' perspective was:

The attitude towards patient involvement was generally positive amongst HCPs but in some cases patient involvement was constrained due to wider professional values and expectations, for instance patient involvement in decision-making was sometimes not allowed when nurses wanted to protect patients from negative experiences; GPs (not in all cases) would rather not allow shared decision-making if there was only one good option, or if it was something to do with technical details or practical issues, or if patients were not willing to compromise.

HCPs were aware of the importance of good communication but they did not think it would work in practice such as with patients with communication difficulties, or when there was lack of time. HCPs' shared decision-making was dependent upon the context, e.g. they would consider shared decision-making more with patients with chronic disease and less with life and death situations. As a result, one conclusion in the report was that patient involvement cannot be constant or smooth.

The outcomes of patient involvement were different for patients, reduction of anxiety and fear, greater control, new knowledge, reinforcement of knowledge, in comparison with professionals, improved patient compliance, change in health related behaviour leading to better health outcomes. As a result the report concluded that shared decision-making does not necessarily lead to more shared decisions.

c) The value of public involvement from the perspectives of the public was:

Although public awareness of what public involvement means was low, people had some view of how and whether members of the public should be involved in NHS decision-making. The motivation for public participation was driven by altruism, personal and family experiences and the desire to improve services. The findings suggested that people who pay tax should have a say in how the NHS works. People were concerned that a counter balance should exist in public participation, keeping people's interests balanced against those of political parties. This was important because people could be asked to give their views for service development and delivery but might not be included in making decisions about services. Several people preferred to be kept informed about the NHS national and local plans because the NHS should be accountable to its citizens. Whereas some people felt the public should not be involved in the NHS because diverse views or opinions would complicate matters, make it bureaucratic and costly.

d) The value of public involvement from institutional perspectives:

The members of voluntary organisations saw their involvement as being to: represent people's views; represent their organisation; fulfil their organisational aims; get resources for these aims; and develop relationships and services within the NHS. On the other hand, some primary care trust members did not see the value of public involvement and believed that those who volunteer might not be true representatives and might be getting involved to address their own self-interested agenda. This view was also expressed by some clinicians.

The outcomes of public involvement were that it increases confidence, understanding and skills of the people who participate; influences policies, plans and services of primary care organisations; and partnerships will enable learning, resources and expertise to be shared across health economies.

The background section presented a historical account of the origin of patient participation in health care and in health policy guidelines mostly in relation to chronic disease management. Next, the conceptual review helps to answer the review questions.

2.2 Methods

2.2.1 Conceptual review

A conceptual review was conducted to address the review/research questions. Conceptual review (CR) is a methodology or a review of a methodological nature to understand concepts which may be contested because they have multiple meanings.[161] This type of review is also carried out to help in the interpretation of results of the systematic review of both quantitative and qualitative studies.[162] This CR was conducted in parallel to the systematic review (Chapter III and IV).

Three published articles were used as a guide to inform the process of CR, recognising its limitations and how they might be addressed.[161-163] Unlike a conventional systematic review which needs to be conducted in a very systematic and consistent approach i.e. explicit and transparent searching strategies, specific inclusion and exclusion criteria and quality assessment, a less structured approach was taken to conduct this review.[162] The process included identifying key papers, using different databases and sources that were relevant to the study. The relevance of the literature was decided mainly by discussion with the study supervisors. Due to the diverse nature of the work, the necessity of an exhaustive search of the literature to identify all definitions and concepts on the topic under study has been questioned.[161] The cyclical process of searching, analysis and writing was continued (with input from the study supervisors) until an understanding about the research topic was developed which then helped to answer the review questions.

2.2.2 Literature search

The literature was identified from three sources: relevant texts after discussion with study supervisors and a colleague health psychologist (LS), biomedical databases and relevant citations from identified journal articles. The database PubMed was used to identify studies that explained the meaning of 'patient participation' in health care and further studies that defined and described patient participation in health care were obtained from the citation list of the included studies.

Four databases were searched Medline/PubMed, EMBASE, Web of Science and PsycINFO to identify studies that had used theoretical models to explain participation in health care or health care utilisation among patients with chronic disease.

The search terms were:

1. "behavior and behavior mechanisms"/ or "psychological phenomena and processes"/ or "behavioral disciplines and activities"/ or behavior control/ or behavioral sciences/ or behavioral medicine/ or behavioral research/ or sociology/ or sociology, medical/ or "health care (non mesh)"/

2. conceptual adj (framework or review or guide or model).ab.

3. Models, Psychological/ or Models, Theoretical/

4. ((behav* or social or psych*) adj (theory or model)).ab.

5. Psychological Theory/ or Health Knowledge, Attitudes, Practice/ or Health Behavior/ or Behavior/

6. Sociology, Medical/ or Sociology/ or Social Environment/ or Social Sciences/

7. Attitude to Health/ or "Patient Acceptance of Health Care"/

8. help-seek* adj model.ab.

9. (health adj (care or seek*) adj model).ab.

10. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9

11. Health Services/ut [Utilization]

12. "Delivery of Health Care"/ut [Utilization]

13. Health Services Research/ or Health Services/

14. ((health or medical) adj (care or service) adj utili*tion).ab.

15. (health adj (service or care) adj uptake).ab.

16. 11 or 12 or 13 or 14 or 15

17. Health Education/ut [Utilization]

18. Patient Education as Topic/ut [Utilization]

19. ((health or medical) adj educat*).ab.

20. 17 or 18 or 19

21. 16 or 20

22. Chronic Disease/nu, pc, px, rh, th [Nursing, Prevention & Control, Psychology, Rehabilitation, Therapy]

23. (chronic adj (disease or illness)).ab.

24. 22 or 23

25. Patient Participation/ut [Utilization]

26. Consumer Participation/ut [Utilization]

27. ((patient or client or consumer) adj participat*).ab.

28. 25 or 26 or 27 (the four search terms were omitted from the search strategy as the search at this level yielded 0 results in all except in EMBASE)

29. 21 and 10

30. 29 and 24

31. limit 30 to (english language and humans)

The titles and abstracts of all identified papers were assessed to check their relevance. The review included all studies that explained health care utilisation and participation in health care interventions particularly, SM interventions amongst patients with chronic disease via theoretical models.

2.2.3 Data extraction and synthesis

Following the methods adopted by a previous, published CR,[161] a data extraction form was not used but the studies identified were succinctly summarised and structured. This was continued until data saturation was achieved.[161] (Priebe S. Professor of Social and Community Psychiatry. Personal communication. 2011.). As a result, the studies identified were succinctly summarised and structured into: meanings, definitions, concepts of patient participation and non-participation in health care; and theoretical factors that explained health care seeking behaviour and participation in SM interventions amongst patients with chronic disease. The literature was presented as a narrative using a non-quantitative approach.[164]

2.3 Results

Literature on the meanings of 'patient participation' in health care was identified from journal articles, online dictionaries and texts. Regarding the databases searches for studies using theory to explain patient participation in health care including SM interventions among chronic disease patients, when the search term 'participation' was added to the existing search strategy, the searches yielded either none or less than 10 results (only in the EMBASE database). As a result, this term was excluded from the search strategy following which 634 references were identified. Next, based on title and abstract screening 27 articles were identified that seemed potentially relevant. Subsequently, on reading the full text, five studies[5,165-168] met the review's inclusion criteria. In addition, a further 20 studies[142,169-187]

were identified from citations of the included studies and from discussion with LS (Figure 2.1).

The results are presented under two headings: definitions of 'patient participation' in health care (section 2.3.1) and theoretical factors that influence HCU and participation in health care interventions particularly, SM interventions amongst patients with chronic disease (section 2.3.2).

Figure 2.1 Selection of articles for review to explain theoretical factors that might influence participation in health care interventions including SM interventions

Articles identified and screened based on title and abstract, n=634

Papers excluded, n= 607
Reasons for exclusion – not focused on explaining patient participation, did not use theory to explain patient participation; population not chronic disease

Potentially appropriate papers, full text scrutinised, n= 27

Papers excluded, n= 22
Reasons for exclusion – not focused on explaining patient participation, did not use theory to explain patient participation; population not chronic disease

Papers included in conceptual review, n= 5

Plus studies identified and included from citations of included articles and discussion with health psychologist and included in review, n=20

Total number of articles included in the review, n= 25 (discussed in section 2.3.2)

2.3.1 Results: Definitions and concepts of patient participation in health care

This results section focuses on the varying definitions of participation, definitions and descriptions of patient participation and non-participation in health care; and, differentiates, where possible, between patient participation and patient involvement, patient-centred care, the activated patient, patient engagement in policy documents, research studies and in practice.

The studies that explored the meaning of patient participation were a mix of quantitative and qualitative studies but in most a qualitative perspective was obtained from HCPs and patients including those with chronic disease.

2.3.1.1 Dictionary definitions and descriptions of participation and non-participation

The noun 'participation' is from Latin *participatio(n-)*, from *participat* http://oxforddictionaries.com/definition/english/participation?q=participation

(accessed 1-10-2012).

'Participate' is a verb which means, *be involved*; *take part*. The origin of 'participate' was in late 15th century: from Latin *participat* 'shared in', from the verb *participare,* based on *pars, part-*'part'+ *capere* 'take'.

http://oxforddictionaries.com/definition/english/participate?q=participate (accessed 1-10-12).

'Participation' is the act of participating; the state of being related to a large whole. The first known use of the term 'participation' was in the 14th century http://www.merriamwebster.com/dictionary/participation (accessed 1-10-12) for peasant women in court http://www.marginalia.co.uk/journal/05margins/smith.php (accessed 18-5-14)

In addition, 'participation' has specific meanings in several different areas such as:

Participation (in decision making), *a notion in theory of management, economics and politics;*

Participation (in ownership), *sharing something in common with others;*

Participation (in finance), *getting some benefit from the performance of a certain underlying asset.* http://www.reference.com/browse/participation?s=t (accessed 1-10-12)

On the other hand, 'Non-participation' has been defined as the *"absence of participation"* (http://dictionary.reference.com/browse/non-participation?s=t (accessed 1-10-12)

The meaning 'take part' and 'absence of participation' given above matched the definition of 'participation' and 'non-participation' adopted by this study (see glossary page).

2.3.1.2 Definitions and descriptions of patient participation and non-participation given by medical dictionaries

'Patient participation' is a Medical Subject Heading (MeSH) term within the world's largest biomedical library, the US National Library of Medicine, The MesH term defines 'patient participation' as *"patient involvement in the decision-making process in matters pertaining to health"*

http://www.nlm.nih.gov/cgi/mesh/2013/MB_cgi (accessed 19-2-13)

The webpage has differentiated between this term and 'patient compliance' which was noted as the *"voluntary cooperation of the patient in following a prescribed regimen"*

http://www.nlm.nih.gov/cgi/mesh/2013/MB_cgi?mode=&term=PATIENT+COMPLIANCE (accessed 19-2-13)

The term 'non-participation' is not a MeSH word; however, 'Refusal to participate' was noted as *"Refusal to take part in activities or procedures that are requested or expected of an individual."* This may include refusal by health personnel to participate in specific medical procedures or refusal by patients or members of the public to take part in clinical trials or health promotion programs."

http://www.nlm.nih.gov/cgi/mesh/2013/MB_cgi?mode=&term=Refusal+to+Participate (accessed 19-2-13).

2.3.1.3 Research studies definitions and descriptions of patient participation and non-participation in health care

Brownlea[147] referred to the process of involvement of people in health care decision-making from 'tokenism' to actual participation which involved people getting their voices heard, which was from the rise in consumerism and legislation (section 2.1.1 and 2.1.2). Brownlea defined participation as, *"getting involved or being allowed to become involved in a decision-making process or in the delivery of a service or the evaluation of a service or being consulted on an issue or matter."*

a) Nursing practice/Outpatient context

Because of the importance given to 'patient involvement' in government policy, and the move from the medical model of health to patient-centred care[135] in particular, patients position in nursing care was given importance whereby one of the roles of nurses has been to encourage patients to participate in their care.[138] Thus, Cahill and Sahlsten's[135,138] review analysed the concept of 'patient participation' in care particularly in nursing practice.

Cahill's review[135] explored the concept of 'patient participation' in nursing within a hospital context and reported several definitions of participation of a collective/collaborative nature. Brownlea's abovementioned definition was one amongst the four mentioned under this approach. Other definitions included:

Participation *"relates to the act of participating, which implies that one becomes actively involved in or shares in the nature of something with others."*

Participation *"is the involvement of many people in decisions, giving them some feeling of control or responsibility."*

Within a human relations perspective, participation *"is the involvement of subordinates in a task".*

According to Cahill, the abovementioned definitions did not capture the complexity of 'patient participation' within the hospital context and hence presented definitions that suggested the role of an individual in the delivery of medical or nursing care. The following definitions were given:

"patient participation in health care relates to: the activities performed by an individual on behalf of others in the maintenance and promotion of health, the prevention of diseases, detection, treatment and care of illness and the restoration of health, or, if recovery is not possible adaption to continuity of disability."

This definition corresponds closely with the definition of 'self-care' given by Barlow[52] which suggests that 'patient participation' and 'self-care' are interlinked or that one aspect of patient participation in health care includes self-care.

Cahill presented that patient participation *"implies patient engagement in problem identification and prioritisation, establishment of change objectives and the process of making decisions about how change will be accomplished."*

"Patient participation is an active process which involves a patient performing clinical or daily living skills or partaking in the decision making process from the time of admission to discharge".

Cahill further noted that the role of an individual or patient participation included other aspects of care such as patient compliance, self-medication, self-monitoring, patient education, goal setting, sharing information and taking part in physical care and hence concluded that 'patient participation' was indeed an ill-described concept in nursing and further research was required for clarification of the term.

Cahill's review also explored patients' and professionals' perspectives on the value of patient participation; the rationale behind it was the assumption that patients' want and benefit from having, a more active role in their health care. Based on the literature examined (self-completed questionnaires, interviews and recall, with small sample sizes and limited to within the nursing care context but without observation of patient participation in practice), Cahill concluded that the results could not be generalisable. Briefly, the results revealed that certain patient characteristics such as, younger patients, better educated, increased knowledge of their condition, and higher social class were predictors of desire for participation and these characteristics may have a role within participation in medical care as decision-makers. Older patients, the seriously ill or patients with a chronic or terminal illness preferred a less active role in their care, they were happy for nurses to make the decisions and accepted the passive role. This view was considered unusual by the author who believed that patients with chronic disease do need to participate in their care as it is necessary for the management of their illness. The author further explained that adoption of the passive role by patients with chronic illness was perhaps because they lacked knowledge and hence were happy for others to make decisions about their care and thus a solution offered was more provision of information.

Patients' views on the outcomes from participation in care were reported as control of the interaction, patient satisfaction, and compliance and goal attainment.

On the other hand, views of professionals on patient participation in care were mainly that they continued to see patients as passive recipients of care, or were not ready to give up control or power over patients during consultations. An explanation given for this reluctance of HCPs was attributed to the Government trying to reduce professional services or reduce costs of services. Other reasons given were that professionals had reservations about people's abilities to look after themselves, or they would be bombarded with unreasonable requests.

Despite the negative findings, Cahill felt that professionals prepared to facilitate participation would find it beneficial in some scenarios such as clarifying aims of the practice, providing feedback for evaluation of services to patients, improving communication and relationships, increasing job satisfaction and reducing or defusing complaints.

Sahlsten et al[138] in their review attempted to unpick the concept of 'patient participation' and acknowledged that the term may have varying interpretations and the concept may mean different things to patients and nurses within the nursing care context. Commenting on previous reports Sahlsten stated that the term 'participation' had been discussed as *'collective or indirect participation',* which is practiced as lay participation in research, formulation of policy, and commissioning of services, or as a third-party parent, close relative or carer; and *'individual or direct participation'* which may be practiced for example, in health care and promotion, mental and social care and in different situations such as discharge planning, decision-making in treatment or care, and bed-side reporting. Sahlsten presented definitions of 'patient participation' in relation to nursing practice from a *'philosophical approach'* and a *'practical approach'.* From the former approach, definition of 'patient participation' given was: *"individual or holistic care, realistic plans based on negotiation, a positive outcome for patients and encouraging patients to be active rather than passive during their hospital stay."* From the latter approach, 'patient participation' involves: *"using the nursing process, seeing what the patient wants regarding discharge, self-care i.e., physically take part in care, and informing patients during their hospital stay."*

Two other definitions were cited: *"Patient participation means being involved in the decision-making process concerning the delivery and evaluation of the patient's own care."* For this to happen, patients need to be treated as individuals, their opinions need to matter and more control in their own care needs to be handed to them. This definition seemed to be similar to Brownlea's[147] abovementioned definition. *"Patient participation is a dynamic process that changes over time and is integral to the work of nurses and carers."* The dynamic nature involves understanding, facilitation and partnership between patient and nurse. 'Partnership' is essential for participation to take place as here one's values and beliefs are identified on which negotiation is based (This is the premise of the 'CENTREd' Model, in Chapter VII).

Moving on, Sahlsten described some of Eldh's[188] work (which I have described below). Eldh has explored the meaning of 'patient participation' from the perspective of patients and

professionals in nurse-patient clinical scenarios not captured in Cahill's study[135] Based on the analysis of the definitions and descriptions of the 'patient participation' concept, Sahlsten[138] produced a list of four attributes of the concept of 'patient participation' in nursing practice:

1. *"An established relationship"*

2. *"A surrendering of some power or control by the nurse"*

3. *"Shared information and knowledge"*

4. *"Active mutual engagement in intellectual and/or physical activities"*

These attributes are further described by referring to Eldh's work next.

Eldh has published several studies that have specifically explored the meaning of 'patient participation'[188-190] and is the only author to have explored the concept of 'patient non-participation' in health care.[188,190,191] Some of Eldh's studies[188,189] recognised that patient participation was more than just decision-making which was in contrast to the above mentioned studies.[135,138] In one of their first studies,[188] Eldh listed various descriptions of participation which included, 'the action of partaking', 'taking part', 'associating', or 'sharing' with others in some action or matter, more specifically described as *"the active involvement of members of a community or organisation in decisions which affect their lives and work."* Eldh further described 'patient participation' as common desires between patient and health professional. The process of participation is twofold, whereby the professional and patient must have a common understanding as well as respect for each other's contribution. Another perspective of participation given by Eldh was the perception of self-determination; patients want their right to self-determination. However, Eldh,[188] similarly to Cahill's study,[135] also acknowledged that some patients may not want to be involved in decisions and they are confident in the care and treatment they receive.

Other descriptions of 'patient participation' given by Eldh included: taking part in planning; performing tasks of self-care, and to participate in making decisions on treatment. These descriptions have been reported in the abovementioned studies. Eldh's qualitative study findings[188] showed that according to patients with chronic heart failure in a nurse-led clinic 'patient participation' in health care meant:

- *"to be confident"* in one's own ability, in the caregiver and in one's goals;
- *"to comprehend"* information, body's reactions and symptoms, disease and benefits and barriers of treatment;

- *"to seek and maintain a sense of control"* which involved demanding proper care, making appointments before being asked to make appointments, but also recognising the need to stand up for oneself.

'Non-participation' to patients' meant:

- *"to not understand"*, the health care structure, expectations from others, the treatment given and why, not recognising the signs and signals from one's own body, the disease process and progression.

- *"to not be in control"*, over the disease and treatment which included not setting any goals or plans for treatment. It also meant that these patients wanted more access to the care which they felt they needed.

- *"lack of relationship"* is the lack of continuity in care provided by the health professional or lack of support by the professional.

- *"to not be accountable"* included four other subthemes: (1) not being respected, (2) lacking value as an individual, (3) being exposed both (physically and emotionally) and (4) the individual was looked at not as a person but as a body with disease.

Eldh et al[188] compared the above with the definition for 'patient participation' in the national Swedish report, *"the possibility to choose treatment and to seek a second opinion."* and the WHO, The International Classification of Functioning, Disability and Health (ICF), *"as involvement in a life situation."* and concluded that there was a difference.

Eldh[188] went on to state that the phenomenon of patient participation and non-participation changed for patients with time and during different phases of the disease and treatment, e.g. regarding creating relationships, patients had no expectations to participate in care in the emergency department, but they expected to participate in their care at the heart failure specialist clinic. This demonstrated that participation was a dynamic process and this process was recognised in a definition presented above by Sahlsten[138] and, unlike the findings in Cahill's study[135] mentioned above, patients in Eldh's study wanted to participate in their care as outpatients.

A second study by Eldh[189] explored the phenomena of 'participation' and 'non-participation' by means of narrative interviews with chronic heart failure patients and nurses and observations of the nurse-patient interaction/consultation in an outpatient clinic. The study on the one hand reported that patients *experienced* 'participation' as taking responsibility,

obtaining knowledge they lacked and being treated like an individual. The study differentiated between the term 'taking responsibility' and 'accepting responsibility'. Taking responsibility is a personal trait which is dependent solely on an individual, whereas accepting responsibility is an interaction that is dependent on the both patient and HCP. While, patients *experienced* 'non-participation' as not knowing what was planned for them, not having the same information as a HCP or perhaps information being withheld from the patient, and not being seen as an individual. On the other hand, nurses viewed 'patient participation' as patients having received information based on their individual needs for their disease and its treatment, and 'non-participation' as lack of bonding and perceived that patients did not acknowledge the provision of information (not accepting). Meanwhile, the observed nurse-patient interaction demonstrated that nurses dominated the consultation, patient followed the nurse's initiative and the information given was standardised.

A third study by Eldh[190] explored the conditions for 'participation' and 'non-participation' from both inpatients and outpatients by means of a structured questionnaire. The results suggested that conditions for non-participation included lack of knowledge and lack of respect, and, conversely, having knowledge and being respected were reported as conditions for participation.

Finally, Eldh[191] moved from presenting a simple definition of 'non-participation' as *"not taking part"* to assessing the meaning of 'patient non-participation' in health care from a diverse group of patients with somatic disorders who had recently experienced being patients in an acute care hospital via a study questionnaire. The findings suggested that 'non-participation' was not about not being involved in decision-making and treatment planning related to their care, or did not refer to the legislative focus on participation and, 'patient involvement' as seen above, but it was about not being listened too and not receiving proper information from HCPs. The latter finding had been reported by Eldh previously.[189]

b) The primary health care context

In a primary health care consultation context of promoting patient participation, Protheroe[192] defined participation in health care as:

"an interaction, or series of interactions between a patient and the healthcare system or health care professional in which the patient is active in providing information to aid

diagnosis and problem-solving, sharing his/her preferences and priorities for treatment or management, asking questions and/or contributing to the identification of management approaches that best meet his/her needs, preferences of priorities"

Here the patient was acknowledged as a 'co-producer' of their health and was considered an integrated member in the care process. This definition was also presented in another study by Protheroe[193] within the context of shared decision-making which mentioned that the gap between 'having choices' and 'making choices' was best filled by the notion of patient participation. Choices were explained as decisions ranging between predetermined options such as different health care providers to different options for treatment which were in fact outcomes. And the role of decision-making and participation were concerned with collaboration between HCP and patient which was required to develop that list of options. So participation is more than offering choice versus no choice and was conceptualised as a process. Protheroe[193] stressed that this process was necessary to avoid the problem of disempowerment and 'personal identity threat' which could lead to patient's dissatisfaction with health care. However, the study reported that achieving participation is difficult and characteristics of patients who participate include being younger, female, educated, belonging to higher socioeconomic status with similar backgrounds and values as their health professional. Some of these patient characteristics were also reported in Cahill's review.[135]

The term 'active' has been used in relation to 'participation' in each of the abovementioned studies, e.g. participation has been referred to as: 'becoming actively involved', 'an active process',[135] 'active involvement',[138,188] and the 'patient is active'.[192]

Hence, definitions of 'active participation' are presented: *"recognising an individual's right to participate in the activities and relationships of everyday life as independently as possible; the individual is an active partner in their own care or support rather than a passive recipient."* These definitions highlight two key principles underpinning care, 'the rights of the individual' and 'the independence or autonomy of the individual'.

http://freedomtoteach.blogspot.co.uk/2012/01/health-and-social-care-benefits-of.html

(accessed 5-4-13). One study reported that 'active' patients ask questions, seek explanations, state preferences, offer opinions and expect to be heard;[81] these behaviours have been considered active forms of participation by another study[194] as they bring the patient's perspective into the patient-professional interaction which can influence the professional's behaviour and decision-making.

Hibbard[195] has defined the term 'patient activation' as *"an individual's knowledge, skill, and confidence for managing their health and health care"* and suggested that these three components were important for active engagement and participation. These three components have also been described to cause behaviour change necessary for patient SM (Chapter I). This demonstrates that the terms 'patient activation', 'self-management' and 'participation' are interlinked.

Hibbard has further explained the four levels of patient activation:

Level 1:   Individuals tend to be passive and feel overwhelmed by managing their own health. They may not understand their role in the care process.

Level 2:   Individuals may lack the knowledge and confidence to manage their health.

Level 3:   Individuals appear to be taking action but may still lack the confidence and skill to support their behaviours.

Level 4:   Individuals have adopted many of the behaviours needed to support their health but may not be able to maintain them in the face of life stressors.

A study[136] explored the meanings of 'active participation' from patients' (including those with chronic disease) perspectives by examining their illness-management stories to help health professionals understand how patients conceptualise participation in order to promote more productive illness-management strategies amongst patients. The first two emergent themes were: (1) the central position taken by the illness in the individual's life story and (2) the individual's perception on how changeable the illness was in terms of getting better. The next two themes were: (3) the extent the patient engages in their illness-related activity and (4) the role of partnership with the patient's HCP in health decision-making and illness management. Haidet[136] developed a conceptual model (Figure 2.2) of patient participation based on the relationships between the four themes across participants' illness-management narratives. Five illness management strategies were described with a decreasing level of participation which was dependent upon patients' perspectives of their illness and the actions taken as a result of the illness including the role of partnership with HCPs:

- *"Negotiated empowerment"* was the most productive strategy in terms of generating patient behaviours such as disease monitoring, preventive actions, and engagement with HCP.

- *"Self-motivated change"* was where the patient gathered most of their illness-management behaviours without great influence from HCPs.

- Within *"Adherence"* the patient's main strategy was to strictly follow the orders of the HCP without questioning, explanation or a need to engage with the HCP other than to receive orders.

- *"Unguided searching"* was when the active patient searched for illness-related information on their own and continued, unsuccessfully to try to find a HCP they could trust and work with.

- *"Passivity/fatalism"* was the least productive strategy and served to block efforts toward illness management by either patient or HCP.

These strategies were not necessarily static but sometimes changed as the four themes (1-4 above) and their associations changed. The dynamic nature of patient participation was exemplified: for one diabetic patient their condition took central role which meant their whole life revolved around their condition (centrality, 1). The patient did not think their condition would get better as they were unable to control their diet (change for the better, 2). But the patient, unlike their other family members, wanted to manage their condition so they could keep their limbs intact till the end. This led the patient to actively seek a doctor (self-initiated unguided searching) who might be able to help keep their limbs and to find a doctor with whom they developed a good (partnership, 4) who suggested activities more suited to the patient's personality (illness-related activity, 3). As a result, the patient gained control over their illness, felt empowered and was able to engage in SM activities (negotiated empowerment).

Figure 2.2 A conceptual model of patient participation in communication and illness care.
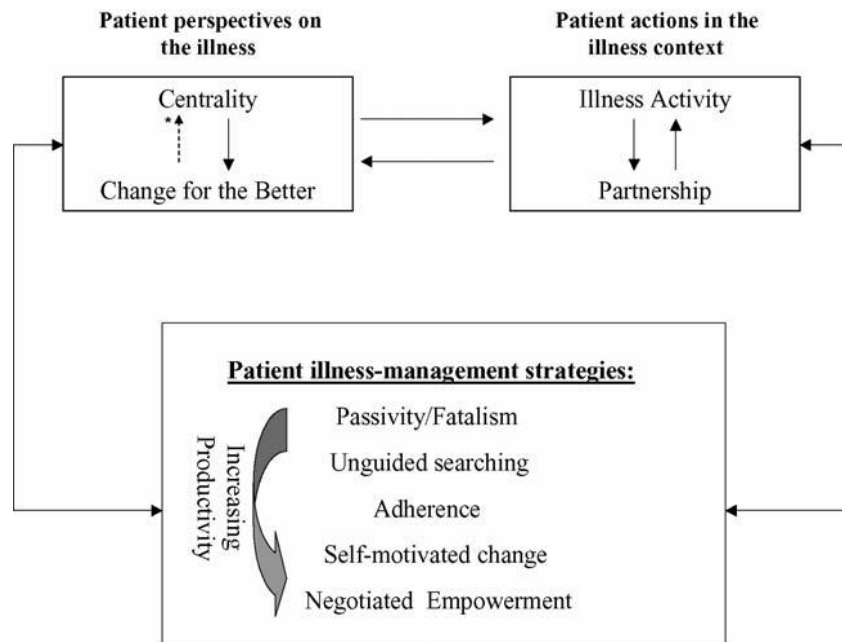
Source: Haidet (2006) (*) The dashed arrow from 'Change for the Better' to 'Centrality' indicates that this association, while theoretically possible, was not observed in any of the participants' narratives.

2.3.1.4 Synonymous terms of 'Patient participation'

The term 'patient participation' being used interchangeably with 'patient involvement', 'patient collaboration', 'patient partnership', 'patient empowerment' or 'patient-centred care' has led several studies[135,137,138] to report that it causes confusion and has made it difficult to reach a consensus on the definition of 'patient participation' in health care. One study suggested that the above terms might be used in policy documents for different agendas and hence could have different meanings.[138]

This section attempts to highlight any differences, where possible, between 'patient participation' and these other terms.

1) Patient participation and patient involvement

According to the previously mentioned MeSH definition, patient participation was referred to as 'patient involvement'. Eldh's study[191] indicated that a legislative focus of patient participation is denoted by 'patient involvement' - which has been demonstrated in the abovementioned health policy documents (section 2.1.2).

The policy documents have normally referred to 'public involvement' alongside 'patient involvement' except in the 'Health in Partnership' report[160] (section 2.1.2) and the lack of clear distinction between the two terms has been acknowledged.[196] Florin and Dixon[196] explained the difference whereby 'patient involvement' was referred to as the *"involvement of individual patients, together with their health professionals, in making decisions about their own health care"* and 'public involvement' was referred to the *"involvement of members of the public in strategic decisions about health services and policy at the local and national level."* The public comprise of volunteers who represent the views of patients, public and hard to reach groups http://healthandcare.dh.gov.uk/patient-and-public-engagement-and-involvment/ (accessed 21-8-12). The EPP Task Force can be used as an example here because the Task Force comprised members of the public who were patients or service users and they contributed to the development and piloting of the EPP (public involvement) aimed at patients with LTCs.[153] Participation of patients in the EPP was to result in the empowerment of patients, and one role of these 'expert patients' was to become key decision-makers so they could participate in decision-making about their care with HCPs (patient involvement).

Sahlsten et al[138] has further attempted to differentiate between patient, client, consumer and user involvement and reported that a 'patient' or a 'client' is a person receiving health/mental or social care; 'consumer' relates to the right to make a choice; and 'user' is an individual who is a current, or potential, recipient of health care.

A study by Thompson[148] demonstrated a distinction, and a relationship between 'patient participation' and 'patient involvement' within a clinical consultation context to help professionals, managers and policy makers understand the difference between these two concepts and produced a taxonomy (Table 2.1). Thompson utilised Arnstein's[197] ladder of citizen participation and explained that 'patient involvement' occurs at one of three levels of increasing power (consultation, partnership and lay control) and these levels of power are seen in the four most discussed models of treatment decision-making:

- *"paternalism",* where the professional knows best and patient involvement is limited to being given information or giving consent
- *"shared decision-making",* where both the process and outcome of decisions about treatment options are shared between patient and professional (similarly reported in Protheroe's study[193] as discussing shared discussion-making)
- *"professional as agent",* where professionals possess the technical expertise, but patient preferences are incorporated into their decision-making
- *"informed decision-making",* where the technical expertise is transferred to the patient, who makes the final decision

Thus, along the continuum of high level of patient power to low level of patient power, professional-determined patient involvement would start at: informed decision-making, shared decision-making, professional as-agent, paternalism and exclusion. Thompson[148] explored these levels of involvement from patients' and citizens' perspectives and the results suggested that 'involvement' for participants meant, one or more of information, explanation, openness, building partnerships and access for all. On the other hand, 'patient participation' in consultation was understood as involving patients in discussions about their condition, providing them with the relevant information, asking for their opinion on possible treatment and involving them in the decision-making process. But it was noted that not everyone wanted to be involved at all times and in all situations. These findings are consistent with studies reported above.[135,138,188]

Thus, patient-determined involvement ranged from:

- *"Non-involvement"* is the patient putting their trust in the professional, that they would do their best for them
- *"Information-seeking/information receptive"* where it is normal for patient to expect information and being receptive to such information is the initial stage of involvement
- *"Information-giving/dialogue"* patient is confident that they have the knowledge, the patient wants to be heard and believes professionals should listen
- *"Shared decision-making"* where the patient wants to makes an informed choice, patients should be guided and allowed to express opinions in partnership with professional
- *"Autonomous decision-making"* where patients can make decisions independently without support, patients believed they had more knowledge about their condition than professionals, particularly amongst patients with chronic illness

The views ranged from patients not wanting to be involved at all in consultations to an active role resulting in full autonomy dependent on the context. Based on these findings, Thompson developed a taxonomy (see below) and explained that patients' desire to be involved in dialogue or the sharing of decisions, can only be possible if professionals are willing for patients to engage in dialogue and allowed to express opinions and make decisions. Thompson labelled this is as 'co-determined involvement', or, 'participation'. Patients' desire for involvement was determined by three main characteristics including:

(1) The nature of health care need, the type of illness, whether it was acute or chronic. There was an increased chance of involvement by patients with chronic disease because of their longer experience and the seriousness of the condition which was related to a degree of expert knowledge. This view is different to Cahill's study[135] where patients with chronic disease were reluctant to be involved in care, especially giving opinions related to medical expertise. (2) Personal characteristics of individuals such as socio-demographic factors linked to knowledge and experience and personality factors. (3) A patient-professional relationship characterised by trust. Trust featured when patients had little experience or knowledge. Break in trust could result in greater involvement until trust was restored but it was possible that greater demand for involvement would be less strong. However, trust which emerged through greater involvement may have created the conditions for a sustained desire for involvement, as self-confidence and competence grow and mature.

The main distinguishing feature between 'patient involvement' and 'patient participation' concerned the degree to which patients take part in the decision-making process, suggesting a

degree of transfer of power from the professional to the patient in the form of increased knowledge, control and responsibility. The same patient may wish to be involved at different levels in relation to different circumstances, and it may change over time for the same person in the same context. Patient involvement is, therefore, a complex, multi-faceted and dynamic concept and based on the study findings 'patient participation' is an aspect of 'patient involvement'.

Table 2.1 Levels of involvement

Patient-desired level	Patient-Determined involvement	Co-Determined (PARTICIPATION)	Professional-Determined involvement
4	Autonomous decision-making		Informed decision-making
3		Shared decision-making	Professional as-agent
2	Information-giving	Dialogue	Consultation
1	Information seeking/receptive		Information giving
0	Non-involved		Exclusion

Source: Thompson 2007

2) Patient participation and patient partnership or collaboration

The term 'collaboration' or 'partnership' is the working together of patient and professional in a primary care or clinical consultation context which is necessary or essential for 'participation' and decision-making to take place.[138,148,193]

3) Patient participation and patient-centred care

Patient-centred care is encouraging involvement of patients in decision-making about their care and has been defined as *"as a philosophy of care that encourages: (a) shared control of the consultation, decisions about interventions or management of health problems with the patient and/or (b) a focus in the consultation on the patient as a whole person who has individual preferences situated within social contexts".[55,160]*

4) Patient participation and patient engagement

'Engagement' has been defined as *"actions individuals must take to obtain the greater benefit from the health care services available to them".[198]* 'Patient engagement' is *"active participation in health care"*. It includes patients preparing for appointments, exchanging relevant information with clinicians, shared decision-making, and adherence to agreed plans

of care.[199] Based on the latter definition one can assume that 'patient participation' is synonymous with 'patient engagement'.[135]

5) *Patient participation and patient empowerment*

Within a clinical context, the partnership between patient and professional can result in 'patient empowerment'.[136,200] While, outside of a clinical setting, participation and completion of a group-based SM support programme or the EPP can result in 'patient empowerment' via peer sharing, learning and working in groups.[201]

In summary, the dictionary definition of 'participation' and 'non-participation' were in line with the definitions given in the glossary of this thesis. In addition, various definitions have been presented for the term 'patient participation' in health care with regard to patients with chronic disease by studies through use of different approaches, philosophies and perspectives within a nursing, hospital or clinical consultation context. The definitions presented could be assembled into a broad individual context whereby, patient participation was about patients taking responsibility for their own health. Within a clinical consultation setting through patient engagement, patient-centred care the aim was to help patients to take responsibility for their health. Besides decision-making, studies that explored the meaning of patient participation from the perspectives of patients and health professionals showed that patient participation and non-participation was about the type of relationship/extent of bonding between patients and professionals. In addition, patient participation was not static but dynamic in nature and this process was dependent upon multiple patient, professional and contextual factors. From existing evidence, figure 2.3 illustrates the various meanings given to the concept of 'patient participation' in health care and its synonymous terms.

This section has briefly highlighted some factors or patient characteristics that might influence an individual to participate in their care and have been mainly within a clinical consultation context. The next section, further demonstrates other factors, specifically, theoretical factors, that might influence both health care seeking and participation in health care including SM interventions amongst patients with chronic disease.

Figure 2.3 Illustration of definitions, concepts and meanings given for patient participation in health care and differences between its interchangeable terms in health care

In legislative or policy focus it is **PATIENT INVOLVEMENT** e.g. patient choice; chronic disease patients taking responsibility for their own health

Meanings in a patient-professional consultation context

DYNAMIC NATURE

Professional-determined involvement
4. Informed decision-making
3.
2. Consultation
1. Information giving
0. Exclusion

PATIENT PARTNERSHIP

PATIENT COLLABORATION

working together of patient and professional

PATIENT-CENTRED CARE

encouraging patient participation or to be active

Role of patient: being active, asking questions, sharing information, stating preferences.
Label of patient 'co-producer'

Accepting responsibility with the help of professional

Role of professional: involves negotiation, identifying what patients want, seeing patient as a whole

Patient is being involved in decision-making

Setting requires: an established relationship, power shift to transfer control, active mutual engagement

co-determined between patient and professional

SHARED DECISION-MAKING/ DIALOGUE

Decreasing level of patient participation:
Negotiated empowerment includes
PATIENT ENGAGEMENT

Self-motivated change

Adherence

Unguided searching

Passive

Meanings in an individual context

Taking responsibility (trait of a person)
Decision-making
Performing activities /SM activities/ self-care tasks

Active patients: asks questions, seek explanations, offer opinions and expects to be heard

Means to be confident in oneself and professional;
To comprehend information about condition and treatment
Seeking and maintaining a sense of control

Patient-determined involvement
4. Autonomous decision-making
3.
2. Information giving
1. Information seeking
0. Not involved

DYNAMIC NATURE

Influenced by:
type of illness, actions taken in relation to illness;
patient characteristics; and relationship with professional (trust) or role of partnership

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2.3.2 Results: Theoretical models that explain patient participation in health care and health care interventions

The previous section revealed that patient participation in health care, particularly within a clinical consultation context, could be influenced by the type and nature of illness, patient characteristics and the relationship between patient and professional;[135,136,148,193] and patient participation may result in a patient becoming actively involved or engaged in making decisions about their health and health care.

Patients making decisions about health care can include accessing and seeking appropriate care from professionals, and making decisions about health could include participation in health care interventions such as, health promotion interventions to prevent disease or participation in SM interventions for chronic disease.[198]

This results section presents findings of the included 25 studies that utilised theoretical models to explain health care utilisation or participation in SM interventions among patients with chronic disease. The findings of these studies are presented under the following three headings.

2.3.2.1. Theoretical factors that may influence health care utilisation within a clinical setting

2.3.2.2. Theoretical factors that may influence the utilisation of ongoing SM/health services, outside of a clinical setting, for the maintenance of SM behaviours

2.3.2.3. Theoretical factors that may predict or influence attendance in SM interventions or in studies of SM interventions

The number of studies described under each heading was six, four and fifteen respectively. Table 2.2 presents a summary of the study characteristics.

Table 2.2 Summary characteristics of the 25 studies

Author (Date)/Country	Title of study	Aim of study	Study design	Theoretical model	Chronic disease
de Boer (1997)/ The Netherlands	Predictors of health care utilization in the chronically ill: a review of the literature	To identify predictors of health care utilization in the chronically ill.	Literature review	Andersen's socio-behavioural model	Chronic disease
Uphold (2005)/USA	Use of health care services among persons living with HIV infection: state of the science and future directions	To describe the current status of health care utilisation research and to provide recommendations to guide researchers, clinicians, and policy makers to improve utilisation patterns among person living with HIV infection.	Literature review	Andersen's socio-behavioural model	HIV
Ciechanowski (2003)/ USA	The relationship of attachment style to depression, catastrophizing and health care utilization in patients with chronic pain	The hypothesis was in a sample of persons with chronic pain, fearful and preoccupied attachment style would be associated with higher levels of reported pain intensity, depression, catastrophizing and physical dysfunction. To explore whether catastrophizing might influence the relationship between attachment styles and health care utilization following multidisciplinary pain management.	Quantitative – secondary analysis	Attachment theory	Chronic pain
Ciechanowski (2006)/ USA	The interpersonal experience of health care through the eyes of patients with diabetes	Hypothesized that compared to patients with secure attachment style, those with dismissing and fearful attachment style would be: (1) less satisfied with interactions with health care providers; (2) less trusting of health care providers and (3) less able to collaborate in health care settings.	Qualitative	Attachment theory	Diabetes
Ciechanowski (2006)/USA	Where is the patient? The association of psychosocial factors and missed primary care appointments in patients with diabetes	To predict that compared to secure attachment style, fearful and dismissing attachment styles would be associated with greater number of missed primary care visits in patients with diabetes.	Quantitative – predictor study	Attachment theory	Diabetes

Gately (2007)/UK	Re-thinking the relationship between long-term condition self-management education and the utilization of health services	To explore participants' perceptions of illness, ascertain the nature of self-care and engagement with health care services over time, with participants being interviewed pre- and post-training course.	Qualitative – longitudinal design	Social theory – Illness work	Chronic disease
Gucciardi (2009)/Canada	Education and psychological aspects individual and contextual factors associated with follow-up use of diabetes self-management education programmes: a multisite prospective analysis	To identify factors influencing follow-up use of diabetes self-management education services.	Quantitative – prospective analysis	Andersen's socio-behavioural model	Diabetes
Sniehotta (2010)/UK	Adoption of community-based cardiac rehabilitation programs and physical activity following phase III cardiac rehabilitation in Scotland: A prospective and predictive study	To test, compare and combine the predictive utility of the Common-Sense Self-Regulation Model (CS-SRM) and the extended Theory of Planned Behaviour (TPB) with action planning for two rehabilitation behaviours: physical activity and phase IV CR attendance.	Quantitative – prospective cohort design	CS-SRM; TPB with advanced action planning	Varied chronic heart disease patients
Dohnke (2010)/Germany	Motivation and Participation in a Phase III Cardiac Rehabilitation Programme: An Application of the Health Action Process Approach	It examines the correlates of motivation and participation 6 months after inpatient phase II CR (T1) and the predictors of dropout 6 months later (T2) using the health action process approach (HAPA).	Quantitative – longitudinal study	HAPA	Varied chronic heart disease patients
Pentecost (2011)/UK	Understanding exercise uptake and adherence for people with chronic conditions: a new model demonstrating the importance of exercise identity, benefits of attending and support	To identify the influences on uptake and adherence behaviour for people with chronic conditions, using a diverse sample by age, gender, ethnicity and attendance level and presenting a new model of exercise uptake and adherence, with implications for a diverse range of people.	Qualitative	A conceptual model of exercise uptake and adherence	Chronic disease
Petrie (1996)/New Zealand	Role of patients' view of their illness in predicting return to work and functioning after	To examine whether patients' initial perceptions of their myocardial infarction predict subsequent attendance at a cardiac	Quantitative – predictor study	SRM	CHD

	myocardial infarction: longitudnal study	rehabilitation course, return to work, disability, and sexual dysfunction.			
Cooper (1999)/UK	Why patients do not attend cardiac rehabilitation: role of intentions and illness beliefs?	To determine whether the illness beliefs held during hospitalisation by patients who had suffered acute myocardial infarction or who had undergone coronary artery bypass graft surgery could predict cardiac rehabilitation attendance.	Quantitative prospective study	SRM	CHD
Whitmarsh (2003)/UK	Illness perceptions, mood and coping in predicting attendance in cardiac rehabilitation	To identify psychological variables in poor/non-attendance at cardiac rehabilitation.	Quantitative cross-sectional study	SRM	CHD
French (2005)/UK	Do illness perceptions predict attendance at cardiac rehabilitation and quality of life following myocrdial infarction?	To examine the extent to which illness perceptions predict attendance at cardiac rehabilitation and quality of life following myocardial infarction (MI)	Quantitative prospective predictor study	SRM	CHD
French (2006)/UK	Illness perceptions predict attendance at cardiac rehabilitation following acute myocardial infarction: A systematic review with meta-analysis	To examine whether illness perceptions really predict attendance at cardiac rehabilitation and to examine factors that moderate this relationship.	Systematic review and meta-analysis	SRM	CHD
Blair (2013)/UK	The influence of non-modifiable illness perceptions on attendance at cardiac rehabilitation	To examine the influence of socio-demographic factors, illness perceptions and social isolation on patient attendance at cardiac rehabilitation.	Quantitative	SRM	CHD
Cooper (2005)/UK	A qualitative study investigating patients' beliefs about cardiac rehabilitation	To elicit patients' beliefs about the role of the cardiac rehabilitation course following myocardial infarction.	Qualitative	NCF	CHD
Cooper (2007)/UK	Assessing patients' beliefs about cardiac rehabilitation as a basis for predicting attendance after acute myocardial infarction	To develop a valid and reliable measure of patients' beliefs regarding cardiac rehabilitation and to ascertain the relationship between such beliefs and attendance.	Quantitative	SRM; SRM-NCF	CHD

Keib (2010)/USA	Poor use of cardiac rehabilitation among older adults: A self-regulatory model for tailored interventions	The self-regulation model was used to guide the development of interventions targeting other health behaviours, and may provide a useful guide for the development of interventions tailored to improve older adult participation in cardiac rehabilitation.	Quantitative – descriptive study	SRM; SRM-NCF	CHD
Wyer (2001)/UK	Predicting attendance at cardiac rehabilitation: a review and recommendations	To investigate how attendance at CR could be increased	Literature review	SRM; TPB	CHD
Wyer (2001)/UK	Deciding whether to attend a cardiac rehabilitation programme: an interpretive phenomenological analysis	To explore beliefs held on recovery and CR by attenders and non-attenders; and to examine the usefulness of the Self-Regulatory Model and the Theory of Planned Behaviour when interpreting the results.	Qualitative study	SRM; TPB	CHD
Lemaigre (2005)/Belgium	Understanding participation in an asthma self-management program	To investigate social cognitive determinants of the intention to participate in an asthma self-management program.	Quantitative	ASE	Asthma
Helitzer (2007)/USA	Relationship of Stages of Change to Attendance in a Diabetes Prevention Program	To determine whether pre-intervention stage-of-change measures are indicative of subsequent attendance at diabetes prevention intervention sessions.	Quantitative cross-sectional study	SoC	Diabetes
O'Brien (2009)/UK	Predicting adherence to phase III cardiac rehabilitation: should we be more optimistic?	Aim not specified	Quantitative	SoC	CHD
Toth-Capelli (2012)/USA	Stage of Change and Other Predictors of Participant Retention in a Behavioural Weight Management Program in Primary Care	To investigate stage of change and other predictors of retention in a behavioural intervention program that enrolled adult obese patients at three primary care sites.	Quantitative	SoC	Obesity
Key: HIV- Human immunodeficiency virus; CHD – coronary heart disease; SoC – Stage of Change; ASE - Attitude-Social Influence-Self efficacy; NCF-Necessity-Concerns Framework; SRM - Self-Regulation model; TPB – Theory of Planned Behaviour; CS-SRM - Common-Sense Self-Regulation Model; HAPA - Health Action Process Approach					

2.3.2.1 Theoretical factors that may influence health care utilisation within a clinical setting

Health care utilisation or health care seeking was viewed as a health behaviour in this study. 'Behaviour' denotes something that people *"do* or *refrain from doing",* although not always consciously or voluntarily. It is not something *"done to them".*[202]

Gochman[202] defined 'Health behaviour' as *"those personal attributes such as beliefs, expectations, motives, values, perceptions, and other cognitive elements; personality characteristics, including affective and emotional states and traits; and overt behaviour patterns, actions, and habits that relate to health maintenance, to health restoration, and to health improvement."*

A definition has been given for 'Health care utilisation (HCU) behaviour' which *"is the use of health services, whether it be clinical public health services or the services of medical professionals".* HCU behaviour can range from *"using preventive services, such as getting immunisations or early detection and screening tests to elective surgery or involuntary hospitalisation after an injury"* http://www.healthline.com/galecontent/behavior-health-related#2 (accessed 14-2-13).

Among the 25 included studies, six studies (see Table 2.2), described below, explained HCU among patients with chronic disease via the following three theories: the 'Andersen's Socio-Behavioural model', the 'Attachment theory' or the Social theory – 'Illness work'. The studies explained HCU patterns of patients within the context that lack of optimal use of health services was associated with worse health outcomes and higher costs to health services.

Box 2.2 briefly describes the three theories. Table 2.3 presents a summary of the theoretical factors that influenced increase in HCU in the six studies.

Box 2.2 Brief description of the 'Socio-behavioural model', the 'attachment theory' and the social theory - 'illness work'

Andersen's Socio-Behavioural model

This model explains that[4] people use health services due to their predisposition to use health services and the *predisposing characteristics* include demographics, social structure – occupation, ethnicity, education and health beliefs; *enabling factors* enable or prevent use of health services such as personal/family income, insurance, community resources- physician and hospital bed ratios, place of residence; and *need* for care or services through *perceived needs* of an individual and/or *evaluated need* considered important by professionals. Andersen and Newman found that predisposing characteristics had low mutability; health beliefs had medium mutability and some enabling factors had high mutability e.g. health insurance benefit and personal need could be changed through health education programmes or changing financial incentives and evaluated needs could change as a result of emergent clinical guidelines which in turn could be changed to promote equitable access. The *health care system* (policy, resources, and organisation) and the *external environment* constructs (physical, political and economic components) were also recognised as primary determinants of health care utilisation along with population characteristics to further explain health care use (such as type, site, purpose and when these services were used in case of an illness) and changes of use over time which were dependent on health outcomes such as consumer satisfaction, perceived health status and evaluated status. The model recognised that *personal health practices* such as diet, exercise, self-care would interact with the use of health care and thus affect health outcomes. Figure 2.4 illustrates a dynamic model with a recursive nature. The feedback loop showed that the health status outcomes in turn affect subsequent predisposing, enabling factors and needs which influence health behaviour (health service utilisation and personal health practices).

Figure 2.4 Behavioural model

Box 2.2 continued

Attachment theory

Ciechanowski[5] describes Bowlby's[10] attachment theory as a theory about how interpersonal development process may affect care seeking behaviour in response to illness. Early experiences with health care providers lead to formation of cognitive schema or representations of relationships that influence whether an individual perceives themselves to be worthy of care (view of self) or whether they trust others to provide care (view of other). These representations influence how an individual interacts with others, and the interpretations of these interactions, all through life. There are four main attachment styles that are a result of interpersonal experience (Figure 2.5): (1) *Secure* – persons may have consistently experienced responsive early caregiving. These persons are comfortable and readily comforted by others. They have a positive view of themselves and are worthy of care and others are trustworthy to provide care when needed. (2) *Dismissing* – persons are believed to have experienced early caregiving as consistently unresponsive and as a result these individuals become compulsively 'self-reliant'. They are uncomfortable trusting others but nevertheless have a positive view of themselves and hence are 'self-reliant'. (3) *Preoccupied* – here persons have received inconsistently responsive caregiving and as a result these individuals become vigilant and emotionally dependent on others. They become 'clingy' in terms of seeking support especially when distressed. Persons here are associated to have low self-esteem, negative affect and have increased subjective stress. (4) *Fearful* – persons here share characteristics of the 'preoccupied' style where they desire social contact when they are distressed but the desire to seek support is inhibited by fear of rejection. Individuals may have received harsh caregiving in early life and as a result adults express patterns of fleeing when they receive certain amount of closeness. These persons may not see themselves as worthy of care or others as trustworthy to seek needed care. They too have low self-esteem, negative affect and have increased subjective stress.

Figure 2.5 Attachment style categories and model of self and other

Model of self

	+	−
+	**Secure** - trusting of others; feels worthy of others attention	**Preoccupied** - emotionally dependent on others; low self-esteem; focus on negative affect
−	**Dismissing** - low trust of others; compulsively self-reliant	**Fearful** - low trust of others; fearful of intimacy; low self-esteem; focus on negative affect

Model of Other

Box 2.2 continued

> **Social theory – 'Illness Work'**
>
> Corbin and Strauss[1] have viewed illness as a sociological concept and used the term 'illness trajectory'. The trajectory refers to the (1) course of illness, (2) to all the related work' including (3) the impact on the person and their relationships that (4) affect the management of the course of illness and the fate of the person who has the illness. Specifically, the related work includes 'illness-related work' and 'everyday life work'.
>
> Corbin and Strauss explain that: Illness-related work/Illness work consists of regimen work, crisis prevention and symptom management.
>
> Everyday life work is act of living or the essential daily tasks/actions taken for living e.g. employment, marital work, housekeeping, eating. Between the illness work and everyday life work there is interactions with family, friends, HCPs and others who might be providing information, show or express concern and care for patients. In addition, several clusters of tasks/jobs take place within and between the illness and everyday life work need to fit into an individual's daily routine. As illness trajectory and everyday life can differ from day to day, the tasks to be done can differ in amount, degree of difficulty, time it takes and consistency with which it must be done. In addition, at each change within the illness trajectory e.g. patient returning home from an acute exacerbation or everyday life work there will be changes in the type and nature of work. The structure e.g. in home in which management needs to take place might need to change with every change in the illness trajectory change to meet the needs of trajectory management. A person's trajectory management takes place in everyday life context which might change to temporary or permanent depending on change in the performance ability. Trajectory management would vary depending on the severity of illness and type of trajectory. As a result, depending on the severity or type different tasks might need to be performed or required for trajectory management and various different resources might be necessary to perform the tasks. A change in illness can bring change in management of the illness trajectory and also affect the management of everyday life. And a slight change in everyday life can affect trajectory management.
>
> The ill person's biography or biographical work gives direction to the management process and has a reciprocal impact.
>
> To live (illness work, everyday life work, biographical work) requires balance and development of action plans that will satisfy these works. The equilibrium achieved would be relative – achieving equilibrium regardless of struggle put forward is not easy – there is tendency for instability of the balance because of consequences via: competition of resources, unbalanced workloads, distribution of workflow and conditional motivation. Equilibrium is needed to prevent the downward spiral and so to prevent the irreversibility of downward spiral the equilibrium needs to be checked in the early stages of the illness. So to keep the consequences in check and maintain a sense of relative equilibrium there needs to be "management in process" with emphasis on adaptation to change. Four basic strategies include: (1) Resources calculation; (2) Maintaining fluid boundaries in division of labour; (3) Ongoing articulation work (requires planning and coordination for work to proceed smoothly and completion); and (4) Mutual sustaining.

Table 2.3 Summary of factors that influenced health care utilisation

Study (year); theoretical model used, n=6	Factors
(a) de Boer (1997); Andersen's socio-behavioural model	Perceived need
(b) Uphold (2005); Andersen's socio-behavioural model	Perceived need; To some extent – Pre-disposing, Enabling factors and Contextual factors
(c) Ciechanowski (2003); Attachment theory	'Preoccupied attachment style' and clinical factor - catastrophizing
(d) Ciechanowski (2006); Attachment theory	Clinical factor - depression To some extent - 'Preoccupied attachment style'
(e) Ciechanowski (2006); Attachment theory	To some extent - 'Fearful attachment style'
(f) Gately (2007); Social theory	Factor was 'Illness work'

(a)

Andersen's ***behavioural model*** of health services utilisation (HSU)[4] (Box 2.2) has often been referred to as 'the health services utilisation model'.[202]

de Boer's review[142] comprising 53 studies utilised Andersen's and Newman's 1970s model to evaluate the effects of 'predisposing', 'enabling' and 'need' factors on hospital admissions (admissions and length of stay) and physician visits (number of visits at outpatients) amongst patients with chronic disease.

The main findings suggested that the predisposing and the enabling factors had less predictive value and the need factors were strong predictors of HCU amongst the chronically ill (heart disease, arthritis, stroke and diabetes).

The need factors were strongest predictors of utilisation particularly perceived health status (both physical and psychological). Worse perceived health, specifically depression and psychological stress, led to more HCU. While professional assessed need which included disease duration or comorbidities did not affect HCU.

(b)

Uphold's literature review[168] examined, using Andersen's socio-behavioural model population characteristics and contextual factors, the HIV-related HCU of people living with HIV who were older, non-white, heterosexual men or women and injection drug users (IDUs) to ensure that these patients received services according to their needs.

The study findings showed that HIV-related HCU was influenced by predisposing and enabling factors but perceived needs were the most important predictors of HCU.

Patients' perceived needs were dependent upon patient perceptions of health and symptoms and influenced HCU. Increased symptom intensity plus adverse effects from medication led to increased use of inpatient, outpatient and emergency visits. Two or more clinical HIV-related symptoms were the most important predictors of HCU. Poor functional status and health-related quality of life resulted in increased HCU; depression and mental illness also led to higher HCU and could also lead patients to miss scheduled appointments and not seek care. Comorbidities also affected HCU.

Professionals' evaluated need, whether a person with HIV needed appropriate services was dependent upon clinical guidelines.

Contextual factors such as the type of care received (e.g. VA centres – had longer lengths of stay), geographical area (e.g. the northeast area had a longer lengths of stay) and place of residence at individual level (those living in rural areas were less likely to receive HAART compared to urban areas), including provider characteristics, such as experience (experienced providers provided more antiretroviral therapies and patients received primary care visits), gender, and training of HCPs (patients cared for by nurses reported fewer problems with their care and had better outcomes in terms of accessing care), influenced HCU amongst this patient group. Experience and perceptions of the health care system also influenced HCU, e.g. if patients with HIV had problems accessing primary care due to long waiting times, or experienced difficulties making appointments, then that influenced primary care visits.

(c)

Ciechanowski utilised the ***attachment theory***[10] (Box 2.2) to study three different aspects of HCU amongst patients with chronic pain[5] and diabetes.[165,169]

In the first study, Ciechanowski[5] conducted a secondary analysis on a subsample of chronic pain patients who had previously participated and completed a pain treatment programme which resulted in a significant decrease in measures of depression, catastrophising, pain perception, pain-related HCU and physical dysfunction from a pain programme to 12 month follow-up. The results suggested that the preoccupied attachment style predicted high post-treatment pain-related utilisation after controlling for baseline utilisation, catastrophising and depression, and there was no significant correlation between depression, catastrophising and the pre-occupied attachment style. In addition, the study found that the 'fearful attachment

style' predicted moderate time levels (greater than monthly visits, more than three visits in three months) of post-treatment pain-related HCU. However, this finding became insignificant when catastrophizing was controlled. The author explained that the *fearful attachment style* may lead to higher pain-related HCU (greater than weekly visits, more than 12 visits in three months) only in the presence of catastrophizing. This is because chronic pain patients with the *fearful attachment style* may overcome their anxiety to seek care when they are faced with a catastrophic threat.

(d)

Ciechanowski in another study[165] examined whether the attachment styles and depression was associated with the number of routine missed primary care visits amongst diabetics. The rationale behind it was that non-attendance in primary care clinics was associated with worse health outcomes e.g. poorer glycaemic control, non-adherence to medications. The findings suggested that depression was associated with missed primary care visits via an individual's attachment style. Patients with the pre-occupied attachment style were associated with more scheduled and same day appointments; while, those with the fearful attachment style had significantly more same day appointments but were not scheduled visits. This is consistent with the fearful attachment style where patients may approach HCPs with needs and problems but are fearful and unable to trust others; they make same day appointments (a solution to them) in desperation because they have delayed making scheduled appointments for acute somatic symptoms or psychological distress. Patients with the fearful attachment style had 25% fewer scheduled preventive care visits in the study sample. Missed appointments were more likely in patients with the dismissing or fearful attachment style amongst patients without major depression (88% of sample). But in patients with major depression, the depressive symptoms may override the tendency amongst these individuals to take care of things themselves and so in this case they may not miss the scheduled appointments. Furthermore, the study compared patients with one or more missed scheduled visits with those who did not miss any scheduled visits, and the presence of depression presented a greater risk of missed appointments compared to presence of either the fearful or dismissing attachment style.

(e)

A third study by Ciechanowski[169] explored the experience of interaction between patients with diabetes and professionals in tertiary care, and how that might influence the engagement

of the patient in the interaction. The study rationale was because of a system-wide fragmentation (where patients with chronic disease may not be receiving chronic disease management support) may especially be challenging for patients with the fearful or dismissing attachment style which might affect their interaction or engagement with the health care system.

The study found that regardless of the attachment style most patients perceived the health care system as rushed, impersonal and fragmented. In addition, patients with the dismissing or the fearful attachment style also perceived (e.g. via professionals' attitude or body language) a power divide or difference between themselves and the HCP which affected their interaction. In line with the cognitive schema of the attachment theory, patients with the fearful attachment style were aware of indications of rejection and those with the dismissing attachment style were sensitive to being controlled. But despite this, if they noticed that HCPs were trying to get to know them and they were accepted in a non-judgemental manner, then these patients would be more likely to engage in the interaction. In addition, patients with the fearful attachment style, when they were dissatisfied with the interaction with HCPs instead of changing HCPs, they played the role of 'the good patient', as a way of tolerating the interaction and because changing HCPs was perceived as difficult.

(f)

Gately[166] looked at chronic illness and health care seeking from a sociological perspective. They reported that a sociological approach questions the assumption that people are consistent in their preferences, knowledge level and ability to make rational decisions. Gately proposed that instead of an individual following a static framework where the individual might make choices from a list of options provided, a social process approach works in a different way and that the process of help-seeking is an ongoing contact lasting months or years which is modified by individuals based on adaptations and their responses to living with a chronic illness. Gately continued that most illness management usually takes place outside of formal health services and referred to Corbin and Strauss's[1] work where the process of symptom management is included within *'illness work'* (Box 2.2) and is different to *'everyday life work'* (daily housework tasks) and *'biographical work'* (relating to the ill person's biography). However, Gately pointed out that normally patients with chronic disease have some level of interaction with health services for their symptom management making illness work a shared activity between patients and professionals. So, Gately et al. in a

longitudinal qualitative study explored patients' perceptions of their illness, the nature of self-care and utilisation of health services over time before and after attending the EPP. In addition, they described two case studies to highlight the point of the social context, illness trajectory and HCU through everyday life work and biographical work.

The study found that a reduction in HCU patterns (one of the impacts as expected from the delivery of SM education) was not seen among patients with chronic disease despite improvement in self-efficacy because patients might have not made the connection that they could reduce the need for medical care by changing their behaviour. The study highlighted health service use, amongst patients with chronic disease, was routine and habitual for management of their condition; the study participants knew their way around the health services and used strategies to access services that had been adapted over time; and the content of the programme had focused upon improving communication between patient and one professional (as in GP-patient), and had not acknowledged the importance of the biographical context and patterns of pre-existing health services utilisation of patients. The authors further stated that people who find the EPP useful might be those whose needs have been unmet by traditional services whilst those with chronic conditions who use health services on a regular basis may find it difficult to change their behaviour - especially if the professionals also have a different agenda to self-care.

2.3.2.2 Theoretical factors that may influence the utilisation of ongoing SM services, outside of a clinical setting, for the maintenance of SM behaviours

Among the 25 includes studies, four studies (Table 2.2), described below, explained utilisation of ongoing health/SM services outside of a clinical consultation setting but within the wider health services via the following three theories: the Common-Sense Self-Regulation Model (CS-SRM), the Theory of Planned Behaviour (TPB) or the Health Action Process Approach (HAPA). The SM services mentioned in the four studies were referred to as ongoing or follow up services that were offered to patients with chronic disease for maintenance or long term adherence of behaviours that were deemed necessary for the prevention and management of chronic condition to have better health outcomes. These studies are described below.

Box 2.3 briefly describes the three theories. Table 2.4 presents a summary of the theoretical factors that influenced patient participation or the utilisation of ongoing SM services in the four studies.

Box 2.3 Brief description of the Common-Sense Self-Regulation Model, The Theory of Planned Behaviour and the Health Action Process Approach

The Common Sense Self-Regulation model (CS-SRM)

Leventhal[8] explained that a health threat can generate an emotional response (fear or distress) and a corresponding need for procedures to manage the emotional response; and simultaneously a cognitive representation of the threat is formed (via information about the threat and physical stimuli) along with a corresponding need for procedures to manage the threat by using action plans. Leventhal went on to state, that symptoms experienced as a result of an illness and the name of the illness form one small part of an illness representation – termed *'identity'* – a label given to illness and the symptoms people associate with illness. Four other domains of illness representations identified from several studies of different conditions included: *'timeline'* - expected duration of illness or expected age of onset of illness; *'consequences'* - severity and impact on life functions; *'cause'*-internal (e.g. genes) or external (e.g. infection); and whether the illness was perceived as '*preventable', 'curable' or 'controllable'*. As a result, these illness representations (Figure 2.6) can lead one to generate goals, develop action plans and evaluate response self-efficacy (evaluation of whether the threat has been eliminated or controlled). In 2002, new constructs were added to the model[13] comprising *coherence* (extent to which patients understand their illness/symptoms); *cyclical timeline*; *personal* and *treatment controllability* and *emotional representations* (emotional impact of the illness).

Figure 2.6 The five domains of illness representations

IDENTITY (label)	TIMELINE (duration)	CONSEQUENCES (expected outcomes)	CAUSE	CONTROL (yes/no)
Symptoms	Perceived time	e.g, Physical disability	e.g. Lack of sleep contact with sick individual	Treatment effective?
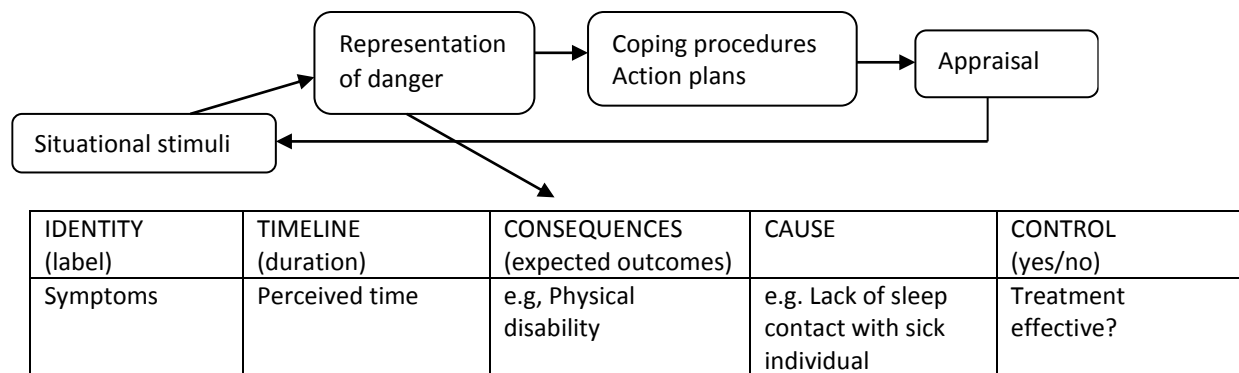
The action plans or coping procedures can also be classified in the five domains and hence an individual can form representations of a coping procedure via expectations from a procedure, information about a procedure or experience of a procedure. As a result, Leventhal pointed out that both illness and treatment representations can prove useful in understanding an individual's adherence to their medication and behavioural regimens. Furthermore, Leventhal stated that self-regulation by an individual is dependent upon age, health self-assessment and perception of strength of immunity. Self-regulation is not done in isolation but is dependent on the input and expertise of others (e.g. families, clinicians) and cultural factors.

The Theory of Planned Behaviour (TPB)
The Theory of Planned Behaviour (TPB) was developed by Ajzen[3] and is an extension of Fishbein's and Ajzen's[12] Theory of Reasoned Action (TRA). The TPB was used to predict and explain human behaviour under incomplete volitional control (if a person can decide at will to perform or not perform a behaviour) in a specific context (whereas the TRA is about behaviour undertaken under volition control). Ajzen explained that *intention* or *motivational factors* are needed to carry out an action or behaviour; in addition, *non-motivational factors* such as opportunities and resources (e.g. time, money, skills, co-operation of others) are needed which represent an individual's actual control over the behaviour. An important construct of the model is *perception of behavioural control* that impacts on an individual's intentions and actions in the TPB.

Perceived behaviour control (PBC) refers to an individual's perception of ease or difficulty of performing the behaviour of interest. According to the TPB, PBC and intention can be used to predict behaviour change. However, at times a person has to undertake a behaviour that is new, or if they have little information about it, or if available resources have changed, or if something new has occurred or changed in the situation, then under these conditions PBC has little to offer in terms of accuracy of behavioural prediction.

The TPB suggests three conceptually independent determinants of intention: (1) *Attitude* towards the behaviour which may be favourable or not after its appraisal; (2) *Social factor or subjective norm* which is the perceived social pressure to perform the behaviour or not; and (2) *PBC*. These factors in the prediction of intention may vary across behaviours and situations. Ajzen, based on empirical studies, stated that for behaviours that have been considered an individual's personal *attitudes* tended to overshadow the influence of perceived *social pressure*.

Next, Ajzen explained that the TPB have tried to not only predict human behaviour but also explain human behaviour through the role of beliefs via the expectancy-value model which suggested that salient beliefs could be the main determinants of an individual's intentions and behaviours. The beliefs are: *behavioural beliefs* which influence attitude towards behaviour; *normative beliefs* underlie subjective norm and *control beliefs* provide basis for PBC. However a direct relation between the beliefs and the corresponding intention determinants has not been demonstrated. Despite this, Ajzen believed that it is at the level of beliefs that perhaps more understanding can be obtained about how one person can engage in positive health behaviour and another person might follow a different course of action. In addition, other predictors outside of the model that might help to predict intentions and behaviour reported were personal pressures/moral obligation or responsibility to perform, weighing the costs and benefits of an action (evaluative judgement) versus feelings after performing an activity (affective judgement) and the role of past behaviour.

Box 2.3 continued

The Health Action Process Approach (HAPA)

The HAPA has been developed by Schwarzer and Fuchs[7] which is an extension of other behavioural models such as the health belief model (HBM) (not described in this chapter), the TPB and has been particularly influenced by the socio-cognitive theory (SCT).

The authors explained that the adoption, initiation, and maintenance of health behaviour must be conceived as a process that consists of 2 stages: 1) *motivational* phase and 2) *volitional* phase which is further divided into i) planning phase, ii) action phase and iii) maintenance phase. Self-efficacy plays a crucial role at all stages (to adopt, initiate and maintain behaviour because if one does not believe in one's capability to perform a desired behaviour they will fail), whilst other cognitions are of limited scope such as risk perception (perceived susceptibility and vulnerability of the HBM) which start the contemplation process early in the motivation phase but do not progress beyond it; outcome expectancies (attitude) are important in motivation phase when an individual thinks about the pros and cons of certain consequences of behaviours but they lose predictive power after a personal decision has been made.

In detail, within the motivational phase (what people choose to do), outcome expectancies can be seen as the precursors of self-efficacy as people normally make assumptions about the possible effects of behaviours before inquiring whether they can take the action themselves. If self-efficacy is specified as a mediator between outcome expectancies and intention, then the direct influence of outcome expectancies on intention may dissipate. However, both factors are important for motivating change. In conditions where an individual does not know the behaviour to perform or, has no experience with the behaviour they are contemplating it is assumed that outcome expectancies may have a stronger direct influence. And when sufficient experience is gained then self-efficacy can effect the intention variable. Social outcome expectancies (a subset of outcome expectancies) should be considered as a determinant within the motivation phase. Our intentions and actions depend on our desire to maintain or enhance self-esteem or self-consistency within normative reference groups and from a social support perspective which suggests that people draw on their social networks and resources when making decisions. A certain amount of threat/risk perception helps to stimulate outcome expectancies which further stimulate self-efficacy.

Although intentions are influenced by the socio-cognitive constructs, behavioural intentions are far from being sufficient to initiate a difficult action. The volitional phase consists of the postintentional and preactional stage. The authors explain this phase via the transtheoretical model (TTM) wherein, the *preparation stage* reflects a postintentional preactional state. In HAPA an individual at this stage prepares to carry out the intended behaviour by imagining scenarios of how and under what circumstances, they could perform the action -'action plans'. Here self-efficacy plays an important role as individuals rely more or less on optimistic self-efficacy beliefs when facing self-imposed challenges. So when the individual carries out the action then that represents a successful outcome of cognitive activities in the *planning* and *preparation* stage.

Once action is initiated, it needs to be controlled by cognitions in order to be maintained. Action has to be protected from being interrupted and abandoned prematurely due to incompatible competing intentions which may become dominant when carrying out behaviour. Self-efficacy will determine the amount of effort invested in perseverance (e.g. self doubt – chance of failure, optimistic self-efficacy – chance to succeed). Self-efficacy helps to re-establish (through action plans and goals) the perseverant efforts needed for the accomplishment of self-imposed goals. All this depends on the evaluation of the success or failure and attributes the perceived outcome to possible causes. Depending on this cognitive event, emotions and expectancies are varied and volitions strength may be increased or decreased for subsequent similar actions. Situational barriers play a part here too – influenced by perceived and actual environment.

Table 2.4 Summary of factors that influenced participation, mainly attendance in ongoing SM services

Study (year); theoretical model, n=4	Factors
(g) Gucciardi (2009); Andersen's socio-behavioural model	Contextual factors; Enabling factors; Predisposing factors
(h) Sniehotta (2010); Self-Regulation model and Theory of Planned Behaviour and action planning	Intention; Action planning
(i) Dohnke (2010); Health Action Process Approach	Motivation; Intention
(j) Pentecost (2011); Conceptual model of exercise uptake	Exercise identity; Availability of support; and Perceived benefits of attending

(g)

Gucciardi et al[167] utilised Andersen's *socio-behavioural model* (Box 2.2) to identify factors that influenced the ongoing utilisation of diabetes self-management education services (DSME) (comprised diabetes counselling or educational classes) over a one year period. The study rationale was that these services undergo high attrition rates and evidence suggested that those who dropout prematurely adhere less to SM activities and have worse glycaemic control.

The following factors influenced the ongoing utilisation of DSME services:

Contextual factors or health system characteristics such as the referral source to the diabetes management centre (DMC), which was an important predictor of DSME utilisation. Self-referrals were higher than primary care referrals perhaps because these patients were highly motivated and more proactive in seeking DSME support; different delivery methods adopted by the participating DMC might have influenced greater utilisation from Centre 2 in comparison to Centre 1. (DMC 2 delivered SM education more frequently, classes were less intensive and included options on delivery of interest-specific modules to patients which may have led to further patient participation in centre 2.)

Enabling factors such as employment status enabled DSME utilisation and patients were less likely to attend the DMC which had highly structured or inflexible interventions.

Within predisposing characteristics, men were less likely to utilise DSME than women. Patients who smoked were less likely to follow up DSME services. Perception of health status also influenced utilisation of DSME services - high BMI scores led to decrease in mean

number of contacts, possibly due to embarrassment. Utilisation was not associated with HbA1c values. Furthermore, recently diagnosed patients had lower usage of DSME services than those living longer with diabetes - one explanation was perhaps these patients experienced fewer symptoms and complications and did not realise the preventive benefit of DSME.

(h)

Sniehotta et al[170] tested, compared, and combined the *SRM* and the *TPB* with *action planning* (Box 2.3) to predict physical activity during phase III cardiac rehabilitation (CR) and attendance in phase IV CR amongst coronary heart disease (CHD) patients. Phase III CR, in the UK, is a hospital-based structured exercise programme and includes provision of education and psychosocial support; Phase IV CR is a recommended community-based programme to promote long term adherence to physical activity and a beneficial lifestyle. This phase IV CR public health service sat outside of the NHS.

The results of this study are presented only with respect to factors influencing attendance and **not** levels of physical activity. After measuring participants' illness perceptions with regard to their 'heart condition', predictors of behaviour (intention and PBC) regarding 'attending phase IV CR', and action planning items, the results suggested that intention and action planning (i.e. when and where to attend the programme whilst in the last week of phase III CR) were strong predictors of phase IV CR uptake and illness perceptions were not.

(i)

A German study by Dohnke[171] utilised the *HAPA* to identify factors that influenced participation in phase III CR six months after participation in phase II CR (an inpatient programme).

The study participants in the 'motivational phase' were labelled 'non-intenders'; and those in the 'volitional phase', in the 'preactional' stage, – were labelled 'intenders' and those at the 'actional' stage – were labelled as 'actors'.

In phase III CR 31% participated ('actors'). Amongst non-participants, 13% were 'intenders' and 56% were 'non-intenders'. Patients who 'intended' to participate expected more positive consequences and reported higher self-efficacy in comparison to 'non-intenders'. However, risk perception and negative outcome expectancies did not differ significantly between 'intenders' and 'non-intenders'. An explanation given was that negative behavioural

consequences seemed to be a characteristic of the mindset of 'non-intenders' and 'intenders' and a decrease in negative outcome expectancy characterises the mindset of 'actors'. Thus, expecting negative consequences as a result of participation in phase III CR prevented 'intenders' translation of their intentions into action. Regarding risk perception, the authors suggested that risk perceptions should still be considered as a factor that influences motivation because all patients were well informed about any personal risks after phase II CR.

Amongst 'actors' and 'intenders', 'actors' reported higher *self-efficacy* and expected more *positive outcomes* in comparison to 'intenders'. The cognitive constructs amongst 'non-intenders', 'intenders' and 'actors' differed significantly and above age, gender and eligibility of phase II CR which confirmed the independent influence of these factors.

Regarding dropping out of the phase III CR programme at 12 months follow up, 21% of participants were programme dropouts in comparison to maintainers (79%). Dropouts had lower intention and 'maintenance self-efficacy' which were reported as the strongest predictors of dropout. They also appeared to have lower 'recovery self-efficacy'. Dropouts from phase III increased with decrease in 'actors' intention and maintenance self-efficacy. One reason given was that a new behaviour cannot be maintained with strong intention alone. Here self-regulatory skills and strategies to cope with barriers might occur after adopting the new behaviour which is reflected by maintenance self-efficacy. Recovery self-efficacy was not predictive. Both constructs of self-efficacy were considered important by the study because these constructs support the stage-specific differentiation (mindsets) whereby recovery self-efficacy may reflect the confidence an individual has in strategies for readopting phase III CR after a break and not in maintaining exercise. In addition, volitional factors such as intention and maintenance self-efficacy differed between 'actors' and those 'actors' who did and did not drop out of the programme.

(j)

In a qualitative study, Pentecost[172] developed a new ***conceptual model of exercise uptake and adherence*** from exploring factors that influenced participation in community-based exercise programmes amongst patients with chronic disease. These exercise programmes were funded by the UK primary care trusts (PCTs) to increase physical activity for the prevention and treatment of chronic disease and included exercise-on-referral services, a pulmonary rehabilitation service, community venues with local authority facilities and PCT

subsidized exercise classes. The study explored patients' views based on different attendance levels: non-attendance; low attendance (those who did not attend the programme following assessment or dropped out of the exercise programme); and high attendance (those who completed the programme as per the criteria of the programme and who were continuing with exercise post programme).

The core categories of the model comprised of 'exercise identity', 'benefits of attending' and 'support' (Figure 2.7).

Figure 2.7 A new model of exercise uptake and adherence for people with chronic conditions
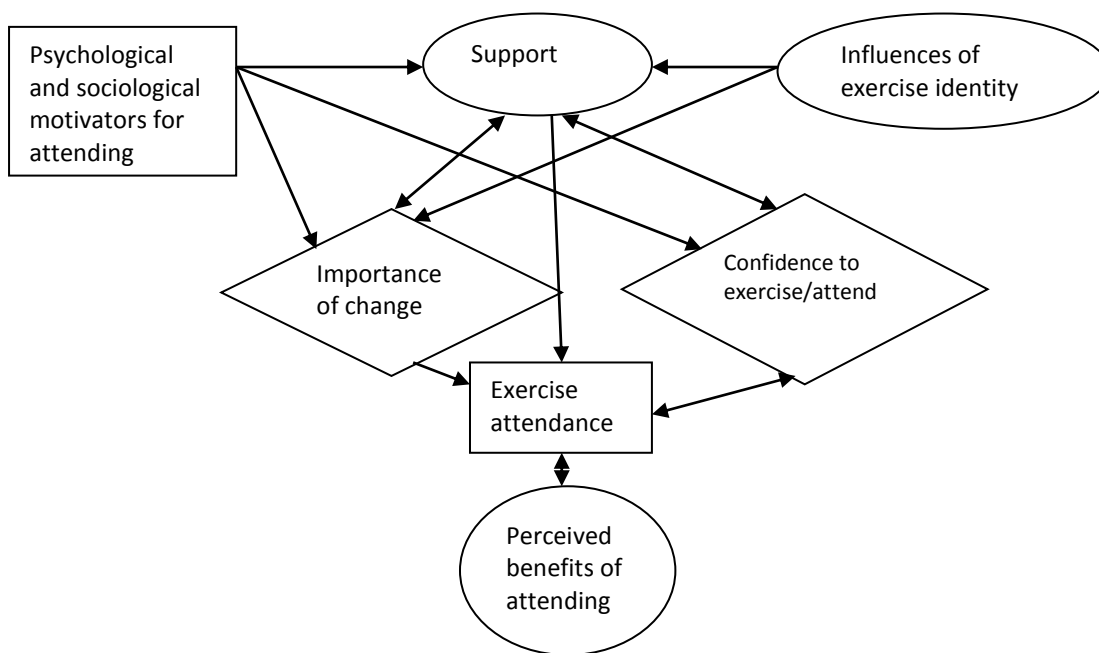
Source: Pentecost 2011

Exercise identity was the way an individual described themselves in relation to exercise or physical activity and how this description influenced exercise behaviour. The major influences on exercise identity were social and cultural norms which were dependent upon: age – expectations of physical ability, when comparing themselves to younger people, influenced exercise behaviour; gender – men who wanted to see themselves as sporty and women who wanted to see improvement in health attended to exercise; and cultural identities – such as nurturing activities (e.g. finding time to exercise when experiencing family time-related pressures), and body shape e.g. big body shape was considered normal in some ethnic groups. These latter social and cultural norms impacted upon expectations of appropriateness and influenced importance of exercising and confidence to exercise. However confidence and

importance independently impacted on willingness to overcome pre-existing social or cultural identities in order to exercise.

Perceived benefits of attending specifically, positive social or psychological benefits were more important than physiological benefits for high attenders. The social benefits comprised comparison with others (how others were coping with the condition) and put their problems in perspective, and group or peer support (perceiving everyone was similar, was like a club). These social benefits had psychological benefits including increased confidence to exercise and increased optimism about the future. In addition, attendance was important to people who believed their discomfort could be reduced, feeling low or loneliness could be abated (referred to psychological and sociological motivators)

Support was associated with both uptake and adherence and was a key factor in overcoming negative exercise identities, increasing confidence and importance to exercise and impacted upon perceived benefits of attending and benefits of uptake.

So, non-attendance occurred when importance or confidence to exercise was low in association with lack of support.

The factors associated with attendance were presence of psychological and social motivators for attending, availability of support and overcoming negative exercise identities through support.

Low attendance was a result of low levels of support and lack of perceived benefits.

Adherence or high attendance or completion was most strongly associated with the perceived benefits of attending and support.

2.3.2.3 Theoretical factors that may predict or influence attendance in self-management interventions or in studies of self-management interventions

Among the 25 included studies, 15 studies (Table 2.2), described below, predicted, described or explained attendance and/or non-attendance, including dropout behaviour, in SM interventions via the following five health behaviour theories: the Self-Regulation Model (SRM), the Necessity-Concerns Framework (NCF), the Theory of Planned Behaviour (TPB), the Attitude-Social Influence-Self efficacy (ASE) model or the Stage of Change (SoC) model. The aim of these studies was to understand these behaviours and target the cognitions of patients with chronic disease to help improve the uptake of the intervention

Box 2.4 except the TPB (described in Box 2.3) briefly describes the four remaining theories. Table 2.5 presents a summary of the theoretical constructs that explained patient attendance and/or non-attendance behaviour.

Box 2.4 Brief description of the Necessity-Concerns Framework, the Attitude-Social Influence-Self-efficacy model and the Stage of Change theory

The Necessity-Concerns Framework (NCF)

Horne[9] suggested that to understand adherence, more importance should be given to an individual's treatment perceptions. Horne explained treatment adherence via the Necessity-Concerns framework (NCF) which are essentially summative evaluations (about potential benefits and costs about a treatment where, one aspect is perceptions of *necessity* or personal need for the treatment and *concerns* about the negative effects. These two categories were commonly reported from exploration of beliefs about medicines. Studies had demonstrated that medication beliefs were stronger predictors of adherence in comparison to clinical and demographic variables. Adherence was positively correlated with *necessity* beliefs and negatively correlated with *concerns*. Horne confirmed that an individual's judgement about their personal need for the treatment relative to their concerns would have a greater influence on uptake of treatment and adherence than considering these beliefs in isolation. Hence treatment adherence was related to the NCF and it was suggested that these conclusions could extend towards other treatments e.g. rehabilitation.

Horne believed there was a symbiotic relationship between the NCF and the CS-SRM whereby the CS-SRM helps to understand how treatment perceptions influence adherence; furthermore, perceptions of treatment necessity and concerns in relation to illness beliefs and treatment perceptions can be used to extend the explanatory power of the CS-SRM in relation to treatment adherence.

The Attitude-Social influence-Self-efficacy (ASE) model

According to de Vries[14] an individual's health behaviour was explained mostly from *attitude* and *social influence* socio-cognitive variables. de Vries wanted to show that a third cognitive factor, *personal efficacy expectations* or *self-efficacy* was also a relevant variable in explaining behaviour. de Vries first described 'attitude' and 'social influences' from the Fishbein-Ajzen model[12], *Attitude* is determined by: (i) the expectation of various consequences and beliefs about the behaviour, and (ii) the corresponding evaluations of these consequences; *Subjective norms* consist of: (i) the expectation of other important persons opinions, normative beliefs, and (ii) the degree to which an individual is inclined to agree with these opinions, their motivations to comply.

Following on, de Vries adopted self-efficacy from Bandura's (1977) social learning theory, behaviour and behavioural change depend on both *outcome expectations* and *personal efficacy expectations*. *Outcome expectations* consist of beliefs about whether a particular behaviour will lead to particular consequences. de Vries explained that *outcome expectations* match closely with Fishbein-and Ajzen's conception of beliefs regarding the 'attitude' variable. *Self-efficacy* refers to a person's expectation regarding his capability to realise a (desired) behaviour. It does not reflect a person's skills but rather one's judgements of what one can do with whatever skills one possesses. Hence self-efficacy is related to beliefs about capabilities of performing specific behaviours in specific situations.

Based on the above, de Vries proposed the ASE model to explain behavioural intentions and behaviour. He suggested that when someone intends to perform a particular behaviour, it is determined by personal conceptions concerning the behaviour (*attitude*), the social pressures experienced from other important persons (*subjective norms*) and personal expectations about the *skills* needed to realise the behaviour (*self-efficacy*). These three variables are proximal social cognitive factors and together they result in the intention to perform the behaviour (Figure 2.8).

Figure 2.8 The Attitude-Social influence-Self-efficacy model
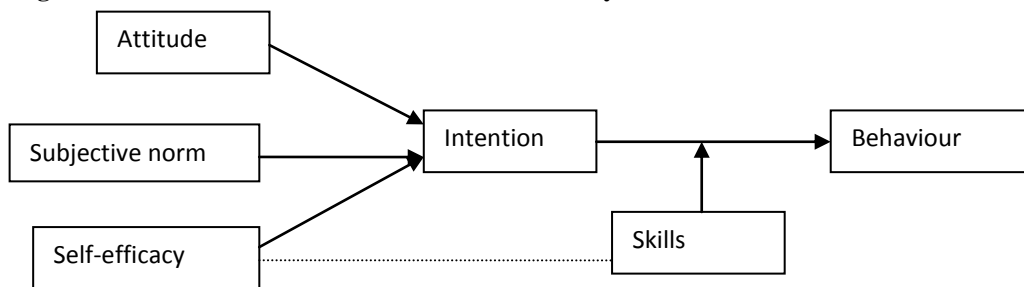
The Stages of Change (SoC) theory
The Trans-theoretical model (TTM) was developed by Prochaska, DiClemente and Norcross in 1992.[6] [11] In this model, behaviour change is conceptualised as a process that takes place over time and involves progression through five stages which explain *when* a particular shift in attitudes, intentions and behaviours occur. The steps are supposed to be sequential but are cyclical and recycled before an individual obtains the desired behaviour change. The five *stages of change* are: *Precontemplation* – there is no intention to change behaviour in the foreseeable future; *Contemplation* – patients are aware that a problem exists and are thinking about overcoming it but have not made a commitment to act; *Preparation* – individuals are intending to take action in the next month and have started to make some small changes; *Action* – individuals modify their behaviour, experiences and/or environment to overcome their problems (time period for an individual to be considered in the action stage is from one day to six months); and *Maintenance* – individuals work to prevent relapse and consolidate the gains achieved in the action stage (extends from 6 months to an indeterminate period past the initial action).

Table 2.5 Summary of factors that might influence/influenced attendance and/or non-attendance behaviour

Study (year); use of theoretical model, n=15	Factors
During hospital admission	
(k) Petrie (1996); SRM	Controllability/Curability
(l) Cooper (1999); SRM and TPB	Controllability; Cause associated with lifestyle; Intention
(m) Wyer (2001); SRM and TPB	Controllability; Cause; Attitude; Subjective norm
(n) French (2005); SRM	No influence of theory
(o) French (2006); SRM	Controllability/Curability
(p) Cooper (2007); NCF	Perceived necessity; Perceived concerns
Following hospital discharge prior to programme attendance	
(q) Whitmarsh (2003); SRM	Identity; Consequences; Cause; Emotional representations
(r) Cooper (2005); NCF	Cause; Perceived necessity
Following attendance and/or non-attendance in programme	
(s) Blair (2013); SRM	Cause
(t) Wyer (2001); SRM and TPB	Cause; Consequences; Controllability/Curability
Descriptive study	
(u) Keib (2010); SRM and SRM-NCF	Identity; Timeline; Consequence; Cause; Controllability; Intervention representation; Perceived necessity; Perceived concerns
(v) Helitzer (2007); Stage of Change (SoC)	Action stage
(w) Toth-Capelli (2012); SoC	No influence of theory.
(x) O'Brien (2009); SoC and optimism	Action; Maintenance stage
(y) Lemaigre (2005); ASE	Attitude; Social influence; Self-efficacy (external barriers)

Out of the 15 studies, 11 studies had either utilised the SRM or in combination with the NCF or in combination with another theory, the TPB to explain attendance and/or non-attendance in CR amongst patients with CHD at different points in the illness journey either prospectively or retrospectively. Among these 11 studies, the attendance or non-attendance

behaviour was explained in six studies among hospitalised patients; in two studies among patients following hospital discharge but prior to their programme attendance; in two studies among patients following their attendance or non-attendance in the programme; and one study described the process of attendance and non-attendance. The patient perceptions were assessed by the studies through use of the Illness Perception Questionnaire (IPQ)[203] or the Revised Illness Perception Questionnaire (IPQ-R)[13] and the CR questionnaire.[180]

Three out of the 15 studies utilised the SoC theory to predict attendance and dropout behaviour in CR, in diabetes SM or a weight management intervention

One study out the 15 utilised the ASE model to study intention to participate in an asthma SM programme.

Patients' perceptions assessed during hospital admission:

   (k)

In one of the earlier studies Petrie[173] utilised the IPQ to assess patients' illness beliefs. The results indicated that patients, admitted with a first myocardial infarction (MI), with stronger beliefs about 'controllability/curability' were more likely to attend an outpatient CR programme.

   (l)

Cooper et al[174] utilised the IPQ amongst hospitalised patients who had suffered an acute MI or those who had undergone coronary artery bypass graft (CABG) surgery to predict CR attendance and an additional question on 'intention' to attend (a feature of the *TPB*) CR was also posed. Of recruited patients, only 40% "had actually attended CR". The study suggested that patients' illness beliefs were not influenced by them undergoing CABG surgery or having a MI, but their beliefs were already established by having CHD over a number of years, and by gaining knowledge of the condition from the prevalence of CHD in society. It was suggested that patients may have also drawn beliefs from media coverage and the experiences of friends and colleagues and these beliefs may have remained fairly stable over the varying course of their own illness. However, the study did show that certain illness perceptions measured during hospital admissions were associated with future CR attendance; patients with stronger beliefs that their condition was controllable and those who attributed the condition to their lifestyle 'cause' showed higher attendance in CR, suggesting that this causal belief was associated with a commitment to change behaviour. Patients' knowledge of

the risk factor cholesterol was associated with attendance while their knowledge of blood pressure was not, perhaps because people perceived they had more control over their cholesterol owing to dietary changes than over their blood pressure. As patients in the study were first time acute MI patients under 65 years of age, they perceived their condition was controllable or curable and hence they were more likely to attend CR.

Although 40% of patients actually attended CR, 72% had expressed an intention to attend CR and the intention to attend rate in those actually attending CR was over 90% in comparison to 58% amongst those not who did not attend. This suggested that intention to attend was a useful indicator but insufficient to predict future health behaviour.

(m)

Wyer et al[182] had conducted a literature review to identify factors that influenced CR attendance, via the **SRM** and the **TPB**, with the aim to suggest how participation in CR might be increased. The review included the abovementioned studies by Petrie[173] and Cooper[174] and showed that CR attendance was limited to control/cure and cause variables.

Wyer explained that those who attended CR believed strongly their friend/family and HCP wanted them to attend the programme (subjective norm), they perceived fewer barriers to attending (PBC) and perceived CR was beneficial to their health (attitude). Attenders were also confident that the programme would help them to initiate a healthy lifestyle and adhere to medications and they perceived that the programme might help to prevent another heart attack (attitude).

(n)

A study by French[176] prospectively assessed illness perceptions of patients with MI in hospital and assessed outpatient CR attendance and health-related quality of life at six months follow up. Although one session of the programme was attended by 45% of the patients, unlike the previous studies, attendance was *not* related to any of the illness perceptions.

(o)

Due to the inconsistent results reported in the above studies, French[177] conducted a systematic review and meta-analysis which investigated whether illness perceptions predict CR attendance, and which specific perceptions were most strongly related to CR attendance amongst patients admitted with acute myocardial infarction (AMI). The review (comprising

11 studies including the three studies mentioned above) concluded that AMI patients with positive 'identity', 'cure/control', 'consequences' and 'coherence' beliefs were more likely to attend CR. Specifically, the cure/control beliefs were the strongest predictors where the patients believed their condition was curable and controllable they were more likely to attend CR.

Regarding disease identity, the perceived symptoms associated with the condition, rather than severity of the condition determined CR attendance.

Regarding coherence beliefs, where the condition did not make sense to the patient then they were less likely to attend CR. The lack of understanding about the nature of AMI, or the underlying disease process which caused the AMI, resulted in patients not seeing the importance or relevance of behavioural interventions such as CR.

In addition, if patients' perceived their condition was a result of a one-off stressful event (cause) rather than a result of an atherosclerotic plaque, then they might not have understood why they were being asked to exercise and/or change their diet.

(p)

Cooper et al[180] assessed the perceptions of AMI patients admitted in hospital via a questionnaire about CR based on the **NCF** alongside assessment of their illness perceptions to predict attendance. The results demonstrated that attenders were more likely to believe that CR was 'necessary' and understood its role; patients who felt CR was more 'suitable' for younger, active patients were less likely to attend CR, and there was some suggestion that patients who were 'concerned' about exercise, or who reported 'practical barriers' to attending CR, were less likely to attend.

Patients' perceptions assessed following hospital discharge but prior to their programme attendance:

(q)

Whitmarsh et al,[175] in a cross-sectional study assessed illness perceptions of CHD patients who were discharged from hospital before attendance in an outpatient CR programme to predict and differentiate between attenders and non-attenders. The results suggested that attenders perceived a greater number of symptoms (identity) and consequences as a result of their illness, experienced greater distress (emotional representation), and attenders had less strong beliefs that their illness was a result of a germ or virus (cause) and as a result, used

problem-focused coping strategies (e.g. actively planning) more frequently. While, non-attenders perceived less severity of symptoms and controllability/curability of illness, and used more maladaptive coping strategies (e.g. denial).

(r)

Cooper's[179] study explored patients' beliefs about the role of CR amongst patients discharged from hospital following a MI but before attendance to CR to understand barriers to CR attendance and explain their findings via the *NCF*. As part of usual care, patients were informed about their disease such as cause of the MI, the content and role of CR was explained following which patients were then invited to attend the programme. The findings suggested that the patients' were unaware of the course content, assumed that CR comprised of only exercise, and did not understand how exercise would help with their recovery (intervention representation). Some patients perceived that exercise would be more suitable for people who were fitter and was not for people who have just had a heart attack. In addition, patients had misconceptions about the cause of MI and lack of cardiac knowledge led some patients to doubt the necessity or appropriateness of the course. Patients did not realise that their heart attack was a result of underlying CHD and could happen at rest; patients perceived their illness was a one-off, discrete event, unconnected to underlying disease and that it could only happen with a trigger e.g. an unstable emotional state. As a result, Cooper suggested that these patients would be less likely to make lifestyle behaviour changes and would not attend CR. Furthermore, patients who were unsure how CR was going to help were more likely to cite transport barriers.

Patients' perceptions assessed following their attendance or non-attendance:

(s)

A recent study[178] assessed CHD patients illness perceptions, via a postal survey, who had been offered CR over two years ago and also explored whether non-modifiable factors, such as socio-demographic and social isolation, influenced attendance at hospital-based/outpatient CR. The results showed that only illness perceptions significantly influenced non-attendance. Non-attenders had higher illness perceptions scores particularly with respect to perceived cause of the illness. These patients did not believe the cause of disease, or risk factors, could be modifiable (smoking behaviour, poor diet, inactivity). Hence these patients might be less likely to attend CR and adopt health-related or lifestyle behaviours.

(t)

In a qualitative study by Wyer[183] patients' perceptions or beliefs were explored amongst CR attenders and non-attenders and the findings were interpreted via the *SRM* and the *TPB*. The results suggested that one difference between attenders and non-attenders was that the majority of attenders held a psychological model of health whereas non-attenders held a medical model of health. This was because attenders and non-attenders differed in their beliefs particularly regarding responsibility for illness (control) and treatment of illness (cure). Attenders saw themselves as being more responsible for their health and wanting to achieve more good health, whereas non-attenders felt that their recovery was the responsibility of professionals and gave medications a lot of importance. Unlike non-attenders, attenders were more likely to attribute their MI to their own lifestyle (cause), viewed their illness as having serious consequences but believed that they could have control over it. Regarding coping strategies, attenders used strategies such as information-seeking which was often seeking help from others, as a coping behaviour, whilst non-attenders seemed more likely to use avoidance strategies, such as denial or minimisation.

Utilisation of the TPB showed that an individual's 'attitude' towards CR and the 'subjective norm' in the form of medical recommendation was important in the decision-making process. In terms of 'attitude', beliefs about outcome were important with those believing that the CR programme was going to improve their health and reduce the chances of recurrence and were more likely to attend. Interesting findings were that few had a proper understanding of the course content, with non-attenders seeming to have poorer understanding. But this could be explained in a way that non-attenders may be rationalising their decision not to attend. In 'subjective norm', referral by a professional had been found to be the single most important motivating factor for both men and women attending CR programme; recommendations from nurses also appeared to have an impact.

On comparison of the findings, the study concluded that attendance could have been a result of an individual giving their illness meaning, who then explored ways of coping (SRM) as a precursor to thinking about CR and whether the programme was recommended (TPB).

A descriptive study explaining patient attendance and non-attendance behaviour

(u)

Keib[181] in their descriptive study explained how illness representations of older adults with CHD in relation to perceptions of the purpose and benefits of intervention representations (CR) via the SRM and the SRM-NCF may influence CR participation behaviour. Understanding participation behaviour in CR in this study was to help guide the development of tailored interventions for the CHD population at risk and to help improve participation rates of CR. According to Keib, patients were less likely to attend CR if an individual interpreted CHD symptoms negatively (disease identity); perceived a CHD event to be an acute event that could be fixed in short term (timeline); perceived CHD did not affect quality of life (consequence); was unaware, or had no knowledge, about the cause of disease (cause); believed that own efforts would not help to control disease or that a recommended treatment might not bring benefits (controllability); with negative perceptions about the exercise component of the programme (intervention representation); perceived CR was not necessary to improve health (necessity); was perhaps more appropriate for younger patients (suitable) and was concerned about the exercise component of the programme including practical concerns to attendance (concerns). Figure 2.9 illustrates CR utilisation using the SRM. Keib's framework below was utilised for the qualitative synthesis in Chapter IV.

Figure 2.9 The SRM of CR utilisation
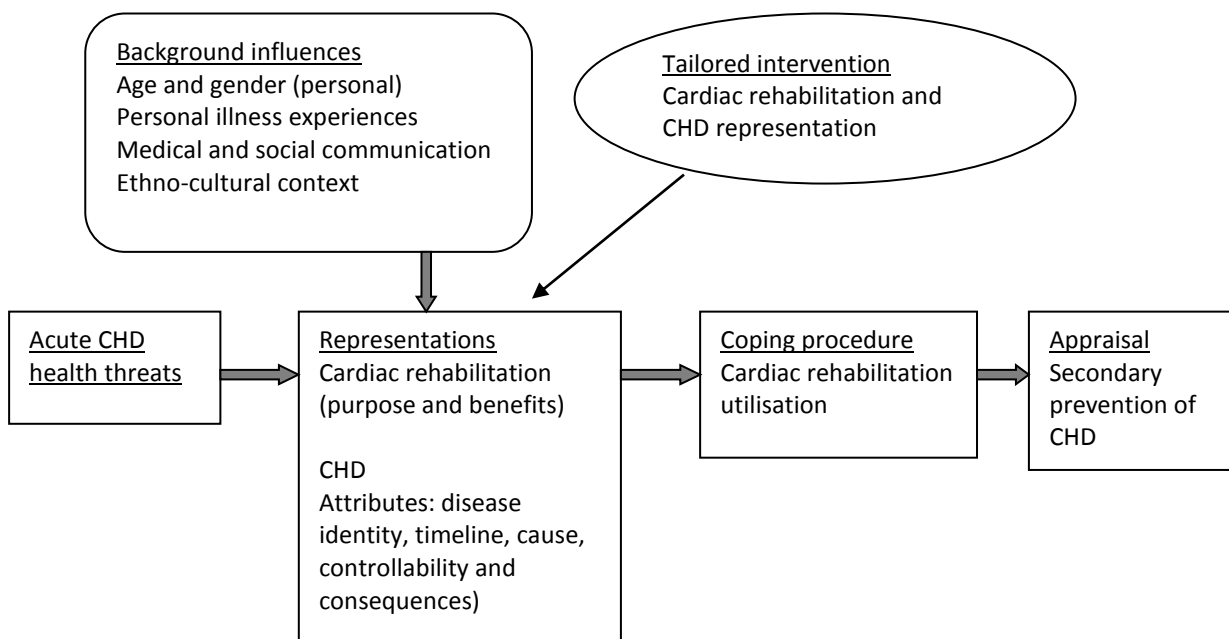
(v)

Helitzer[185] assessed low attendance in a diabetes prevention programme and the study concluded that the *SoC* model may be a good predictor of attendance (there was a relationship between high attendance and being in 'action' stages of change for individual diabetes preventive behaviours e.g. eating healthily), but further research was needed.

(w)

Toth-Capelli[186] assessed dropout behaviour of obese patients in a weight management programme but found the SoC model could not predict dropout behaviour.

(x)

O'Brien[187] utilised the *SoC* model and dispositional 'optimism' to explain attendance in phase III CR programme (supervised exercise delivery in a hospital setting) amongst patients with CHD who had attended the programme. The findings suggested that patients who were in the action and 'maintenance' stages were more likely to adhere to the programme. Non-adherers were pessimists who believed that, regardless of what they did, the outcome would be the same and hence they reduced their efforts and quit.

(y)

Lemaigre[184] had utilised the *ASE* model to predict intention to participate in an asthma SM programme by means of a structured interview amongst patients with asthma but with no prior experience of participation in an asthma SM programme. The structured interview was based on the proximal socio-cognitive factors of the original ASE model and was piloted to identify patients' beliefs about the asthma SM programme via open-ended questions. The questions addressed the possible advantages of, and barriers to, participating. Following the pilot, the answers were used to draft a final structured interview which was administered to study participants. The questions assessed the patient's 'attitude' toward the programme in terms of personal benefits, assessed beliefs about barriers to participate – set up as a 'self-efficacy' measure and assessed 'social influence'. The questionnaire also included patient characteristics and health outcome measures (referred to as distal factors that can also explain behavioural intention).

The significant predictors of intention behaviour were educational level (high), perceiving personal benefits (having a more positive attitude), self-efficacy (having fewer barriers to

participate – having higher self-efficacy expectations)[3] and social influence (higher influence for better self-care). Figure 2.10 illustrates the factors that explained intention to participate in an asthma SM programme. Lemaigre's framework below was also utilised for the qualitative synthesis in Chapter IV.

Figure 2.10 The ASE framework
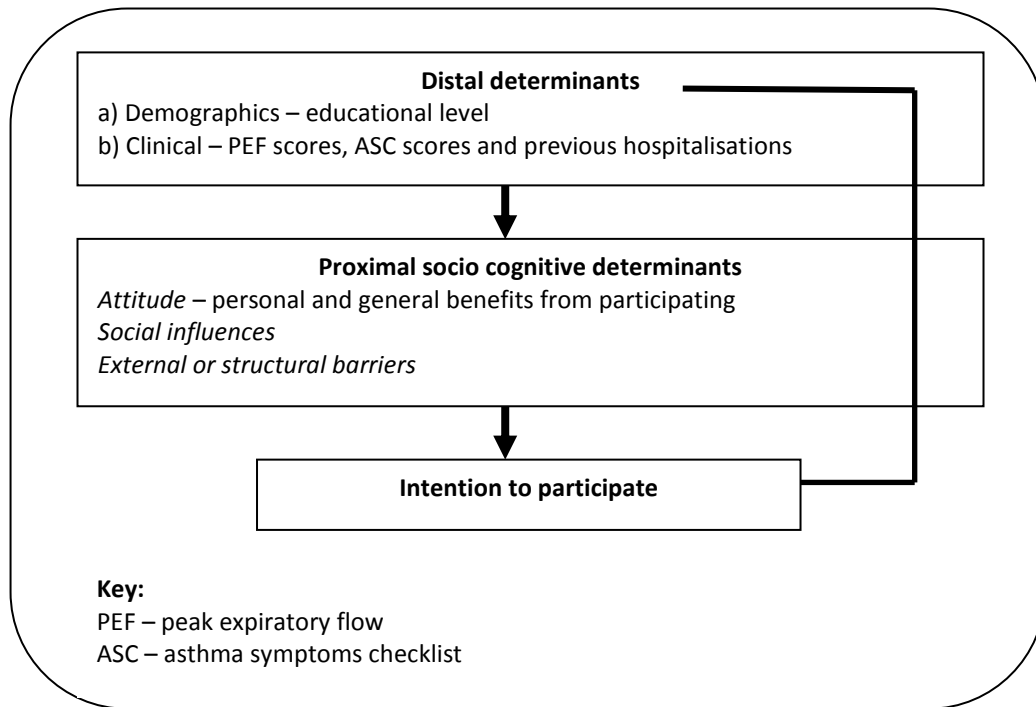
Based on the preceding work, Figure 2.11 summarises the social/psychological/behavioural factors that may influence health care utilisation and participation in SM interventions amongst patients with chronic disease.

Figure 2.11 Illustration of socio-behavioural, interpersonal and psychological factors that may influence participation in health care and health care/ self-management interventions among patients with chronic disease

Participation in health care for a patient with chronic disease is

Factors that may influence help-seeking behaviour

2.3.2.1 Help-seeking professional care or utilising health services optimally

Increase in use due to perceived worsening of health status/*perceived need*; non-White (*pre-disposing*); lack of support (*enabling*); problems accessing primary care (*contextual factors*)

Increase in use by people with a *preoccupied attachment style* plus clinical factors such as, depression and catastrophisizing

For management of illness particularly, *symptom management*

Factors that may influence utilisation of ongoing self-management services

2.3.2.2 Utilising ongoing public health services/self-management services for health maintenance and adherence of self-management behaviours

Non-participation due to lack of *perceived severity of the condition*; amongst male smokers (*predisposing);* people in employment (*enabling factors);* not referred by primary care (*Contextual factors)*

Person's *intention;* and *action planning e.g. when and where to attend the programme* prior to attending the programme influence attendance

Motivation, intention formation influenced by *positive consequences,* higher *self-efficacy and* high *risk perception*

A person's *exercise identity* influenced *importance of exercising and confidence to exercise; availability of support and perceived benefits* influenced attendance

Factors that may influence attendance in self-management interventions

2.3.2.3 Attending self-management interventions to learn skills to better self-manage condition includes use of health services optimally & communicate effectively with clinicians

With no prior experience of intervention

Attitude e.g. perceived personal benefit; *Subjective norm* e.g. perceived social influence to attend and fewer *external barriers* would influence desire/intention to participate

1) While hospital admission

2) Following discharge prior to programme

3) Post-offer and post programme attendance

Increased *perceived cure/controllability;* or *perceived necessity* influence attendance

Positive *Attitude* e.g. believe programme would benefit; *Subjective Norm* e.g. believe family /professional wanted patient to attend; and *Perceived behavioural control* e.g. perceives fewer barriers *to attending all more likely to attend programme*

Perceived greater number of symptoms *(Identity)* and *consequences from illness influenced attendance*

Non-attenders did not understand the *Cause* of illness *and perceived the programme as unnecessary*

Perception of cause of illness as modifiable influenced attendance and non-attendance; *Perceived personal controllability* of condition influenced attendance

Attitude e.g. believed that programme would help; *Subjective norm* e.g. programme was recommended by professional more likely to attend

Being in *action stage* may influence attendance

2.4 Discussion

The aim of this review was to present the meanings, concepts and definitions of patient participation in health care and identify factors, using theory, that influence health care seeking behaviour and participation in SM interventions amongst patients with chronic conditions. The scope of this review, unlike a conventional systematic review, was to identify key papers from various sources to understand the various meanings given to the concept 'patient participation' in health care; to differentiate, where possible, between 'patient participation' and the many interchangeable terms often used in the literature e.g. 'patient involvement'; and, to review various theoretical or conceptual frameworks that have explained patient participation in health care and SM interventions. This section compares the findings of the review between the included studies and with other literature.

2.4.1 Conceptual confusion

2.4.1.1 What is the meaning of 'patient participation' in health care?

Comparison among the included studies of the review

The emphasis placed by governments on patient involvement in their health and health care led several studies to explore and examine the various meanings and definitions given to the term 'patient participation' in health care.

The dictionary definition of 'participation' and 'non-participation' were in line with the definitions given in the glossary of the thesis. In addition, this conceptual review took account of all the varied definitions that were presented in the included literature and regardless of the type of approach, or philosophy or perspective underlying the definition of patient participation, the various definitions could be assembled into a broad patient/individual context and a patient-professional context. In addition, the distinction and relationship between 'patient participation' and its synonymous terms was also deduced in this review (Figure 2.3).

The findings of this review (the numerous patient participation definitions), supports the contention in previous reviews[135,138] examining the meaning of patient participation in health care, that there are indeed, many functions that are associated with the term 'patient participation'. However, instead of seeing the functions as distinct entities which as the previous studies[135,138] had done, this review has helped in understanding that patient

participation/active patient participation for patients, particularly those with chronic disease, is about taking responsibility for their health themselves, individually and within a clinical setting, through patient engagement, patient-centred care, patient partnership, and shared decision-making. The aim is to help patients participate in and take responsibility for, their health and their use of health care.

Specifically, within an individual context, the meaning of the term 'patient participation' was about an individual 'actively' making decisions about their health and health care; performing self-care tasks; and taking responsibility. Patients who participate in care were labelled as 'engaged' or 'active' which meant they asked questions, sought explanations, stated preferences, and expected to be heard.

Within the patient-professional context, the definitions of 'patient participation' included a role for both patients and professionals. The role of patient was similar to that mentioned in the individual context above while, the role of the professional was to involve negotiation, identify from patients what they want and need. Within this context, the patient had to be involved in decision making, and the outcome of the interaction was that the patient would accept responsibility with the help of the professional - thus the label given here to a patient was 'co-producer'. The setting included transfer of control from professional to patient, an established relationship and active mutual engagement between patient and professional.

Furthermore, the various synonymous terms for 'patient participation' can be included into 'patient participation': 'patient partnership' or 'patient collaboration' denotes the working together of patient and professional; 'patient-centred care' denotes encouraging patients to participate as a partner in their care, or to be active; 'shared decision-making' denotes the dialogue decisions that are co-determined/co-produced by patient and professional; and 'patient engagement' denotes negotiated empowerment. And within policy documents patient participation is 'patient involvement' in health and health care.

Comparison with other literature

Within studies that have examined or included the meaning of patient participation in health care, the role of actively participating in health and health care was largely attributed to patients with chronic disease[81] as they have more responsibility compared to those who suffer with acute conditions[204] and participation was seen necessary for management of the chronic illness.[135] The sick role – that includes 'the person exempt from normal role', 'the person is

not responsible for his/her condition' was not considered appropriate for patients with chronic disease.[204] Instead, a new role was felt more appropriate, the 'impaired role' where 'the individual with chronic illness does not give up normal role responsibilities but is expected to maintain normal role behaviour within the limits of the illness, the individual does not have to 'want to get well' but is encouraged to make the most of the remaining capabilities".

One health policy initiative[153] to encourage patients to participate in their care was through delivery of the EPP – to give people the skills and learning to promote self-care/self-management, a concept taken from the self-care movement of the 1960s and 1970s. However, sociologists believe that delivery of the EPP is no longer about what patients should do to manage their health but, that patients should become, 'empowered', 'activated' and 'expert'[157] and that if patients with chronic disease do not adopt this role then they are considered deviant or inconsistent with their medical condition[204] or shifting away from responsibility.[55]

However, the review highlighted the fact that not all patients with chronic illness want to participate in their care, including participating in health care/self-management interventions and this has been acknowledged elsewhere.[159,204] In addition, participation may change with time and across different phases of the disease and treatment e.g. patients with chronic disease in one study[188] did not want to participate in care while receiving care in an emergency department but expected to participate in their care at outpatients. In another study[135] chronic disease patients did not want to get involved in decisions and were confident in the care and treatment they received from professionals.

Within a patient-professional setting, two studies[136,148] found that patient participation was not static, but a dynamic process due to the influence of multiple patient, professional and contextual factors. Haidet[136] described a hierarchy of decreasing levels of patient participation comprising: negotiated empowerment which denoted 'patient engagement', self-motivated change, adherence, unguided searching and passivity. The level of participation depended on a patient's perspective of their illness, and the actions taken as a result of the illness including partnership with the professional.

Thompson[148] developed a taxonomy placing patient-determined involvement and professional-determined involvement in parallel (in increasing order 0 to 4) to each other. In

patient-determined involvement, level 3 denoted 'dialogue' while in professional-determined involvement, level 3 denoted 'shared decision-making'. As a result, Thompson called this level 'patient participation' and explained that this level meant that if a patient desired to be involved in decision-making, it would only be possible if a health professional allowed the patient to engage in dialogue, express opinions and make decisions. In addition, the different levels of patient involvement (such as, autonomous decision-making, shared decision-making/participation, information-giving, information-seeking, non-involvement) was dependent upon the nature of health care need, e.g. there was an increased chance of involvement among chronic disease patients because of their longer experience and greater knowledge of the condition, patient characteristics linked with personality factors and a patient-professional relationship characterised by trust. In addition, Protheroe[193] reported that shared decision-making was difficult and this partnership working was mostly seen among young, female, educated patients with higher socio-economic status and similar values as health professionals and this has been reported previously.[194]

Furthermore, Protheroe[205] in another recent study, on exploration of understanding of participation from chronic disease patients of low and high socio-economic status, found that patients from lower socio-economic groups felt they were less able to ask questions to the doctor and if they did it was mainly about medicines, while some thought it was not their role to question the doctor as it could be taken that they do not trust the doctor. The wider proactive questioning about diagnoses and management plans was reported among patients with higher socio-economic groups and understanding in detail about chronic illness and its management positively reinforced engagement with active self-management and shared decision-making.

To understand ones illness and its treatment was the meaning given to 'patient participation' by patients with chronic disease in one of Eldh's studies[188] that went beyond decision-making. In addition, from Eldh's several studies,[188-191] 'patient participation' to a patient living with chronic disease in an outpatient clinical setting meant being confident, being in control, gaining knowledge and being respected. Conversely, non-participation meant not being in control, lack of support from professionals, not having the same information as or not receiving information from professionals, not being respected or

listened to. These meanings could perhaps be viewed as factors that may influence a patient with chronic disease to participate in the consultation with the professional.

Eldh, in one study,[190] also observed the interaction between patients and nurses and reported that the interaction was dominated by nurses and patients just following their initiative. The lack of engagement of professionals as an influence on patient participation has been reported previously.[194,206] One study[194] found that patients were active participants in clinical consultations when professionals frequently engaged in partnership-building (e.g. through use of open-ended questions) and supportive talk (such as encouragement) and so professionals' lack of engagement could affect patient participation in medical consultations.[194] Some patients with chronic disease, e.g. those with lung cancer interacted more with professionals in comparison to patients with systemic lupus erythematosus. Street[194] explained that this could be because patients with lung cancer were fearful and uncertain about their new diagnosis and more time might have been allotted to them than to patients with lupus. The same study reported other contextual factors such as type of practice and medical speciality that could influence active patient participation; in addition, they found white patients initiated more active participation than non-white patients which was explained not owing to demographics but the communicative style of professionals particularly, lack of any encouragement given to non-white patients. This lack of engagement among professionals could either be due to their understanding of patient participation being different to what is expected from their new role; they could feel threatened by their role change i.e. moving from instructing and making decisions to advising, supporting and navigating.[207] Perhaps professionals need further information, education or training in seeking patient preferences for decision-making to encourage patient-centred consultations or patient participation in care.[194,206]

An avenue to help patients participate in their care or to become active, was through the delivery of the EPP/SM programmes for chronic disease; the role of the EPP was to help make more patients with chronic disease become informed about their condition to enable them to become involved in decisions about their care, to help them better communicate their needs to professionals by working with them and take better control of their lives.[153] However, the problem of poor participation reported in studies of the EPP including a COPD-specific programme[85,208] led this review to explore the next question (see below).

2.4.1.2 Can theory help to explain the factors that influence an individual with chronic disease to seek health care and participate in SM interventions?

The findings showed that a patient with chronic disease to better manage their condition is required to participate or attend SM support interventions to learn skills to better manage their condition, enable better communication with clinicians and use health services optimally; utilise or attend ongoing SM services for maintenance and adherence of SM behaviours which may help optimal use of health services; and utilise health services optimally. These forms of participation in health care and health care interventions were shown to be influenced or explained, from limited literature, by socio-behavioural, inter-personal and psychological/behavioural factors (Figure 2.11).

Only psychological or health behavioural theories were used to predict or explain attendance, non-attendance in SM interventions possibly because performing self-management has been seen as the responsibility of the individual with chronic disease. Attendance at SM interventions was mostly influenced by patient perceptions of their illness (via the SRM), the intervention (via the SRM-NCF) and beliefs about intervention attendance (via the TPB, ASE). Specifically, patients who chose to attend or attended SM interventions was owing to changes in their illness ('health threat') whereby they perceived greater number of symptoms associated with the illness, perceived greater consequences as a result of the illness, perceived cause of illness was modifiable,[175,182] perceived controllability of their condition[173,174,177,182] and perceived the intervention was necessary[180] for health improvements. In addition, patients who attended SM interventions also believed that attending the intervention would produce health benefits, believed that family, friends or health professionals wanted them to attend the intervention and perception of fewer barriers to attending.[182,183] In contrast, patients were less likely to attend SM interventions if they perceived the intervention to be 'unnecessary' which could be because patient might not know what the intervention involved or how it could benefit them or patient might lack understanding about their illness.[179]

These findings suggested that a patient *taking part* in this aspect of health care is as complex as a patient adopting or maintaining health-related/SM behaviours. A study,[209] in the context of health care use, used the 'illness behaviour' sociological perspective and reported that perception of illness is the first step to behaviour which could influence help seeking

behaviour e.g. asking for help, going to the doctor and that the interaction between perception and behaviour is a continuous process. Based on the behavioural findings above, one can also say that perceptions of illness and, indeed treatment can influence patient participation or patient attendance behaviour in SM interventions and an individual's evaluation of attendance at the intervention feeds back into the perceptions which can further influence continuation or discontinuation of the behaviour.

Other behavioural and several non-behavioural or external factors have also been reported by several studies to influence patient attendance or participation in SM interventions. They were: communication and sharing concerns with others with the same condition, lack of information or receiving contradictory information;[210] cost, transport to venues, and low self-confidence in attending group meetings in an unfamiliar environment;[54] time availability to attend;[211] patients with multimorbidities having higher physical function, primary care providers being *less* supportive of patient activation[212] or patients' needs, not being met by traditional services.[166]

In comparison, illness or intervention perceptions did not explain patient attendance in ongoing SM services.[170] This could be because the illness was no longer perceived as a threat, the condition was stable or that perceptions may change over time.[170] The adoption or maintenance of lifestyle-related health behaviours, including symptom management, in chronic disease involves complex behaviours and long term behaviour change is required in comparison to a person attending for comparatively simple one-off activities such as screening or immunisation.[213] Thus, the maintenance of lifestyle-related health behaviours requires an individual to be more motivated[204] and perhaps this explains the use of socio-behavioural and psychological theories by studies to understand participation in ongoing SM services. One study[172] also explained patient attendance in ongoing exercise maintenance programmes via a conceptual model.

Attendance in SM services was explained by a patient's intention to attend the service (via the TPB) and action planning. Previously, a person's 'intention' has been reported as a useful indictor, but not a useful predictor, of future health behaviour.[144,174] Action planning (facilitating the when and where), a bridge to close the 'intention-behaviour gap', independently predicted attendance and was reported to be a simple and promising strategy to increase uptake of the service.[170] Action planning is one of the core SM skills that enables

confidence-building in patients which in turn helps with adoption and maintenance of health behaviours.[58] However, patients need to be supported to develop action plans which require the support of professionals including professionals valuing the service enough to recommend it to patients.[170]

Attendance was further explained by the forward and backward working of an individual's mindset where an individual passes through different psychological stages from motivational (non-intentional) to the volitional (intentional to action) phase (via the HAPA). Attenders ('actors') had positive outcomes expectancies, higher self-efficacy and higher risk perception in comparison with 'non-intenders' and 'intenders'. 'Intenders' expected more positive consequences and reported higher self-efficacy in relation to regular attendance in comparison to 'non-intenders'. Dropout behaviour from the SM service was also explained in this review. Dropouts had lower 'maintenance self-efficacy' whereby, individuals dropped out of the service who could not maintain the new behaviour in face of barriers.[171]

Other patient perceptions were identified to influence the uptake of a SM service particularly uptake of an ongoing exercise maintenance programme among patients of ethnic minorities and they were: perceived social and psychological benefits, availability of support, positive exercise identity and perceived importance and confidence to exercise.[172]

Finally, in study by Gucciardi,[167] via the Andersen model, population factors e.g. men who did not smoke, flexible service and contextual factors e.g. self-referrals influenced participation in a SM service and not patient perceptions/behavioural factors. The act of self-referral indicates the active approach to self-management that health professionals and policy makers would like to see. However, self-referred patients may already be good self-managers and may not have much to gain from attending the service diminishing the apparent effects at evaluation. In the same study, non-participation was influenced by the lack of perceived severity of symptoms among patients who were newly diagnosed and they might have not seen the value of the service. Hence, Gucciardi suggested that these patients might need more support and attention to improve their adherence to recommendations of self-care behaviours. From a sociological perspective,[204] the service might not be appropriate for patients if their illness is not limiting; newly diagnosed patients might need more time and support to accept the condition; they might be resistant due to stigma. Another explanation could be that patients may already be self-managing but their method might be different to the

professionals' concept of SM.[55] Patient demographics (e.g. more than 80 years of age, low socio-economic status, less education and recent immigration) and clinical factors (e.g. having mental health conditions or comorbidities) have been reported elsewhere to affect patient participation in ongoing SM services.[214]

In contrast to the above findings, on using the Andersen model, patient perceptions particularly perceived need or increased perceived severity of symptoms was shown to influence health care utilisation among patients with chronic disease particularly unscheduled primary care and secondary care services.[142,168] Outside of this, some population factors[168] also explained health care use e.g. being elderly, non-white, lack of social support.

While, Gately[166] via 'illness work' showed that an individual with chronic disease seeking health care cannot be seen as part of a static framework, the behaviour is a result of ongoing contact of months and years in response to changes within an illness and adaptations that follow to manage the illness and hence health care use might not reduce for patients with chronic disease particularly for those whose needs are being met by the health services.

This patient interaction with professionals over the years via the attachment theory explained that patients with the 'pre-occupied attachment style (persons reliant on others) used health services more[5] irrespective of previous use of SM programmes/services in comparison to patients with the 'fearful attachement style' (persons like to seek care but distrust others) or the 'dismissive attachment style' (self-reliant).[5,215]

Besides explaining patient participation, a few of the included studies that used health behaviour theories,[171,180] highlighted the need for assessment of patient perceptions to help improve uptake of SM interventions and SM services. However, if we want to improve patient participation in SM interventions or services and increase optimal use of health service, changes in behaviour cannot occur by focusing solely on an patient perceptions and beliefs. If behaviour change is required from a large number of people living with chronic disease interventions, focus should be placed both on an individual and at the societal level (e.g. social networks, environment, policy).[213]

2.4.2 Limitations

Methodological considerations

The conceptual review in comparison to a conventional systematic review does have several limitations such as: the problem of specifying a search strategy in advance, which can result in far too many or a paucity references;[163] difficulties exist in extracting relevant material in a consistent and unbiased manner and in synthesising the literature;[161,163] at the analysis stage, there is no form of formal quality assessment for the included studies - except in the form of the researchers' views of their merits or relevance.[163] This may influence the transparency and reproducibility of the results. Extensive reliance on the expertise and interests of the research group may bias the review's focus, and important reports can be missed if the study group are not aware of them or if not referenced in bibliographic databases.[163] These limitations can be addressed by setting up a study team to identify relevant texts[161] and discussion with the team about the summarised literature which could include going back to the identified literature if necessary to ensure the review aim is achieved.[161] There should be an overlap in various stages of the review process for example searching, analysis and writing so the precise nature and scope of the review can be clarified.[161,163]

On reflection of these limitations and how they may be addressed, the search strategy was not meant to be exhaustive and involved the identification of publications from several sources that were most relevant to the study; the relevance of the literature was decided mainly by discussion with the study supervisors e.g. explore all health behaviour models that might have examined health care seeking behaviour prior to understanding participation behaviour in SM interventions. A detailed search strategy was not developed to identify the various meanings of 'patient participation' in health care. Instead, some key publications were identified from one bibliographic database (PubMed) and further studies were identified from citations of the identified studies. The cyclical process of searching, analysis and writing was continued (with some input from the study supervisors) until an understanding about the research topic was developed which then helped to answer the review questions. The review could have benefitted from regular and detailed discussions with experts in the methodology/topic area; important publications may have been missed which could limit replicability of the review.

Other considerations

Health care utilisation is commonly utilised as a health outcome measure in the field of health including research studies and several factors can influence HCU e.g. economic models;[144] however, the remit of the review was to gain better understanding of HCU from a behavioural perspective with respect to individuals with chronic disease.

The review comprised of a mix of qualitative and quantitative (mostly predictor) studies including reviews that applied older and newer versions of theories to examine/explore HCU in different health care settings i.e. primary care; secondary care; utilisation of SM services; and attendance at SM interventions, among different disease groups (chronic pain, diabetes, heart disease). As a result, the review has shed light on the numerous factors that could influence an individual to participate in health and health care including SM interventions. A few included studies compared two or three theories to assess participation behaviour; use of multiple theories and comparison of theories has been recommended for the advancement of health behaviour research.[216]

As the study sample of the included studies comprised a variety of different chronic conditions, but it is possible that the factors that might have been shown to influence participation in SM services among one condition, say diabetes could be different for patients with another condition, say heart disease. Overall the findings may not be generalisable to a specific chronic condition but, even if this is the case, they could be used as a conceptual guide to further understand and assess participation behaviour in a patient group of interest for example COPD in this study (see Chapter IV).

2.5 Conclusions

The definition of the term 'patient participation' used in this thesis, 'taking part' in a study of SM intervention or in a SM intervention can be supported by the meanings uncovered in this review. 'Patient participation' is a dynamic process where it involves making a decision to take part in one's own health, health care or health care interventions such as SM interventions through the influence of several non-theoretical and theoretical factors. With regard to the latter, health care seeking can be influenced by perceived need particularly for symptom management and the established interpersonal relationship with health professionals over time. Utilisation of SM services was influenced by some population and

contextual factors, behavioural intention and action planning, motivation, perceived social and psychological benefits, positive exercise identity, availability of support, and perceived importance and confidence to exercise. Attendance in SM interventions was influenced by patient perceptions of their illness and treatment and their beliefs regarding attending the programme.

2.6 Implications

The review findings have suggested that health care seeking could be mostly attributed to increased perceived need particularly, perceived severity of symptoms. Though, living with a chronic illness means ongoing management of the illness including symptom management which professional and policy makers believe can be achieved by patients learning about self-management outside of a clinical setting through their participation in SM interventions and ongoing SM services for maintenance of SM behaviours.

The problem of poor participation in SM services and in SM interventions among patients with chronic disease including COPD is well reported both in the literature and anecdotally. So, application of health behaviour theory to existing evidence of patient reasons for participation in COPD SM support programmes (shown in Chapter IV) and using theory as a conceptual guide to understand the problem of participation from patients with COPD is crucial before suggesting any improvements (shown in Chapter V).

The next chapter is a systematic review which identifies existing participation and dropout rates reported in studies of SM support for COPD patients.

Chapter III. Identifying and reporting 'actual' patient participation and retention rates in research studies of COPD self-management support interventions – A systematic review

Chapter III informs the quantitative aspect of a systematic review while Chapter IV presents the qualitative aspect of the review – qualitative synthesis.

This chapter:

- Quantifies the existing participation and dropout rates in research studies of COPD SM support programmes including in the programmes

- Conducts a meta-regression to examine if any of the study characteristics might have influenced the actual study participation rates.

Note: The initial aim of the review was to identify and compare participation and dropout rates in SM support programmes among patients with COPD, asthma and heart failure. The search results yielded 431 articles comprising the above mentioned conditions including mixed conditions. Keeping the limited time and resources in mind to conduct the review within the bigger doctoral study and following discussion with the PhD supervisors a decision was taken to focus on only the COPD population for the review. Consequently, studies comprising of population other than COPD were placed in the excluded studies pile under 'reasons for exclusion: population'. For the same reasons, observational studies were also excluded and placed under the pile 'reasons exclusion on: study design'.

3.1 Introduction

This review is not a conventional systematic review of effectiveness as the evidence of benefit for SM support programmes particularly, PR programmes is well known (shown in Chapter I). A recent review by Bensten (comprising of four studies)[217] on effectiveness of COPD SM interventions (including education, exercise, action plan) on patient quality of life reported that patients who participated in these interventions were less likely to experience the disease burden, have improved physical condition, increased physical and social activity and better quality of life. However, Bensten's review, similar to a previous Cochrane review[84] of SM education was unable to present concrete conclusions on effectiveness of COPD SM interventions. This lack of tangible evidence could be one reason for the lack of implementation of SM support programmes in practice[84,87] which may affect patient access to these programmes. Another form of provision of SM support for patients with COPD is through PR. Despite considerable evidence of benefit for PR in COPD one study reported that only one to two per cent of patients might be able to access PR programmes and the reasons could be due to a mix of patient factors, lack of referral from health professionals and lack of infrastructure for provision of PR.[124] Besides this, another explanation for the lack of implementation of SM and PR programmes could be because of poor patient participation and retention reported in studies of these interventions[19,110] and this problem is reported more commonly among studies of PR programmes as it has been a longer-running intervention for patients with COPD in comparison to SM programmes. Reduced patient participation or high attrition in studies of PR or SM programmes for COPD patients may, affect the generalisability of the study findings to the target population.

In Chapter I varied reports of poor participation and high dropout rates reported in studies of SM and PR programmes have been presented. In addition, a recent study reported that only 57% of patients with COPD were referred to PR from tertiary care with only 18% attending PR.[218] Another study that examined attendance and completion rates of an integrated PR service in clinical practice also found low uptake (54% from PR assessment) of programme and completion (40% from those referred).[113]

So, before we can begin to address the apparent problem of poor patient participation and retention reported in studies of COPD SM support programmes, it is first important to

identify the actual proportions reported by these studies. Thus, a systematic review was conducted to identify the actual participation and retention rates reported in randomised and non-randomised studies evaluating SM support programmes including within the programmes among patients with COPD.

3.1.1 Review aim

To quantify existing participation and completion rates reported in studies of SM support programmes for COPD patients

3.1.2 Review research question

From published quantitative studies what are the participation and completion rates for self-management support programmes for patients with COPD?

3.1.3 Review objectives

1) Identify study participation and completion rates including dropout rates

2) Identify the intervention attendance and completion rates

3) Identify the process of recruitment including the setting, method of patient identification and method of participant recruitment

4) Identify factors that may be associated with participation or attendance or completion in SM programmes

5) Identify reasons for patient participation/non-participation and completion/non-completion reported in studies

3.2 Methods

The methods followed the guidance laid out in the Centre for Reviews and Dissemination[219] for undertaking reviews in health care.

3.2.1 Literature search

A scoping search was initially conducted typing key words from a previous COPD self-management education review,[84] it included search words such as *'patient participation'* or *patient participation in health'* to identify key articles for the review. Next, a comprehensive search strategy was developed from other self-management systematic

reviews (COPD self-management education, uptake of cardiac rehabilitation, self-management in musculoskeletal pain),[69,84,86,220] MeSH headings and free text words were used. The search strategy and search terms are presented below. A single search strategy was applied to identify both quantitative and qualitative studies for the broader mixed-methods review. This was suggested as a useful approach to reduce the risk of omissions of studies if the quantitative and qualitative studies were identified separately (Booth A. Reader in Evidence Based Information Practice. Personal communication. 9 Sep 2010).

The following sources were used to identify the relevant studies:

- Electronic databases

i) Cochrane Collaboration central register (CENTRAL/CCTR) (available through Cochrane library)

ii) Effective practice and organisation of care (EPOC) (Cochrane library)

iii) Database of Abstracts of Reviews for Effectiveness (DARE) (Cochrane library)

iv) Biomedical science databases

      a) PubMed/MEDLINE (available through OVID)

      b) Embase (available through NHS Evidence Health Information Resources/ NHS library)

      c) CINAHL (Cumulative Index to Nursing and Allied Health Literature) (NHS library)

      d) PEDro (physiotherapy evidence database)

      e) PsycINFO (psychological, social, behavioural and health sciences) (available through OVID)

      f) AMED (Allied and Complementary Medicine) (NHS Library)

      g) British Nursing Index (BNI) (NHS Library)

      h) Research registers UK, USA

j) Applied Social Sciences Index and Abstracts (ASSIA) (available through ProQuest (part of Cambridge Information Group) - CSA Illumina web-based information system)

k) Education Resources Information Centre (ERIC) seminal

l) Social Science Citation Index (available through Web of Science) – forward citation tracking from identified "seminal" papers

- Unpublished material and grey literature were to be included such as internal reports produced by organisations that develop and deliver SM programmes in the UK (e.g. Social Action for Health (SafH) and Expert Patient Programme Community Interest Company (EPPCIC)). A letter (Appendix 3.1) was sent to these organisations requesting them to send published or unpublished reports that might include reporting of participation, attendance and completion rates of self-management programmes for adults living with long term conditions.
- Further studies were identified from reference lists of identified systematic reviews and other studies.

The search terms were (Pulmonary Disease, Chronic Obstructive) OR (Lung Diseases, Obstructive) OR (chronic obstructive adj (pulmonary or lung or airway*) adj (disease* or obstruction or limitation*) OR (Emphysema) OR (Pulmonary Emphysema) OR (Bronchitis, Chronic) OR (Chronic Bronchitis) AND (Pulmonary rehabilitation) AND (Health Education/ or Patient Education as Topic/) OR (Health or patient) adj educat*) OR (Self Care) OR (self adj manage*) OR (psych* or behav*) adj (educat* or manage*) OR (expert adj patient) OR (self help) AND (Patient Participation) OR (patient* or particip*) adj (participat* or attend* or attitude* or motiv* or satisf* or involve* or accept* or refuse* or uptake or recruit* or rate*) OR (Consumer Participation) OR (Patient Acceptance of Health Care) OR (Patient Satisfaction/ or Attitude to Health/ or Aged/) OR Patient Dropouts) OR (drop out* or non attend* or barrier* or non participat*) OR (Program Evaluation) OR (programme evaluation) OR (Self Concept/ or Self Efficacy) OR (self-efficacy) OR (Cognition Disorders/ or Socioeconomic Factors/ or Depression) OR (Predict* adj attend*) OR (Health Services Accessibility) OR (complet* adj rate*).

3.2.2 Study selection

Studies that met the following criteria were included:

- **Studies type**

Controlled clinical trials (randomised and non-randomised) including before-after studies published since 1984.

Rationale:

The first study on Chronic Disease Self Management Programme, underpinned by the self-efficacy construct of the social cognitive theoretical model and developed by Kate Lorig for patients with arthritis, was published in 1984.[221]

- **Population**

Adults with a diagnosis of COPD

COPD definitions for determining COPD severity were adopted using the GOLD classification. These definitions now include 'severe' and 'very severe' COPD.[15]

- **Interventions**

The interventions included structured self-management, self-care, pulmonary rehabilitation, and health education/COPD education programmes. Interventions could be either group-based or targeted at individuals and conducted in any setting e.g. outpatients, inpatients, participant's home, GP surgery, community, or remote (web-based or telephone) or a combination of these settings. Intervention delivery could be by a health professional, or a trained lay person or both.

The definition of the named interventions here adopted for the review have been presented in Chapter I (section 1.1.1.4.2.1)

Only English language papers were included in the review due to lack of funding provision for translation of non-English language papers.

Studies were excluded based on the following criteria:

Non-English language studies, conference abstracts, surveys and interventions that only included exercise, SM plans/COPD action plans.

The full copies of the papers were obtained, following being identified as eligible based on titles and abstracts. The full copies of the potentially eligible papers were obtained to assess whether the studies met the pre-specified inclusion criteria. If additional information was needed, the corresponding authors of the study were contacted via a letter or email (Appendix 3.2).

3.2.3 Definitions of patient participation

For the purpose of the review, the following definitions were adopted (Figure 3.1):

- *'Study participation'-* eligible patients taking part in a study of PR or SM or HE intervention and *'study participants'* - patients that take part in the study

- *'Study non-participation'-* not taking part in a study of PR or SM or HE intervention and *'study non- participants'* - patients who do not take part in the study

- The 'study participant' in the intervention arm can be subdivided into an *'attender'* - one who is exposed to at least part of the intervention (e.g. attends at least one session) and *'non-attender'* – one is not exposed to any part of the intervention (e.g. does not attend any sessions of the intervention)

- The 'attender' can be further divided into *'intervention dropout'* – one who drops out from the intervention and *'intervention completer'* – one who completes the intervention

- *'Study completer'* – A 'non-attender', 'intervention dropout' or 'intervention completer' who completes the study

- *'Study dropout'* - A 'non-attender', 'intervention dropout' or 'intervention completer' who withdraws or is lost to follow-up from the study

Figure 3.1 Illustration of patient participation definitions

```
┌─────────────────────────────┐
│ Eligible patients invited to│
│ a study of PR, SM or HE     │        ┌──────────────────────────────┐
│ intervention                │───────▶│ Patients not willing to take  │
└─────────────────────────────┘        │ part and not recruited –      │
              │                        │ **Study non-participants**     │
              ▼                        └──────────────────────────────┘
┌─────────────────────────────┐
│ Patients willing to take    │        ┌──────────────────────────────┐
│ part and recruited -        │───────▶│ Participants not willing to   │──┐
│ **Study participants**      │        │ attend intervention at all -  │  │
└─────────────────────────────┘        │ **Non-attenders**              │  │
              │                        └──────────────────────────────┘  │
              ▼                                                            │
┌─────────────────────────────┐                                           │
│ Study participants attend   │                                           │
│ intervention (e.g.          │                                           │   ┌─────────────────────┐
│ comprising of 7 sessions) - │        ┌──────────────────────────────┐   │   │ 'Non-attenders' or   │
│ **Attenders**               │───────▶│ Participants dropped out e.g. │──┤   │ 'Programme dropouts' │
└─────────────────────────────┘        │ after 3 sessions –            │  │   │ or 'Programme        │
              │                        │ **Programme dropouts**         │  ├──▶│ completers' may also │
              ▼                        └──────────────────────────────┘  │   │ drop out from the    │
┌─────────────────────────────┐                                           │   │ study to become      │
│ Attenders complete the      │                                           │   │ **Study dropouts**   │
│ programme e.g. all 7        │───────────────────────────────────────────┘   └─────────────────────┘
│ sessions – **Programme      │
│ completers**                │
└─────────────────────────────┘
              │
              ▼
┌─────────────────────────────┐
│ Programme completers        │
│ complete the study –        │
│ **Study completers**        │
└─────────────────────────────┘
```

3.2.4 Validity assessment

The data extraction and quality appraisal of the studies were conducted simultaneously. Quality assessment in systematic effectiveness reviews is normally conducted to remove studies of low methodologically quality. Low methodological quality studies include biases (of different kinds) that can result in overestimation or underestimation of the true intervention effect. This review (which is not an effectiveness review) included studies of any quality to examine whether high participation rates were reported in studies of high quality. The methodological quality of both randomised and non-randomised primary studies including before-after studies was appraised using the criteria generated by Downs and Black[222] (Appendix 3.3). The Downs and Black checklist for quality assessment was selected as it has been developed to use with both randomised and non-randomised studies and is recommended as being suitable for use in systematic reviews.[233,238] Validity and reliability on the original version of the checklist was conducted by experienced epidemiologists and

statisticians and a revised version produced.[222,223] Further assessment of the revised checklist showed that the Quality Index had high internal consistency, good test-retest (r = 0.88) and inter-rater (r = 0.75) reliability and good face and criterion validity (0.90).[222] The checklist allows an overall score for study quality to be reported as well as scores for each of the subscales. The question on power was simplified to a simple check whether the study had conducted a statistical power calculation. The maximum score achievable for each of the subscales was: 11 for reporting, 3 for external validity (an area which has been ignored in all checklists of RCTs), 7 for internal validity - bias in the measurement of the intervention and outcomes, and 6 for internal validity - confounding (selection bias), totalling to maximum score of 27.

3.2.5 Data abstraction

A data extraction form was developed and piloted for particular questions to be addressed by the review and final versions were used to compile summary tables of the data and quality classification (Appendix 3.4A in Word and 3.4B in Excel). Data extracted included: study characteristics (study design, study setting, study eligibility criteria, recruitment process), population characteristics, intervention characteristics, definition of intervention completion and study outcomes that included participation data. The items selected for data extraction were based on the previous review of COPD SM education[84] and research[25,110,114,118,123] that have given some explanation on factors affecting patient participation and retention in SM support programmes, e.g. among population characteristics factors such as, living alone, widowed or divorced and lack of disease specific social support have been reported as predictors of PR non-adherence;[123] Patients smoking currently or with high pack years of smoking drop out of PR;[114,115,118]; It is important to consider the impact of age, gender, stage of illness, and comorbidities on motivation to engage in research trialling SM strategies.[224] Regarding intervention characteristics, location of PR and journey to PR venue have been reported as barriers to attend or withdraw from PR.[115,117]

The patient participation data (before and after recruitment) was extracted from studies by referring to the Consolidated Standards of Reporting Trials (CONSORT) participant flow diagram.[225] and the checklist suggested by extension of the CONSORT statement for reporting of pragmatic trials.[226] The following data was extracted: 'numbers of potential

participants identified' 'numbers assessed for eligibility', 'numbers eligible'[4], 'numbers included (and randomised or not randomised)' to all intervention groups, 'numbers received allocated intervention', 'numbers did not receive allocated intervention', 'numbers lost to follow-up', 'numbers discontinued intervention', and 'numbers analysed for the primary outcomes'.

A second reviewer checked extraction and calculation of participation rate data from 10% of the studies sampled at random using a web-based random integer generator (random.org).

3.2.6 Data syntheses

Due to heterogeneity among the included studies a narrative synthesis approach was followed.

Calculation of patient 'participation rates' from the extracted participation data was based on the adopted definitions (Figure 3.2). The study participation rate (SPR) was calculated based on 'numbers included in study' by 'numbers eligible'. This method of calculation for SPR is consistent with wording used in extension of the CONSORT statement for reporting of pragmatic trials "...numbers were eligible for study of whom (%) agreed to participate".[226] Glasgow[227] also recommended expanding the criteria in the original CONSORT statement to include eight items on external validity, one of which was "report the participation rate among those eligible".

For studies that reported both the number of eligible people and the number who were finally included, participation rate was determined with a 95% confidence interval calculated using a score method with a continuity correction.[228] A random effects logistic regression, with participation of each individual as a binary outcome and a random effect of study, to estimate the effects of different study characteristics on participation rates was utilised. This amounts to a meta-regression of study results, and allows studies to be included even if their estimated participation rate is100%.

Because of the relatively small number of studies with complete data, following discussion with the study team, four study characteristics: year of publication (linear effect per year),

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[4] In five studies *'Numbers eligible'* was not clearly stated. So to calculate study participation rate in the five studies 'numbers eligible' were extracted the following way: reasons reported for not taking part in the study, between numbers assessed for eligibility and numbers included in study, were reported as numbers that declined to participate and numbers that were ineligible for the study. The numbers who declined to take part were added to numbers included in the study and were extracted as 'numbers eligible'.

quality score (linear effect per scale point), exercise versus non-exercise intervention, and group versus individual treatment (divided into three categories: individual, combined group and individual group) were examined. There was heterogeneity between studies in COPD severity, but this variable was inconsistently reported and difficult to categorise, so was not selected for inclusion. Results are reported as adjusted odds ratio from a multivariable regression model including all four study characteristics.

Comparisons of what was reported by studies before and after publication of the CONSORT guidelines were made using chi-squared tests (or Fisher's exact test where any expected frequency was <5).

Figure 3.2 Calculation of participation rates
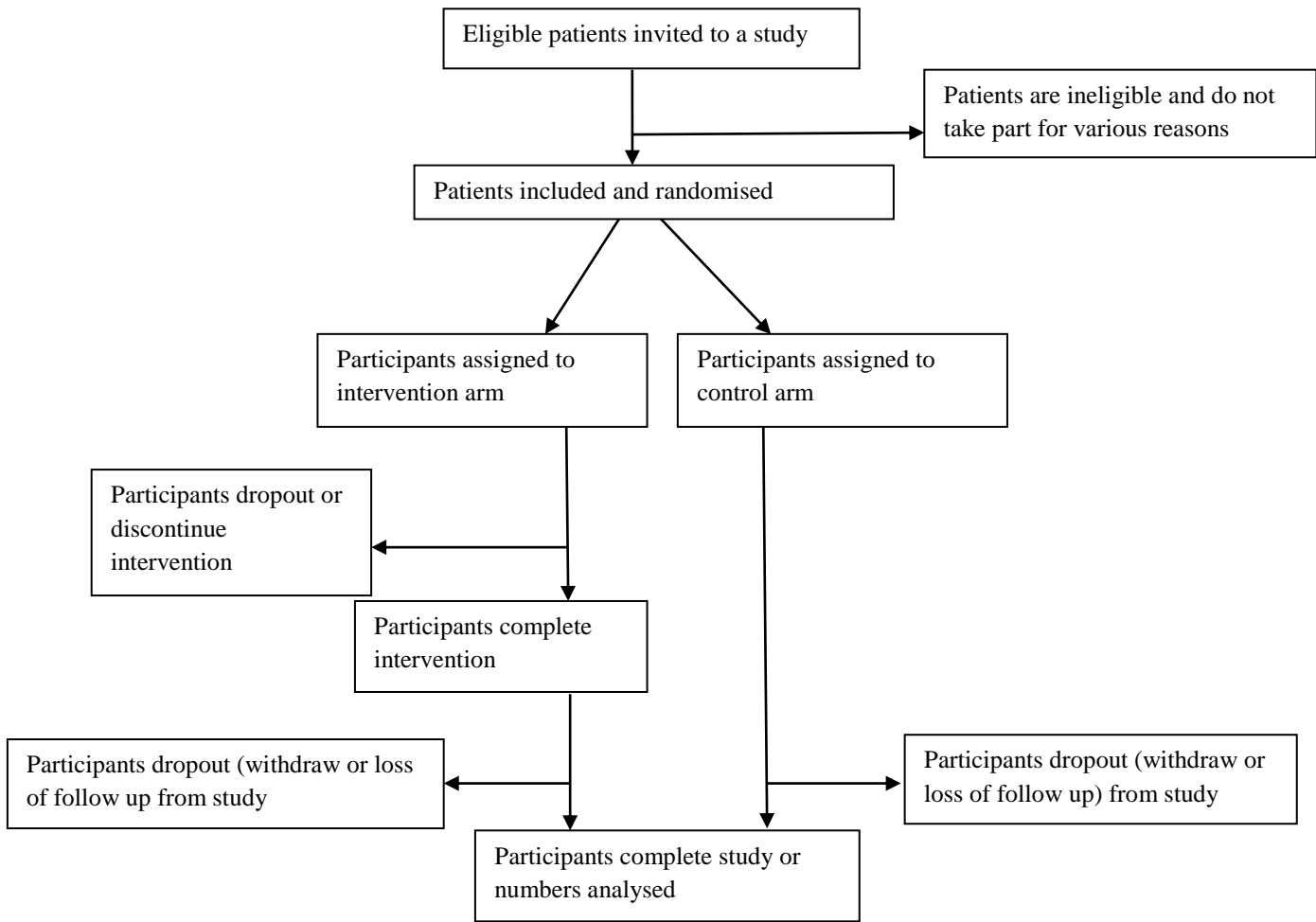
Calculation of participation rates:

Study participation rate (SPR) = $\dfrac{\text{numbers included (randomised and non-randomised) in study}}{\text{numbers eligible for study}}$ X 100

Study completion rate (SCR) = $\dfrac{\text{numbers completed (all groups) study}}{\text{numbers included in study}}$ X 100

Study dropout rate (SDR) = $\dfrac{\text{numbers dropped out (all groups) from study}}{\text{numbers included in study}}$ X 100

Proportion assigned to intervention arm (AIA) = $\dfrac{\text{numbers assigned to intervention group}}{\text{numbers included in study}}$ X 100

Intervention completion rate (ICR) = $\dfrac{\text{numbers complete intervention}}{\text{numbers assigned to intervention group}}$ X 100

Intervention dropout rate (IDR) = $\dfrac{\text{numbers dropout of intervention}}{\text{numbers assigned to intervention group}}$ X 100

3.3 Results

3.3.1 Search results

Table 3.1 presents a breakdown of the number of studies identified from each of the electronic databases.

Table 3.1 Database search results

AMED	109
BNI	40
CINAHL	326
Clinical trials	1
Cochrane library	314
Embase	724
ERIC	9
Medline	1510
PsycINFO	218
SSCI	226
PEDRO	351

In addition, 13 studies were further identified from other sources: reference lists of included studies (n=9), PubMed saved alerts (n=2) and grey reports (n=2) which were published soon after in 2012 (n=2).

3.3.2 Study selection and exclusion

3.3.2.1 Number of studies identified and number of and type of studies included and excluded

The combined database searches yielded 3828 studies with 13 studies from additional sources. After screening, 56 studies met our inclusion criteria (PRISMA flowchart,[229] Figure 3.3), 51 were RCTs, three quasi-experimental studies and two before-after studies. Thirty-one studies evaluated PR programmes, twenty evaluated SM programmes, one evaluated SC programme and was combined with studies of SM programmes and four studies evaluated HE programmes. Appendix 3.5 presents the list of excluded studies (the reasons for exclusion were: systematic reviews, study design, population, not primary study, interim results, same sample published in various studies). The focus of this chapter is quantitative studies.

Figure 3.3 PRISMA flowchart showing the number of included studies in the review
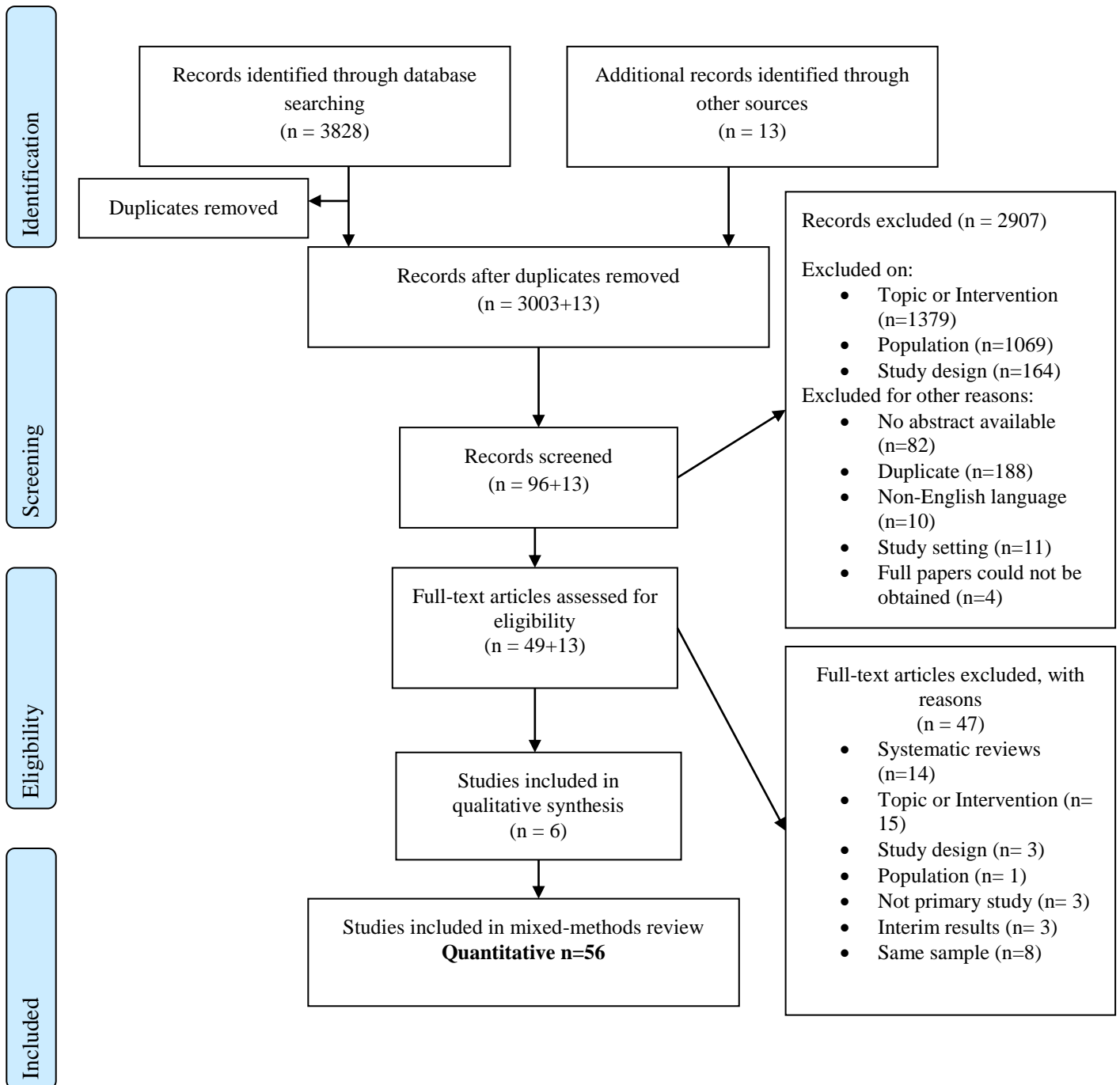
Source: Moher D et al.

3.3.3 Quality assessment of studies

The study quality was variable (Table 3.5). The overall quality of study reporting was good (9.9), external validity was low (1.3), internal validity was better amongst studies but, more bias was present in selection of study subjects (3.6) in comparison to bias in the measurement of the intervention and outcome (4.8). Less than half of the studies had conducted a power calculation. There was no clear pattern observed from the quality assessment that high quality studies had higher participation rates. The second reviewer checked a randomly selected 10% of data extractions and there was 100% agreement between the two reviewers.

3.3.4 Narrative synthesis

The findings are presented under the following headings:

- Study characteristics
- Population characteristics
- Process of recruitment
- Intervention characteristics
- Study outcomes – participation and dropout rates
- Reasons reported by the included studies for patient participation/non-participation and/or completion/non-completion

3.3.4.1 Study characteristics

Fifty six studies were conducted across different parts of the globe, majority of the articles were from Europe (32%), followed by America (29%), the UK (27%), the Far East (5%) and equal number of articles originated from Australia (2%), New Zealand (2%), Egypt (2%) and Iran (2%).

The study setting amongst the included studies were diverse and comprised mainly outpatients (41%), then home of participant (20%), a combined setting (13%), community (11%), primary health care (9%), medical centres (4%), university clinic (2%) and inpatients (2%).

The total sample size of all included studies was 5735 with the highest proportion of sample from studies of SM programmes (44%), a third from studies of PR programmes (34%) and 23% of sample from studies of health education. Sixty six per cent of the studies had a

sample size that was below 100 with two RCT studies[230,231] comprising of only 20 participants, 27% of studies had a sample that ranged between 101 to 200, and 4% of studies had a sample that ranged between 201 to 300 and 300 plus. Table 3.2 presents details on the country of origin, study design, setting and sample size of the included studies.

Table 3.2 Study characteristics

Author	Country	Study design	Study setting	Sample size, n
Studies of PR programmes, n = 31				
Barakat[232]	France	RCT	Outpatients	80
de Godoy [233]	Brazil	RCT	Outpatients	30
Finnerty[234]	UK	RCT	Outpatients	65
Karapolat[235]	Turkey	RCT	Outpatients	49
Carr[236]	Canada	RCT	Inpatient or outpatients – usually inpatients	34
Liddell[237]	UK	RCT equivalency – pilot	Outpatients	30
Reardon[230]	US	RCT	Outpatients	20
Ries[238]	US	RCT	Outpatients	119
Ringbaek[239]	Denmark	RCT	Outpatients	45
Sewell[240]	UK	RCT	Outpatients	100
Theander[241]	Sweden	RCT two group pre-post test	Outpatients	26
White[242]	UK	RCT	Outpatients	103
Seymour[243]	UK	RCT	Outpatients	60
Green[244]	UK	RCT	Outpatients	44
Guell[245]	Spain	RCT	Outpatients	40
Guell[246]	Spain	RCT	Outpatients	60
Prince[247]	UK	RCT	Outpatients	31
Lindsay[248]	Hong Kong	RCT	Primary care teaching clinic affiliated with university (primary care)	50
Boxall[249]	Australia	RCT-cross over	Home	46
Na[250]	Korea	CCT/ quasi-experimental	Home	43
Oh[251]	South Korea	RCT control group pre-post test	Home	23
Resqueti[252]	Spain	RCT	Home	38
Sridhar[253]	UK	RCT equivalency	Home	122
Wijkstra[254]	The Netherlands	RCT	Home	43
Goldstein[255]	Canada	RCT	Inpatients, outpatients and periodic home visits	89
Ghanem[256]	Egypt	RCT	Home and outpatient supervision	39
Strijbos[257]	The Netherlands	RCT	Outpatient and home care	50
Wedzicha[258]	UK	RCT	Home and hospital	110
Man[259]	UK	RCT	Community health	42

			centres	
van Wetering[260]	The Netherlands	RCT	Community-based	199
Zakrisson[26]	Sweden	Quasi-experimental	Primary health care centres	103
				Total n = 1933
Studies of SM programmes, n = 21				
Bourbeau[261]	Canada	RCT-parallel group	Home	191
Effing[262]	The Netherlands	RCT 2X2 factorial design	Community-based	142
Monninkhof[263]	The Netherlands	RCT	Outpatients	248
Ninot[264]	France	RCT-parallel group	Outpatients	45
Nguyen[265]	US	RCT –pilot	Clinical academic medical centres	50
Zimmerman[266]	US	Before-after study	Community hospital	10
Taylor[85]	UK	RCT-pilot	Community centre (community-based)	116
Casas[267]	Spain and Belgium	RCT	Hospital and home	155
Rea[268]	New Zealand	RCT-cluster	Primary care and home visit	135
Emery[269]	US	RCT	PR facility (outpatients)	79
Kara[270]	Turkey	RCT	Outpatients	60
Khdour[271]	UK	RCT	Outpatients	173
Kheirabadi[272]	Iran	RCT-pilot	Pulmonary clinics (outpatients)	42
Hill[273]	Canada	RCT	Primary care	93
Koff[274]	US	RCT –pilot	At clinic once and remote monitoring	40
Moore[231]	UK	RCT –pilot	Home	20
Cockcroft[275]	UK	RCT	Home	75
Sassi-Dambron[276]	US	RCT	University clinic	89
Howland[277]	US	Quasi-experimental	Community-level	538
Efraimsson[278]	Sweden	RCT	Primary health care COPD clinic	52
Coultas[279]	US	RCT	Home	151
				Total n = 2504
Studies of HE programmes, n = 4				
Littlejohn[280]	UK	RCT	Outpatients	152
Lemmens[281]	The Netherlands	Before-after	Primary care	189
Petty[282]	US	RCT-parallel group	Home	214
Rice[283]	US	RCT	Medical centres	743
				Total n = 1298
SUMMARY OF THE STUDY CHARACTERISTICS				
France – 2 Brazil – 1 UK – 15 Turkey – 2 Canada – 4 US – 11 Denmark -1 Sweden – 3 Spain 3 Hong Kong – 1 Australia – 1 Korea – 1		RCT – 51 Quasi-experimental – 3 Before-after - 2	Primary health care - 5 Combined – 7 Outpatients – 23 Home – 11 Medical centres – 2 University clinic – 1 Community level– 6 Outpatient or inpatients (mainly	1 to 100 - 37 101 to 200 – 15 201 to 300 - 2 300 plus - 2

South Korea – 1		inpatients) – 1	
The Netherlands – 6			
Eygpt – 1			
Spain and Belgium – 1			
New Zealand – 1			
Iran – 1			

3.3.4.2 Population characteristics

The number of studies that have reported on each of the population characteristics is presented in Table 3.3. With the exception of age group reported by all 56 studies, none of the other population characteristics were reported by each individual study. In addition, the studies differed in the way they collected and recorded data on the population characteristics e.g. age group was either recorded in the form of mean age of all participants or mean age of participants in each group or median age-range.

Fifty four (94%) studies reported on sex of the study participants and two studies[246,250] of PR programme comprised only male participants; 36 (64%) studies reported on the smoking behaviour of the participants; less than half of the included studies (43%) provided data on severity of COPD using various guidelines such as, the GOLD classification (19.6%) or other such as, MRC dyspnoea group, American Thoracic Society, British Thoracic guidelines, hospital registrar; only 15 studies (27%) reported on educational level; 14 reported (25%) on marital status; 13 (23%) on employment status; 10 (18%) on previous experience of participation in health care interventions which normally was PR; two studies (4%) reported on illness beliefs of study participants; and only one study (2%) reported on carer status.

Table 3.3 Number of included studies that reported on each of the population characteristics

	Population characteristics										
Intervention	Age	Sex	COPD severity- GOLD criteria or other	Educational level	Employment status	Marital status	Carer status	Smoking behaviour	Co- morbidities	Illness beliefs	Previous experience of participation in health care intervention
PR (n= 31)	31	29	9	1	2	2	1	18	4	0	4
SM (n= 21)	21	21	11	13	8	10	0	14	8	0	5
HE (n= 4)	4	4	3	1	0	1	0	4	1	0	1
Total (n=56)	56	54	23	15	10	13	1	36	13	0	10

3.3.4.3 Process of recruitment (Recruitment characteristics)

Table 3.4 provides the number of studies that reported on where and how patients were recruited into the study. It was unclear from five studies (8.9%) where patients were identified and from more than a third of studies (35.71%) on how patients were approached/invited to participate in the study. A third of the studies (33.3%) from 51 studies identified patients from outpatients and these studies were mostly evaluating PR programmes as PR is commonly delivered at outpatients; Nine studies (17.6%) identified patients from a combination of avenues e.g. outpatients and GPs, physician and advertisements, HCPs in primary and secondary care settings, hospital admission and GP records, advertisement, web-based and non-web-based sources; Six studies (11.7%) utilised physician referrals; While, five studies (9.8%) identified patients from hospital admissions, five other studies identified patient using patient database; three studies (6.4%) used PR waiting list; two (3.9%) used flyer; and one study (1.9%) each identified previous PR attendees, patient from ongoing PR programme and Veteran Affairs medical centre.

Of the 36/56 studies who invited patients to participate in the study the most common mode of invite was verbal (44.4%); followed by a written letter (30.5%); four studies (11.1%) invited patients by a combination of letter and phone call, letters, advertisements and announcements and word of mouth, advertisement and telephone; three studies (8.3%) invited patients verbally and by a written letter; on verbal agreement patients were invited by a written letter by one study (2.7%); and one study used a written letter and phone to invite patients.

Table 3.4 Number of studies that reported on various forms of patient identification and patient invite for study recruitment

Place of patient identification												
Intervention	Outpatients	Physician referral	Combination	Hospital admission	Previous PR attendee	Database	Ongoing PR programme	PR waiting list	Another sub study	Flyer	Veteran Affairs Centre	Unclear
PR (n=31)	12	1	4	3	1	2	1	2				5
SM (n=21)	4	4	4	2		3		1	1	2		
HE (n=4)	1	1	1								1	
Total (n =56)	17	6	9	5	1	5	1	3	1	2	1	5

Mode of patient invite							
Intervention	Verbal	verbal & written	written	verbal, agreed, written	written & phone	Combination	Unclear
PR (n=31)	10	3	3	1			14
SM (n=21)	6		6		1	3	5
HE (n=4)			2			1	1
Total (n =56)	16	3	11	1	1	4	20

3.3.4.4 Intervention characteristics

The intervention characteristics data (presented in Appendix in 3.6) comprises information on components of the intervention, description of the intervention such as, setting - group-based or individual, location, duration, delivery, underlying with theory, if the study defined participation and type of control group.

There was heterogeneity in the intervention content among studies of PR, SM and HE programmes and between studies of each programme. A summary of the intervention characteristics is divided and presented under studies of exercise (n=36) (including studies of PR and SM programmes) and non-exercise (n=20) (SM and HE education programmes).

Regarding studies of exercise programmes including education/SM education, 23 studies delivered the intervention in groups, seven individually and it was unclear from three studies. Studies reported location of the intervention as outpatients (n=8), home (n=7), combination (n=5), community (n=2), primary care (n=2), PR facility (n=1) and outpatient and inpatient (n=1). The duration of the intervention ranged between 2 weeks to 24 weeks among the 36 studies, ten studies delivered the intervention for 8 weeks, six studies delivered the intervention for 6 weeks and another six for 12 weeks. In addition, among 22 studies that had reported on the number of intervention sessions delivered, most studies delivered once or twice a week and in a couple of studies it was more than twice a week. Furthermore, two studies also had an exercise maintenance programme of 6 months[246,252] and one study of 20 months.[260] Except one study that was unclear, the intervention was delivered either by health care professional/s (HCPs) or a multidisciplinary team. None of the programmes were based on theory. Among 35/36 studies, the control group comprised of usual care and 21 studies had specified type of usual care. Regarding definition of patient participation, seven studies had reported a pre-definition such as, patients who had attended 75% of the supervised sessions (6 out of 8 sessions) were labelled a 'study completer';[237]; To succeed, patients had to participate in four out of eight weeks;[239] Patients were required to attend at least 10 of the 12 sessions;[242] Non-attendance within three weeks of the designated follow-up was deemed 'failure to attend';[243] Analysis was confined to those who completed 8 out of 16 sessions;[258] 'Adherence' was defined as completion of 7 out of 8 sessions;[264]; and a patient who attended 16 education, 37 exercise and 10 stress management sessions over 10 weeks was labelled an 'intervention completer'.[269]

Regarding studies of non-exercise programmes (SM education/education), five studies delivered the intervention in groups, 12 individually, 1 combined and it was unclear from one study. The intervention was delivered mostly in a combination format e.g. at outpatients and telephone, telephone and tele-monitoring, or at hospital and home (n=8), equally at home and in the community (n=3), in primary care (n=2), at outpatients (n=2), in a university clinic (n=1) and a nurse-led clinic (n=1). The duration of the intervention was reported clearly among 15 studies and varied between studies for example, the duration of the intervention ranged 7 weeks, 6 weeks or 8 weeks; 3, 6 or 12 months; two one to one education sessions, two visits with a 3-5month interval or two hours before discharge and weekly phone calls during first month following discharge. Among 19/20 studies, HCPs delivered the intervention in 18 studies and in one study[85] both lay SM tutors and a clinician delivered the intervention. Five studies evaluated interventions that were underlying with theory namely, socio-cognitive self-efficacy theory,[85,270] self-efficacy theory and the health belief model,[266] the nursing model,[275] the transtheoretical model[278] and socio-cognitive and stage of motivational readiness.[265]. Only one study had reported a definition of patient participation – patients who attended five out of seven sessions were labelled 'intervention completer'. Finally, among the 18 RCTs, 11 studies specified usual care for the control group.

3.3.4.5 Study participation, intervention attendance, intervention completion, study and intervention dropout rates (study outcomes)

Table 3.5 presents the following study outcomes by intervention of interest: time of study assessment and follow-ups, participant flow data ('number of potential participants identified', 'numbers assessed for eligibility', 'numbers eligible' for study, 'numbers included (randomised or non-randomised)' to all intervention groups, 'numbers lost to follow up' and 'numbers discontinued intervention' and patient 'participation rates' – study participation rate (SPR), study dropout rate (SDR) and intervention dropout rate (IDR), the quality assessment scores and whether the intervention was effective on the study primary outcome.

The time points that patients with COPD were followed up ranged between one to eight times with 32/56 (57.14%) studies followed up patients only once. The follow up period ranged from 2 weeks to 72 months and most studies followed up patients at three, six and 12 months.

Excluding three quasi-experimental, two before-after studies and six pilot RCTs, 27/45 (60%) RCT studies had not reported a primary outcome. The interventions were effective in 12 studies (7 PR, 4 SM, 1 HE) and the primary outcomes included either quality of life or health care use (hospital readmission rate, hospital admissions, number of hospital bed days).

Authors of 49 studies were contacted for further information regarding the participant flow data. 25 authors (51%) responded with further information, 10 authors responded but could not help due to studies being old and they no longer had access to the study data and 14 authors did not respond.

Participant flow data was poorly reported in all studies. Only nine (16%) studies reported 'numbers of potential participants identified' (4/31 PR, 4/21 SM and 1/4 HE) and twenty-two (39%) studies reported 'numbers assessed for eligibility' (12 PR and 10 SM). 'Numbers eligible' by studies was better reported, 43 (77%) studies, (21 PR, 19 SM and 3 HE). Fifty-six studies reported 'numbers included (both randomised and non-randomised)' in study, out of five non-randomised studies, two were before-after studies without a control group. Only seven (13%) studies recorded participant flow numbers right up to participant recruitment. Forty-one (73%) studies were published after the CONSORT statement in 2001. Better reporting of participant flow was seen in studies published in and after 2001 in comparison to studies published before 2001, 'numbers of potential participants identified' 9/41 (22%) vs. 0/15 (0%) (Fisher's exact test P = 0.094); 'numbers assessed for eligibility' 18/41 (44%) vs. 4/15 (27%) (chi-squared = 1.37, df = 1, P = 0.24) and 'numbers eligible' 33/41 (80%) vs. 10/15 (67%) (chi-squared = 1.18, df = 1, P = 0.28).

Based on the data available, we were able to calculate SPRs for 43 studies. Half of the highest value in the range of proportions for SPR, SDR and IDR was taken as a cut-off value to show studies with participation rates above or below the chosen cut-off value. The SPR among studies of PR programmes ranged from 35 to 100% (that is, a cut-off value of 50%), only three (14%) studies having less than 50% SPR. In studies of SM programmes, SPR ranged from 23 to 100%, with four (21%) studies having less than 50% SPR. And amongst the three studies of HE programmes, SPR was 43%, 73% and 92%. Altogether for 43 studies (21 PR, 19 SM, and 3 HE) the SPR was less than 50% for only 8 (19%) studies with 12 (34%) studies reporting SPR of 100% (9 PR and 3 SM) (Table 3.5).

The SDR was calculated for all 56 studies and the IDR for all studies except for the two before-after studies (here the result of IDR and SDR was the same). Among PR studies, study

dropout rates ranged from 0 to 59% (that is, cut-off value of 30%) with 27 (87%) studies having SDR of less than or equal to 30%. For studies of SM and HE programmes, the SDR ranged from 0 to 30% and from 11 to 21%. Overall, 52 (93%) studies had an SDR of less than or equal to 30% (Table 3.5).

The IDR among studies of PR programmes ranged from 0 to 54%, 30 (97%) studies having IDR of less than or equal to 30%. Among studies of SM programmes, IDR ranged from 0 to 60% (that is, a cut-off value of 30%), 18/20 (90%) studies having less than 30% IDR. And in studies of HE programmes IDR ranged from 7 to 29%. Overall, IDR for 51/54 (94%) studies was less than or equal to 30% (Table 3.5).

Despite being able to calculate the SDR and IDR, it was difficult to identify and differentiate between the number of participants who were lost to follow-up and participants who discontinued the intervention. We assumed that participants who dropped out of the study also dropped out of the intervention unless papers explicitly stated otherwise.

As SPR was calculated for 43 studies, 31/43 (72%) studies with SPR of >50%, had SDR of ≤30%. However, no obvious pattern could be deduced as 26/31 (84%) studies had not reported on participant flow data ('potential participants identified' and/or 'numbers assessed for eligibility) before recruitment (Table 3.5).

In the analysis of study characteristics, there was no evidence for effects of year of publication, study quality, exercise vs. non-exercise, and group vs. individual treatment on participation rate (Table 3.6). Figure 3.4 illustrates how year of publication had no effect on participation rate. Confidence intervals for effects were wide, and did not rule out the possibility of a five-fold increase in the odds of participation in exercise vs. non-exercise interventions, or a five-fold decrease in group vs. individual interventions.

Table 3.5 Study outcomes

Author (year) and Study design	Time of study assessments and follow-ups	Participant flow data				Quality assessment	Participation rates			What is the primary outcome? Is the intervention effective for the primary outcome?
		Pulmonary rehabilitation programmes, n=31								
		Potential numbers identified, n = 4	Numbers assessed, n = 12	Numbers eligible, n = 21	Numbers included and randomised, n (I, C)	a, b, ci, cii, d	SPR, n (%)	SDR, n (%)	IDR, n (%)	
Barakat (2008) RCT	0, 14 weeks	not reported	80	80	80 (40, 40)	9, 2, 6, 4, no	80 (100)	9 (11)	5 (13)	not reported
Boxall (2005) RCT	0, 12 weeks	not reported	not reported	not reported	60 (30, 30)	10, 1, 5, 3,	n/c	14 (23)	5 (18)	not reported
Carr (2009) RCT	T0- before AECOPD, T1 - 2 weeks, T2 - 3 weeks T3 - 12 weeks	not reported	364	94	60 included, 34 (17, 17)	10, 2, 5, 4, yes	34 (36)	5 (15)	1 (6)	Health-related quality of life (HRQoL) - limited benefit
de Godoy (2003) RCT	0, 12 weeks	not reported	not reported	39	30 (14, 16)	11, 1, 5, 5, no	30 (77)	0	0	not reported
Finnerty (2001) RCT	0, 12, 24 weeks	not reported	108	100	100 (50, 50)	10, 1, 6, 2, no	65 (65)	16 (25)	4 (11)	Change in quality of life (QoL) – YES
Goldstein (1994) RCT	0, 12, 18, 24 weeks	not reported	244	126	89 (45, 44)	11, 1, 4, 3, no	89 (71)	11 (12)	7 (16)	not reported
Ghanem (2010)	0, 2 months	not reported	not reported	50	45 (30, 15)	10, 1, 5, 5, yes	39 (78)	0	0	not reported

RCT										
Karapolat (2007) RCT	0, 8, 12 weeks	not reported	not reported	not reported	49 (27, 22)	9, 1, 5, 2, no	n/c	4 (8)	1 (4)	not reported
Liddell (2010) pilot RCT	0, 2 weeks of end of programme	36 on waiting list	36	30	30 (15, 15)	9, 1, 5, 4, no	30 (100)	10 (33)	4 (27)	measures reflected potential changes in exercise tolerance and HRQoL, n/a
Lindsay (2005) RCT	0, 6 weeks before programme, 12 weeks, 3 months	not reported	not reported	50	50 (25, 25)	10, 1, 5, 4, yes	50 (100)	9 (18)	4 (16)	not reported
Man (2004) RCT	0, 3 months	not reported	69	52	42 (21, 21)	11, 1, 5, 5, yes	42 (81)	8 (19)	2 (10)	exercise capacity and disease specific and generic health status - YES
Na (2005) Quasi	0, 12 weeks, 1 year	not reported	not reported	43	43 (25, 18) (not randomised)	10, 1, 6, 1, yes	43 (100)	20 (47)	5 (20)	not reported, n/a
Oh (2003) RCT	0, 8 weeks	not reported	not reported	34	34 (19, 15)	10, 1, 5, 2, no	34 (100)	11 (32)	4 (21)	not reported
Reardon (1994) RCT	before start of PR, after 6 weeks	not reported	not reported	not reported	20 (10, 10)	11, 1, 6, 3, no	n/c	0	0	not reported
Resqueti (2007) RCT	0, 6 months	not reported	not reported	42	38 (19, 19)	10, 1, 5, 4, no	38 (90)	9 (24)	5 (26)	not reported
Ries (1995) RCT	0, 2 months, for physiologic measures 12, 24, 48, 72 months. For	not reported	352	128	119 (57, 62)	9, 2, 6, 6, no	119 (93)	70 (59)	31 (54)	not reported

	psychological measures 6, 12, 18, 24, 36, 48, 60 and 72 months									
Ringbaek (2000) RCT	0, 8 weeks	not reported	not reported	130	45 (24, 21)	10, 1, 5, 5, no	45 (35)	7 (16)	7 (29)	not reported
Sewell (2006) RCT	0, 4th week and 7th week for intervention group, 7 weeks for control, 6 months	not reported	not reported	not reported	100 (50, 50)	10, 1, 6, 4, yes	n/c	29 (29)	9 (18)	exercise capacity - NO
Sridhar (2008) RCT	0, 2 years	1247	574	297	122 (61, 61)	9, 2, 4, 5, yes	122 (42)	18 (15)	6 (10)	hospital readmission rate - YES
Theander (2009) RCT	0, 12 weeks	64	55	30	30 (15, 15)	10, 2, 4, 5, yes	30 (100)	4 (13)	3 (20)	not reported
White (2002) RCT	0, 3 months	160	116	107	103 (54, 49)	11, 2, 6, 4, yes	103 (96.2)	15 (15)	9 (17)	mastery and emotional subscales of Chronic respiratory questionnaire - NO
Wedzicha (1998) RCT	0, 8 weeks	not reported	not reported	not reported	126: moderate -66 (33, 33) severe-60 (30, 30)	10, 2, 5, 4, no	n/c	17 (13)	16 (25)	Exercise capacity for moderate severity group of patients – YES but not for severe patients.
Wijkstra (1994)	0, 12 weeks	not reported	not reported	not reported	45 (30, 15)	10, 1, 5, 2, no	n/c	2 (4)	2 (7)	not reported

RCT										
Seymour (2010) RCT	72 hours of discharge and 3 months	not reported	not reported	not reported	60 (30, 30)	10, 1, 5, 4, yes	n/c	7 (12)	7 (23)	Hospital admission - YES
van Wetering (2009) RCT	0, 4, 12, 24 months	not reported	355	199	199 (102, 97)	10, 2, 4, 4, yes	199 (100)	41 (21)	18 (19)	Disease-specific QOL - YES; frequency of exacerbations NO
Green (2001) RCT	0, 4 weeks or 7 weeks Unclear	not reported	not reported	not reported	44 (23, 21)	8, 1, 3, 1, no	n/c	0	0	QoL - NO
Guell (2006) RCT	0, end of 4 months	not reported	not reported	not reported	40 (20, 20)	9, 1, 5, 3, no	n/c	5 (13)	2 (10)	not reported
Guell (2000) RCT	0, 3, 6, 9, 12, 18, 24 months	not reported	not reported	65	60 (30, 30)	10, 1, 5, 3, no	60 (92)	13 (22)	6 (20)	HRQoL - YES
Strijbos (1996) RCT	0, 3, 6, 12, 18 months	not reported	not reported	50	50 (18, 17, 15)	10, 1, 4, 2, no	50 (100)	9 (18)	5 (14)	not reported
Prince (1989) RCT	before and after 6 weeks	not reported	not reported	not reported	31 (13, 18)	7, 1, 5, 3, no	n/c	6 (19)	2 (15)	not reported
Zakrisson (2011) Quasi	0, 2, 5 months and 1 year	not reported	1828	176	176 (83, 93) (not randomised but allocated	10, 1, 3, 1, yes	176 (100)	12 (7)	0	Exacerbation – YES, NO for walking and QoL, n/a

Self-management programmes, n=21										
Author (year) Study design	**Time of study assessments and follow-ups**	**Participant flow data**				**Quality assessment**	**Participation rates**			**What is the primary outcome? Is the intervention effective for the primary outcome?**
		Potential numbers identified, n = 4	**Numbers assessed, n = 10**	**Numbers eligible, n = 19**	**Numbers included and randomised, n (I, C)**	**a, b, ci, cii, d**	**SPR, n (%)**	**SDR, n (%)**	**IDR, n (%)**	
Howland (1986) Quasi	0, 1 year	not reported	1834	923	659 (254, 405)	10, 0, 5, 2, no	659 (71)	121 (18)	41 (16)	not reported, n/a
Cockcroft (1987) RCT	November 1984, August 1985	not reported	not reported	92	75 (42, 33)	10, 3, 4, 3, no	73 (79)	11 (15)	3 (8)	not reported
Sassi-Dambron (1995) RCT	0, 6 weeks, 6 months	not reported	497	98	98 (47, 51)	10, 1, 5, 3, yes	89 (91)	13 (15)	5 (11)	not reported
Zimmerman (1996) Before-after	pretest-postest 6 weeks	not reported	not reported	not reported	10 not randomised	8, 1, 3, 1, no	n/c	0	Same as SDR	Self-efficacy - partly
Emery (1998) RCT	baseline T1, T2 –after 10 weeks	not reported	not reported	92	79 (29, 25, 25)	10, 1, 7, 5, no	79 (86)	6 (8)	4 (14)	not reported, n/a
Bourbeau (2003) RCT	0, 4, 12 months. In addition	not reported	not reported	469	191 (96, 95)	10, 1, 6, 5, yes	191 (41)	26 (14)	10 (10)	Hospital admission - YES

	standardised telephone interview every 4 weeks									
Monninkhof (2003) RCT	0, 1 year	615	not reported	509	248 (127, 121)	11, 1, 5, 5, yes	248 (41)	12 (5)	5 (4)	not reported
Kara (2004) RCT	preprogramme and post and 1 month after programme. For control group after 1 and 2 months of initial interview	not reported	not reported	60	60 (30, 30)	11, 1, 4, 4, no	60 (100)	0	0	not reported
Rea (2004) RCT	0, 12 months	not reported	700	158	135 (83, 52)	10, 1, 4, 5, yes	135 (85)	18 (13)	12 (14)	Change in hospital bed days - YES
Coultas (2005) RCT	0, 6 months	2120	535	217	217 (72, 72, 73)	10, 2, 5, 5, yes	217 (100)	66 (30)	44 (31)	not reported
Casas (2006) RCT	0, 6, 12months	not reported	850	160	155 (65, 90)	10, 3, 7, 4, yes	155 (97)	35 (23)	17 (26)	Hospital readmission - YES
Nyugen (2008) pilot RCT	0, 3, 6 months	not reported	173	84	50 (26, 24)	10, 2, 5, 5, no	50 (60)	11 (22)	7 (27)	QoL – YES, n/a
Kheirabadi (2008) pilot RCT	0 – before 8 weeks, after 8 weeks, 3	not reported	not reported	59	42 (21, 21)	10, 1, 4, 4, no	42 (71)	0	0	Health status – partly, n/a

	months									
Efraimms on (2008) RCT	2 visits with a 3 – 5 month interval between first and last visit	110	110	62	62 (26, 26)	10, 1, 4, 4, no	52 (84)	0	0	not reported
Effing (2009) RCT	0, 7, 12 months	not reported	not reporte d	421	153 (77, 76)	10, 1, 5, 5, yes	153 (36)	11 (7)	11 (16)	not reported
Taylor (2012) pilot RCT	0, 2, 6 months	not reported	not reporte d	507	116 (78, 38)	9, 2, 5, 6, no	116 (23)	25 (22)	47 (60)	No primary outcome, n/a
Khdour (2009) RCT	0, 6, 12 months	not reported	not reporte d	295	173(86, 87)	10, 1, 4, 4, yes	173 (59)	30 (17)	15 (17)	Hospital admission and HRQoL - NO
Koff (2009) pilot RCT	0, 3 months	not reported	not reporte d	not reported	40 (20, 20)	11, 0, 4, 4, yes	n/c	2 (5)	1 (5)	QoL – YES, n/a
Moore (2009) pilot RCT	0, 8 weeks for I, 7 weeks for C	not reported	40	33	27 (14, 13)	10, 1, 5, 3, no	27 (82)	7 (26)	4 (29)	No primary outcome, n/a
Hill (2010) RCT	0, for intervention group 1 month after 2nd session and 3 months after baseline assessment in control group to	131	110	100	100 (55, 45)	10, 3, 5, 4, yes	100 (100)	7 (7)	5 (9)	not reported

| | | make timeline similar | | | | | | | | |

| Ninot (2011) RCT | 0, 1 year | not reported | 101 | 61 | 45 (23, 22) | 11, 1, 4, 4, yes | 45 (74) | 7 (16) | 1 (4) | Walking - YES |

| Health education programmes, n=4 | | | | | | | | | | |

Author (year) study design	Time of study assessments and follow-ups	Participant flow data				Quality assessment	Participation rates			What is primary outcome? Is intervention effective for the primary outcome?
		Potential numbers identified, n = 1	Numbers assessed, n = 0	Numbers eligible, n = 3	Numbers included and randomised, n (I, C)	a, b, ci, cii, d	SPR, n (%)	SDR, n (%)	IDR, n (%)	
Littlejohn (1991) RCT	0, 1 year	not reported	not reported	166	152 (73, 79)	11, 1, 6, 4, yes	152 (92)	19 (13)	5 (7)	not reported
Petty (2006) RCT	0, 4, 8 weeks face to face, 4, 9 months by post	more than 500	not reported	not reported	214 (72, 69, 73)	10, 3, 3, 5, no	n/c	40 (19)	21 (29)	not reported
Rice (2010) RCT	0, 12 months	not reported	not reported	1739	743 (372, 371)	10, 1, 5, 4, yes	743 (43)	84 (11)	36 (10)	Combined hospital admissions and emergency visits - YES
Lemmens (2010) Before-after	0, 12 months (postal)	not reported	not reported	259	259 included	10, 2, 3, 1 no	189 (73)	39 (21)	n/a	not reported, n/a

Table 3.6 Odds ratio for participation according to study characteristics

Variable	Odds ratio	(95% confidence interval)	P
Year	0.99	(0.92, 1.08)	0.891
Quality score	0.85	(0.65, 1.10)	0.215
Exercise intervention	1.55	(0.47, 5.07)	0.470
Group intervention Individual	1.00	-	0.506 trend
Combination	0.17	(0.03, 0.81)	
Group	0.60	(0.17, 2.11)	

Figure 3.4 Participation rates in different studies ordered by year of publication. Error bars show 95% confidence interval
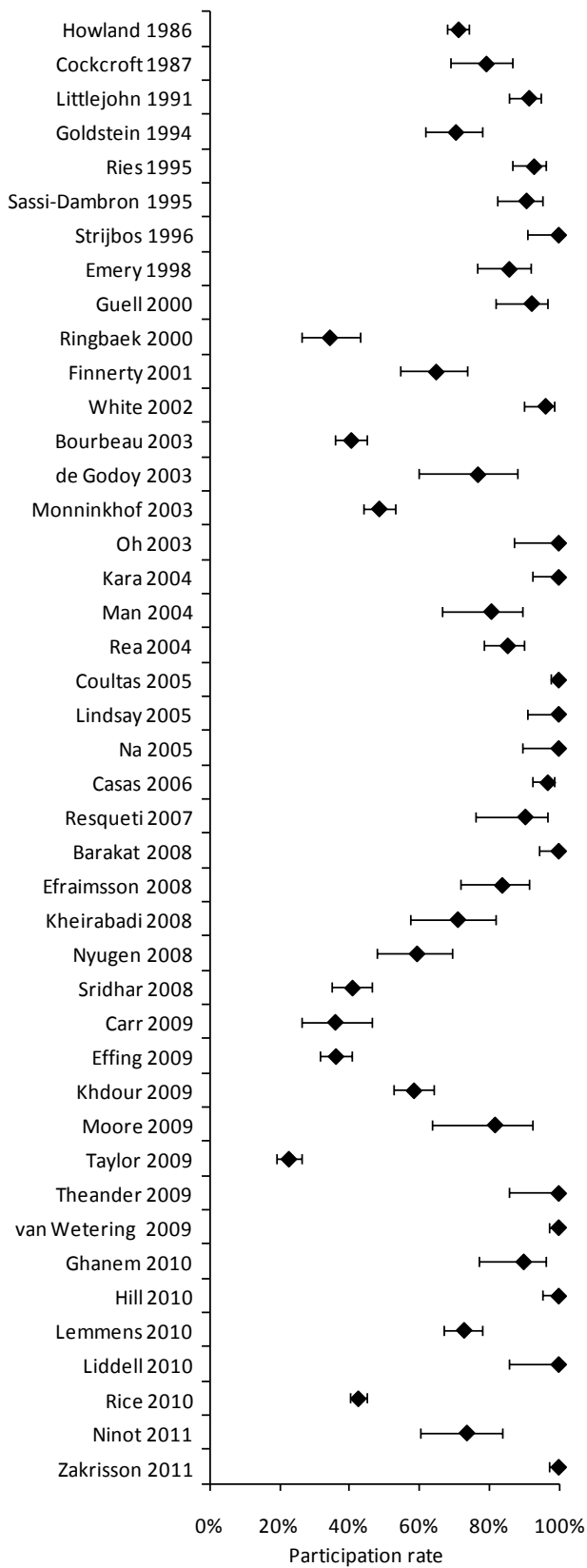
3.3.4.6 Reasons reported by the included studies for participation/non-participation, completion/non-completion

Non-participation among eligible patients was seen among 27 studies, 11 studies did not report any reasons for non-participation and 16 studies reported reasons for study non-participation that amounted to external, programme-related, study-related, personal and clinical/health-related factors and other reasons. It was difficult to differentiate between the participants who dropped out of the study and those who dropped out of the programme however, 48 studies reported reasons for study and/or programme dropout and the reasons given again fell into the same headings given for study non-participation. And two studies stated reasons for programme nonattendance which were mainly health-related. Table 3.7 presents reasons reported by studies for study non-participation, study and/or programme dropout and programme non-attendance

Table 3.7 Reasons reported by studies for study non-participation, study and/or programme dropout and programme non-attendance

Reasons for study non-participation	Reasons for programme non-attendance	Reasons for study and/or programme dropout
- Refused participation or did not wish to participate in study/ programme but no reasons for refusal were recorded/reported - Lived too far away - Lack of time - Transport problems - Participation in other research projects - Clash with other social activities/prior commitments - PR programme too extensive - Not contactable/no response - Failed to attend study appointment - Did not cooperate adequately - Could not commit - Changed mind before start of study - Lack of perceived benefit - Lack of interest - Refused without financial compensation - Too ill	- Ineligible - Fractured hip, exacerbation of low back pain	- Cardiac problems/comorbidities/illness - Surgery/exacerbation - Died - Diagnosed with lung cancer/neoplasm - Hospital admission because of abdominal pain - Admission to respite care/nursing home - Palliative care - Burden of evaluation/unwillingness to complete questionnaire - Lost to follow up - Withdrew extent - Did not return/did not keep appointment - Non-compliant/failed to cooperate - Insufficient diary data (not motivated, not capable) - Unable to use technology - Ineligible - Hypothesis that intervention encouraged uncomfortable levels

- Problems with change in medication - Hospital admission due to exacerbation - Died - Other reasons		of activity - Extent of exercise programme - Inconvenience of hospital attendance (assumed by study) - Transportation problems (inconvenience) - Change of address - Too busy - Angry not receiving oxygen - Lack of interest - Lacked motivation to continue - Language barrier - Phone line problem - Prior commitments - Following alternative therapy - Accident - Do not want to participate in group

3.4 Discussion

3.4.1 Summary findings

3.4.1.1 Incomplete reporting of participant flow data

This review provides information on how randomised and non-randomised studies, including before-after studies, of interventions that help to improve SM in patients with COPD, report participant flow and the actual 'participation rates' amongst these studies. The reporting of participant flow amongst studies of the two main interventions (PR and SM) was generally incomplete but better reporting was seen in studies published in and after 2001 (the publication year of the CONSORT statement). Only 16% of studies reported 'potential participants identified', and slightly more than a third (39%) reported 'numbers assessed for eligibility'. 'Numbers eligible' was better reported amongst studies (77%) but only seven (13%) studies reported on all levels of the participant flow before patient recruitment.

The SPR was not calculated for 13 (23%) studies due to lack of information on 'numbers eligible' for study. The SPR for the remaining 43 studies was higher than expected. Only eight (19%) studies had an SPR of less than 50%. Another unexpected finding was that 93% and 94% of the studies had an SDR and an IDR, respectively, of less than or equal to 30%. However, it was difficult to differentiate between 'numbers lost to follow-up' and 'numbers discontinued intervention'. In addition, 31 (72%) of 43 studies with SPR of >50%, had SDR of ≤30% but no obvious pattern could be deduced because of the lack of reporting on

participant flow data from 26 (84%) of the 31 studies. The incompleteness of data among the majority of the studies, limited the choice of study characteristics (including recruitment characteristics) to assess the effect on study participation rates and the four chosen characteristics did not influence the study participation rates. The reasons reported for study non-participation and for study/intervention dropout were similar and they comprised external, programme-related, study-related, personal and clinical/health-related factors.

3.4.2 Comparison with other literature

Some studies of both pharmacological and non-pharmacological interventions and surgical interventions, have examined reporting of participant flow diagrams (CONSORT statement recommended) including the type of information within the diagrams, in published studies identified from a single electronic database,[284] in six high-quality[285] and four high-impact journals,[286] with most journals endorsing the CONSORT reporting of participant flow.[284] These studies concluded that participant flow was poorly reported. In Toerien's study[285] 40% of studies failed to report 'numbers assessed for eligibility'. Meanwhile, only 39% of studies in this review reported 'numbers assessed for eligibility' but the study selection was not based on the quality of the journal. There was low reporting at this level of participant flow in studies perhaps because studies did not think it important to record numbers for external validity, they might not have considered that patients are part of the trial at that level or before randomisation and hence failed to record and report numbers at this level.[285,287] It has been acknowledged that studies of PR programmes do not include details or discuss adequately 'numbers assessed for eligibility' nor the refusal rate.[121,123]

Regarding reporting 'numbers of potential participants identified' the aforementioned studies did not look at this level (this level is not included in the CONSORT flow diagram). A drawback of strictly designed RCTs may be limited generalisability as the focus is often to have homogenous groups of patients to limit individual variation.[288] A recent literature review[121] of PR programmes looked at reporting of sample selection in studies of PR programmes and only 12% of studies had reported the number of people contacted for the study. In this review, the proportion of studies that reported at this level was slightly higher (16%). Bjoernshave[121] explained the lack of recording at this level was because people with COPD are not normally recruited from prevalence studies as prevalence of COPD is difficult to estimate and recruitment normally takes place from clinics or outpatient settings.

Nevertheless, if an attempt is made to record the total number of patients registered at a recruitment site 'denominator' then this data can be utilised to help generalise the study findings to the target group.[227]

Gross's review[286] found that only 43% of studies had reported 'numbers eligible'. In this review, more studies had reported this (77%) perhaps because most of the studies were published in and after 2001. Numbers at this level and numbers recruited helped to calculate the SPR, SDR and IDR and identify the actual patient 'participation rates' in studies of PR, SM and HE programmes for COPD patients. Only Keating's review[112] has explored patient non-attendance and non-completion, but only in PR programmes and the reported proportions were from a mix of quantitative and qualitative studies. A cut-off value of 20% for SDR is regarded as acceptable according to a quality assessment checklist http://www.sign.ac.uk/methodology/tutorials.html (accessed 20-8-14). And less than a third (29%) of studies in our review had a SDR of >20%, which suggests that most studies in this review would have fulfilled this particular quality criterion. Similarly to other studies[284,285] this review experienced problems in clearly identifying or differentiating between reports of 'numbers lost to follow-up' and 'numbers discontinued intervention'. A distinction needs to be made between these two types of attrition[287] to inform on implementation of interventions.

3.4.2.1 Variable definitions of participation among studies

Based on the study findings, previous reports of poor participation and retention in studies of PR and SM programmes[85,108,109,112] might not be justified. One explanation could be studies having different definitions for patient participation and thus the method of calculation of participation rates may have differed[108,289] or not having clear definitions making it difficult to identify if the proportions refer to the study or intervention.[109] Recent reviews[112,285] acknowledged that their studies gave varying definitions for 'loss to follow-up' and 'non-completion'. Examples here show discrepancies in reports of participation rates: two studies[238,255] in this review (Table 3.5) had high SPRs of 71% and 93%, respectively but Young[123] reported, SPR of 34% and 36% for these two studies. On investigation it appears that Young calculated SPR from 'numbers assessed for eligibility' and not 'numbers eligible'; Another study in this review[240] (Table 3.5) had a SDR of 29% and IDR of 18% respectively but Sabit[115] reported a dropout rate of 30% and it is unclear whether the proportion refers to the study or intervention.

3.4.3 Strengths and limitations

An attempt was made to identify numbers reported at each level of the participant flow from effectiveness studies. These studies may have decided to give more importance towards recording and reporting numbers for internal validity – a key feature of strictly designed or high-quality RCTs[288] rather than external validity. This finding is also acknowledged by the new Medical Research Council guidance on evaluation of complex interventions.[290] There is need to be cautious of the findings of high participation rates as only a minority of studies reported on all levels of participant flow before recruitment and in some cases 100% of eligible patients were recruited without providing the whole recruitment picture.

3.5 Conclusions

This systematic review has identified the 'actual' levels of participation and dropout rates in research studies evaluating PR, SM and HE programmes for COPD patients. These studies should consider recording and reporting participant flow numbers more completely. Only 19% of studies had SPR of less than 50%. The SDR and IDR was less than or equal to 30% in the vast majority of studies. These findings negate previous reports of poor participation and retention in studies of PR and SM programmes. Possible explanations include studies using their own definitions for what constitutes patient participation in both the study and the intervention within the study, or studies, not stating definitions clearly, making it difficult to identify whether the proportions reported refer to the study or intervention. Clear and uniform definitions will help to identify a valid estimate of patient participation rates in the study and the intervention and could promote the correct interpretation of studies and the implementation of effective interventions in routine care.

3.6 Implications

3.6.1 Implications for clinical practice

Based on the study findings of high study participation rates and low dropout rates in research studies of PR, SM and HE programmes, there is still a need to strongly endorse the active implementation of PR and SM programmes in routine care, as patients with COPD are participating, attending and completing them. Despite notable evidence of benefit from studies of PR programmes[291] and some benefit from studies of SM programmes,[84] in practice, these programmes do not seem to be widely implemented or some actively running ones are

closing down (Kennedy A. Senior Research Fellow. Personal Communication. Jun 2012) thereby, reducing opportunities for suitable patients to attend and gain benefits from the programmes.

3.6.2 Implications for future research

A recommendation is that future research studies provide clear definitions when reporting patient participation, enabling a true estimate of patient 'participation rates' and avoiding confusion amongst readers. To calculate 'participation rates', it is important for studies of PR, SM and HE programmes, to provide more information on patient participant flow. Incomplete reporting of patient recruitment data will affect external validity.[121] It is essential for studies to report these data to help HCPs interpret the study results and to decide if the results could be applied to their patients.[285,286]

Much focus on the implementation of non-pharmacological interventions has resulted in a shift, from conducting explanatory trials to pragmatic trials.[288]. One of the features of pragmatic trials is that they tend to recruit a heterogeneous patient group all with the condition of interest to maximise the trial results to usual care settings.[292] To record and report a clear picture of the recruitment process, studies can utilise the checklist provided by the extension of the CONSORT statement for reporting pragmatic trials.[226] Gross[286] stressed that studies should at least record and report 'numbers eligible' for recruitment. The addition of several boxes to the CONSORT flow diagram, before and after randomisation, has been recommended by Toerin,[285] which may help to get a better assessment of generalisability, estimate a true non-participation rate, and to establish a true intervention effect.

The next chapter will explore from published qualitative studies and using theory, factors/reasons that influenced an individual with COPD to participate and/or dropout from studies of PR, SM and HE programmes (SM support programmes) including from the programmes.

Chapter IV. A qualitative synthesis and application of theory to understand participation behaviour of patients with COPD in research studies of COPD SM support programmes

This chapter through the thematic 'framework' synthesis:

- Identifies the reasons reported by patients with COPD for attending, not attending and dropping out of studies of SM support programmes including from the programmes

- Applies behavioural theories to the identified patient reasons to explain patient attendance, non-attendance and dropout behaviour

4.1 Introduction

The previous chapter showed high study participation rates in studies of COPD SM support programmes and low dropout rates that were contradictory to previous reports, however, due to the poor/unclear recruitment picture seen among the majority of the included studies the problem of participation may still remain. In addition, the problem of poor participation and retention in COPD SM support programmes has been acknowledged in clinical practice[113] and there is plenty of anecdotal evidence too. Understanding the problem of poor patient participation and retention is therefore critical[293] to help improve patient participation and retention.

In Chapter I (section 1.1.1.4.5) various reasons reported for patient non-attendance and non-completion have been presented. In addition, a mixed-methods review[112] of participation in PR programmes attributed patient non-attendance and dropout to personal, clinical, social and physical barriers. Only one study[122] of a COPD SM programme has explored reasons for high or low attendance and the findings comprised a mix of socio-demographic, personal and clinical factors. It has been suggested that socio-demographic and clinical factors may be insufficient to understand the problem of poor participation and completion in COPD SM support programmes; a new approach was therefore needed.[19,113,294]

An approach which views participation as a health behaviour, and utilises health behaviour theory and constructs related to behaviour change, could further understanding of participation behaviour.[295] Such an approach could help identify appropriate targets for an intervention[294] with the ultimate aim of improving patient participation in COPD SM support programmes and thus enhancing patient outcomes. Health behaviour theory has been utilised in several studies as shown in the previous chapter to explain or predict participation, particularly attendance in patients with a variety of conditions, however, only one study[110] has used such an approach in COPD.

The aim of this qualitative synthesis was, therefore, to explore the factors that might explain participation in COPD SM support programmes.

4.1.1 Review aim

To explore factors that might explain patient participation, non-participation, completion and non-completion in both studies of interventions that provide self-management support and in the actual interventions by patients with COPD.

4.1.2 Review questions

(1) What are the possible reasons affecting patient participation and/or completion in studies of COPD SM support programmes including in the programmes?

(2) Can behavioural theory help to explain patient participation behaviour in studies of COPD SM support programmes including in the programmes?

4.2 Methods

This qualitative synthesis was part of the broader systemic review in Chapter III and so, one search strategy (section 3.2.1) was implemented to identify the relevant qualitative and quantitative studies. As a result, the population of interest and the interventions were also the same.

4.2.1 Study selection

All qualitative research exploring reasons for participation and/or completion in studies of SM support programmes and including in the programmes by patients with COPD were considered for inclusion.

4.2.2 Quality assessment

The modified checklist from the critical appraisal skills programme (CASP) was used to assess the quality of the qualitative studies as operationalised by Campbell[296] (and personal communication September 2010). Campbell's modifications included identification of a theoretical perspective from the primary studies, overall grading of the quality of the paper, and a summary of questions about specific aspects of the method. Description in qualitative studies, have been differentiated by the 'thickness' or 'thinness' of data.[297] Noyes in their review appraised, using the CASP checklist to assess methodological quality and Popay's checklist[298] to assess theoretical dimensions among the included studies. Studies of high quality or of 'thicker' description, offer greater preference to subjective experiences and meanings e.g. *verbatim* quotes and use theory to offer explanation for a behaviour, which increases the potential for explanations and transferability of findings to other settings.[297] Whilst, studies of low quality or of 'thinner' description offer little if any preference to

respondents' views, and do not use theory. In this review, studies of both high and low quality were included to show the comprehensiveness of the literature.[299] Low methodological quality studies can still produce new insights, grounded in the data, while high quality studies may not be clear in their interpretation, hence none of the included studies were excluded after quality assessment.[300] The study findings were differentiated between participant *verbatim* quotations and authors interpretations of the views. Greater weight was placed on directly reported views[301] or studies of 'thicker' description.

4.2.3 Data abstraction

Unlike Campbell[296] who used the CASP checklist to also identify key concepts emerging from the studies, all of the text given under the 'Results' section of each study was extracted because some studies undertake simple analysis which only includes describing and summarising of data making it difficult to identify key concepts.[301] Data synthesis in this review included either *verbatim* quotations, *verbatim* quotations with authors' interpretations and/or authors' interpretations of the study data but not exemplified by *verbatim* quotations e.g. "Some of the participants described how they wanted to help themselves and be active partners in the management of their condition. The following quote reflects this view:

> *"...giving me the opportunity to help myself and do something positive instead of just taking this, taking that'"* (author's interpretation supported by *verbatim* study data)

<p align="center">Or</p>

> "One patient had asked for pulmonary rehabilitation himself. He had been in rehabilitation before and was very positive about it. Moreover, fear resulting from worsening dyspnoea led him to search for alternative treatments. Being eventually referred was a great relief and the anticipation of being in pulmonary rehabilitation reduced his feelings of anxiety" (author's interpretation of data <u>not</u> supported by *verbatim* study data)

The study characteristics extracted from the included studies were:

- Whether or not they were part of a mixed-methods study
- Sample selection
- Data collection
- Data analysis

- Themes exploring factors influencing an individual's participation (and attendance, non-attendance, or dropout) behaviour in a SM support intervention

- Themes exploring an individual's beliefs, knowledge or behaviour of disease and/or of self-management which might influence participation (and attendance non-attendance, or dropout) behaviour in a health care intervention

Appendix 4.1 includes the data abstraction form with the embedded quality assessment checklist

4.2.4 Data synthesis – Thematic 'framework' synthesis

The thematic 'framework' synthesis[301,302] was conducted to answer the review question. Thematic synthesis[301] has been adopted from the term thematic analysis, translated for the analysis of primary research in reviews. Thematic analysis is 'not another qualitative method but a process that can be used with most, if not all, qualitative methods'. The analysis has been used previously to identify recurring themes, conduct analyses of these themes and draw conclusions in systematic reviews.[303] All the text under the 'Results' section of the included primary studies was uploaded into the Nvivo8 software. The synthesis involved three distinct stages:[301]

1) Coding text

- Line by line coding of the text in each of the primary studies was conducted to identify concepts or initial free codes keeping the review question in mind. This stage is an important stage as it includes the *translation* of concepts from one study to another. Translation is taking the concepts from one study and recognising the same concepts in another study, though they may not be expressed in identical words. For example: data under a subtheme 'positive influence of the referring medical practitioner' in Arnold's study[304] was similar to data presented under the subtheme 'referral to rehabilitation' in Fischer's study.[305]

- In addition to identifying initial codes from primary studies, new codes or concepts not identified in the original studies were also developed, for example: 'last resort to learn to cope'. In some cases, a statement could be categorised into several codes, for example 'last resort to learn to cope' or 'only hope to remain independent'

- Furthermore, codes were generated from texts in primary studies that were interpreted under a single code, e.g. we generated the following codes, 'negative view of programme from experience and created by others', 'negative experience with health care staff in location of programme', and 'location of the programme' from text placed under a single code 'past negative experience(s)' in Taylor's[114] study.

2) Development of descriptive themes and subthemes
- The identified codes or concepts were looked for similarities and differences, grouped accordingly and placed under new codes to capture the meaning of groups of initial codes. This process led to the production of descriptive themes and subthemes, e.g. Theme - 'reasons for attending PR programmes'; Subtheme – 'referrals by health care professionals (HCPs) – with explanation for referral'.

3) Generation of analytical themes
- These descriptive themes and subthemes were 'mapped' onto two a *priori* theoretical models with subsequent 'generation of analytical themes' that went beyond the findings of the original studies. A *priori* 'framework' characteristic to framework synthesis is informed from the literature and team discussion to synthesise findings.[306] In this stage, the recommended 'best fit' framework approach[302] was applied whereby, an existing conceptual model/framework, that most closely matches the research topic under study is utilised to carry out the framework synthesis. This review utilised the 'ASE' model that was previously used to explain intention to participate in an asthma SM programme[184] and the 'SRM' that included the 'NCF' that was used to explain cardiac rehabilitation utilisation[181] and examined whether our results were consistent with either or both these models. Both the original models and how Lemaigre[184] and Keib[181] utilised the respective model to explain patient participation in their studies has been described in Chapter II (section 2.3.2.3, study denoted by (y) and (u)). It should be noted that the definition of one of the ASE model constructs vary slightly from those used in the original de Vries model[14] (Figure 2.8 in Box 2.4), particularly that of 'self-efficacy' which focuses primarily on external barriers and is labelled by Lemaigre as 'external or structural barriers'. Figure 2.10 (Chapter II) illustrates the distal, proximal socio-cognitive and external constructs of

the 'adapted model' that explained intention to participate in an asthma SM programme in Lemaigre's study.[184] Hence, this review refers to the ASE model as the 'adapted ASE model'.

4.2.5 Quality assessment and data validity

A second reviewer (TM, expert in qualitative research) read the included studies to familiarise themselves with the data, extracted emerging themes and subthemes and conducted the quality assessment from a sample of three of the identified studies at random. The coding for the emerging themes and subthemes were discussed between the two reviewers. Following this discussion a list of definitive themes and subthemes was produced. The second reviewer commented on the draft, any disagreements were discussed. A third reviewer (the study supervisor) was consulted to resolve any unresolved disagreements and a final version was agreed.

In addition, another reviewer (LS, health psychologist) independently mapped the themes and subthemes onto the two chosen theoretical frameworks and the mapping was discussed. Following that, a final version was agreed.

4.3 Results

Six studies were included in the review (Chapter III, Figure 3.3, PRISMA flowchart). Two studies[307,308] were excluded because patients reasons for participation and/or completion were not explored. Five of the included studies examined PR programmes,[114,304,305,309,310] just one study examined a COPD SM programme.[122] Table 4.1 presents the study characteristics including the quality appraisal score.

Table 4.1 Characteristics of included qualitative studies

Study	Arnold (2006)	Fischer (2007)	Taylor (2007)	Denn (2008)	Gysels (2009)	Sohanpal (2012)*
Intervention	PR	PR	PR	PR	PR	SM
Country	UK	Netherlands	UK	UK	UK	UK
Aim of study	Explore experiences of patients who had been invited to attend PR to gain some insights into the aspects that may influence adherence	Explore factors (role of patients treatment beliefs, goals and practice barriers) predicting dropout in rehabilitation	Explore why participants who took part in a randomised controlled trial of a nurse-led intermediate care package (intervention: 4 week group-based PR programme) declined to take part in the intervention.	Explore patients understanding and expectations 8 weeks before and after taking part in a PR programme	Understand how people respond to breathlessness: role of PR	Explore reasons for participation to a COPD-specific SM programme from patients with COPD and lay tutors.
The following was explored from the included studies for the synthesis	Experience of PR adherence	Factors predicting participation and dropout in PR	Reasons for non-participation in research study of a PR programme	Expectations before and after taking part in a PR programme which include factors affecting participation	Challenges of participation in PR	Reasons for high and poor attendance in a COPD SM programme
Was the study part of a mixed-methods study?	No	No	Yes	No	No	Yes
Sample	20	12	39	5	5	20
Type of data collection	Individual interviews	Individual interviews	Individual interviews face to face and by telephone	Focus group	Observations, interviews and field notes	Individual interviews
Primary study underpinned by behavioural theory	No	No	No	No	No	No
Emergent themes and subthemes from primary studies on participation and/or completion	1) Experience of adherence to PR: Positive influence of the referring medical practitioner - Self-help	1) Reasons for referral to rehabilitation. 2) Beliefs about PR: - Anticipated benefits of participation in PR programme.	1) Travel to and location of pulmonary rehabilitation class [n = 19/39] (48.7%) 2) Perception of Benefit	1) Stoicism 2) Fear 3) Comradeship 4) Empowerment	1) Pulmonary rehabilitation 2) Challenges 3) Benefits	1) Reasons for poor attendance 2) Reasons for high attendance

	2) Experience of non-adherence to PR: - Negative influence of the referring medical practitioner - Social support and motivation 3) Experience of adherence to PR	- Concerns about participation in a PR programme. - Anticipated reasons for dropout.	[n = 19/39] (48.7%) 3) Competing commitments or demands [n =15/39] (38.5%) 4) Poor or negative understanding of research study [n = 12/39] (30.8%) 5) Past negative experience(s) [n = 11] (28.2%) 6) Perception of health status [n = 10/39] (25.6%)	5) Concept of severity		
Modified CASP quality checklist score (out of 28)	22	25	24	21	24	27
Key: PR – pulmonary rehabilitation SM – self-management CASP - critical appraisal skills programme *The study was included in the review as a grey report (2009) after it met the reviews' inclusion criteria. The grey report was published in 2012.						

4.3.1 Quality assessment and data validity

Reviewer TM conducted the data abstraction and quality assessment on one of the three studies to discuss any queries about the form, and to clarify interpretations of the quality assessment questions. Following that TM carried out the data abstraction and quality assessment on the remaining two studies. The agreement on the modified CASP checklist score was 100%. The studies were judged to be of reasonable quality. There was variation in study reporting. Particularly, there was lack of clear reporting on sampling strategy;[304,305,309] the data analysis process;[310] the research questions;[309] the researcher-participant relationship was not reported in any study; and in some cases the authors' interpretation of data was not supported with verbatim data.[114,305,309]

The level of agreement with LS with regard to the mapping of themes and subthemes onto the adapted ASE model was better (97%) in comparison to mapping onto the SRM (88%). The subthemes did not map quite easily onto the SRM and this might be because the data was not explored in studies in line with illness or intervention representations. An agreement was reached with the mapping following another discussion.

4.3.2 Synthesis findings: Development of descriptive themes and subthemes

The following were the emergent themes with 30 subthemes from studies of COPD SM support programmes:

4.3.2.1 Themes emerging from studies of COPD SM support programmes

(A) Reasons for attending programmes

(A1) Reasons to continue and complete programmes

(B) Reasons for not attending programmmes

(C) Reasons for dropping out of programmes

(C1) Potential reasons for dropping out of programmes

4.3.2.1 Themes with emerging subthemes from studies of COPD SM support programmes

(A) Reasons for attending programmes

1. To help themselves – to improve health status

Participants in three studies[122,304,305] wanted to attend the programme to learn about their condition and to help themselves. One participant saw taking part as a positive step to help oneself:

> *"giving me the opportunity to help myself and do something positive instead of just taking this, taking that"[304]*

Another participant[305] initially decided not to attend the programme as attending would have interfered with their plans for the summer and the exercise would have left them exhausted. But then the same individual decided to attend as their health was interfering with their social activities:

> *"I always say to my friends: 'I'll be back in the summer and then we'll have a good time together'. So I thought I'd be training three days a week and the other days I'd be completely worn out. My summer would be lost. So, at first I decided not to participate. But last time, I went to the beach. It was such a disappointment. And I thought: something needs to happen if I want to be able to do something next year. And that's when I decided to go"*

2. Overcoming prior commitments and demands - to see improvements in health

Nearly all patients in Fischer's study[305] were happy to give up various prior personal or professional commitments and chose to attend the programme to see improvements in their health:

> *"Even if you have to give up those things...you have to make choices. Do you want to grab a cup of coffee with someone or do you want to work on your health?"*

3. Gain control of condition

Three studies[304,305,309] reported that participants felt immense relief on getting an opportunity to participate in the programme as it would help them gain control of their condition (not exemplified by quote). Some participants felt that living with COPD had left them vulnerable to events outside of their control, such as the weather, which left some patients anxious about how they were going to manage:

> *"It's going to be hotter this summer, I'm dreading it."[309]*

4. Last chance to cope and remain independent

For some attending the programme was their only hope or last chance of coping with the disease and remaining independent. The thought of being dependent on others was for some their *"greatest fear"* and described as *"devastating"* (not exemplified by quote).[309]

5. Referrals by health care professionals – with explanation for referral

The majority of participants in two studies[304,305] attended the programme because they were referred by health professionals and were told that attendance may bring health benefits. One participant was explained by their doctor that attending the programme might improve their health and breathing.

> *"she said it would be half-exercising and then talks about it and it might improve your general health which would help your breathing"[304]*

Another participant[305] did not understand or think they needed to be referred but went because the doctor thought it would be beneficial

> *"No, there was no real reason for referral, because the X-rays were unchanged and my lung volume was the same. The oxygen in my blood had gone up so there was no real reason. But [the doctor] thought it might be beneficial. I did not ask why."*

Fischer's study reported that referral to the programme was made for patients who had frequently been admitted to hospital and how the hospital couldn't do anything more for them but that participating in the programme could help improve their condition. A participant attended ~~PR~~ because they were told how other patients were able to take up activities (e.g. walking more than usual) after participation in the programme.

> *"The lung specialist said: 'There's nothing I can do for you'. But he said that he had seen patients who were able to take on some activities after participating in a rehabilitation programme. 'Cos now I can walk up and down the street and that's it. Perhaps I'll be able to walk one block then. And that was the doctor's aim. They also told me: 'We can't cure you. But the intention is to get you some more [lung] volume."*

In some cases participants attended because they themselves had no knowledge of the programme and had no reason to doubt the opinion and advice given by their consultant about the programme.

> *"because X (consultant) advised it and I go on advice from somebody I think should know what they are talking about"[304]*

> *"because if people in those positions make suggestions then I listen to them because I have no medical knowledge"[304]*

These participants completed the programme.

Also, four of the seven participants in Fischer's study[305] did not remember why they were referred and stated that they were not provided any explanation but went anyway (not exemplified by a quote).

A participant (now an enthusiast of the programme) in one study[310] was initially surprised of being invited to enrol in the programme which involved exercise. Perhaps the participant decided to attend because the HCP mentioned they were an ideal candidate to join the programme.

> *"...She did research into exercise for us respiratory patients, […] she said to me: 'I've looked at your papers and you'd be an ideal candidate, would you like to join?' and hardly being able to breathe I said to her: 'Well, what's it all about?' So she said: 'Well, it's a little bit of exercise.' That's when I blew, I said: 'You've gotta be joking love', I said: 'I can't walk, I can't talk, how the bloody hell do you think I can do exercise?"*

6. Previous positive experience of the programme – social and emotional support from staff and other participants

The study by Fischer,[305] unlike the other four studies, explored and reported reasons for attending amongst both participants who were new referrals and those who had attended the programme previously. Reasons for re-attendance from previous attendees included:

One participant took comfort in supervision being provided during the programme and felt their care was part of an integrated system.

> *"See, the good thing is you're being supervised when you're busy. And then they suddenly say: 'You'd better see the speech therapist'. And that's nice. It's one integrated system. All these people are watching you"*

Participants felt understood by healthcare staff and felt they could talk openly with them:

"I noticed it during the intake consultation and when talking to the nurse: they quickly understand what you mean. Of course, they deal with that everyday. Every story, every excuse, they must have heard for at least 80 times. So there's no need for decorum, withholding things. They'll know. There's no point in trying to deceive them"

One participant feared their worsening dyspnoea and wanted to attend the programme again because of their previous positive experience. A timely referral was a welcome relief which reduced feelings of anxiety (not exemplified by a quote).

Participants, both male and female re-attended ~~PR~~ because they enjoyed the social experience. The males enjoyed *"learning from others"* how to do exercises, while the females wanted to learn from others how to cope. Participants gave each other encouragement and emotional support. Some previous attendees felt strongly that they were understood within the programme arena whilst outside they experienced stigma and misunderstanding about their condition, especially those who used a wheelchair.

7. To socialise

Patients' motivation to attend the programme in two studies[122,304] was because it would get them out of the house and meet people with the same condition. For some, it was the only place they could socialize.

"If you're on your own and you go along to these things and enrol with other people, at least it gets you out of the house"

"I don't have many friends so I did use it as a bit of social time"

8. Altruism

Helping others was a motive for programme attendance for two participants.[122]

"I tried to help, really. In myself, I'm all right…I said I'd go...because I'm interested…if it can help other people, and I think it probably did…"

(A1) Reasons to continue and complete programmes

Arnold's study (2006) explored experience of adherence (taking up and completing) to programmes. The reported explanations have been sub-divided, taking up is described under theme A and reasons for continuation and completion of programmes are described here.

9. Personal benefits and peer support

Some participants[304] enjoyed and felt real benefits in attending the programme. The group format was liked as participants could socialise and felt supported. Attendance increased their confidence, self-esteem and mood, illustrated with quotes:

> *"once I'd gone once I wouldn't have missed it for anything"*
>
> *"I enjoyed going there because I liked the exercise"*
>
> *"it made me feel so good that I was achieving so much"*
>
> *"I think psychologically I got really low without realising it...it [PR] was a real turning point...I improved 100% in being able to get around"*

Two participants in Arnold's study missed a couple of sessions of the programme. Both felt that on some days they just could not be bothered going to the programme:

> *"most of my days are like that, get up and feel I can't be bothered"*
>
> *"I just felt I couldn't go"*

However, perhaps because of achieving personal benefits, both these participants continued and completed the programme.

In study by Denn[309] some participants might have continued attendance because of the support and suggestions they received from peers. One participant shared his experience of exhaustion on attending earlier sessions and received understanding and sympathy from peers:

> *"Does it tire you out? It does me [on] that day, the next day I'm alright, I can carry on."*

> "Another said: *When we first started for two days [after attendance] I did nothing.*"

Another participant who was angry over not being able to quit smoking despite trying several methods heard another participant share their experience of how difficult it had been for them to quit and what helped them to quit:

> "*I smoked for nearly 50 years… I can't tell you how many times I tried to give up… a doctor talked nicely and made sense and I never looked at it no more.*"

(B) Reasons for not attending programmes

10. Perceived exercise would worsen health

Taylor's study[114] explored non-attendance from study participants. Ten of the 39 interviewees feared taking part as they perceived the programme detrimental to their health. They felt that the breathlessness would increase from exercising:

> "*I wasn't concerned; I just didn't like the idea of doing meself in. That is hard, but when your breathing is bad it's a disaster!. just, uh, didn't like the idea.*"

Moreover participants perceived the programme content to be vigorous, floor based and strenuous.[114]

11. Perception of health status

Participants' reported that the unpredictability of their health status (a commonly reported feature of COPD) restricted their ability to commit to the programme.[114] Some felt their condition was too severe and no improvement was possible and there was no guarantee of benefit. Participants were frightened that they might suddenly get ill for example from flu or pneumonia and this could become a barrier to attend and dropout from the programmes.[305] In two studies[122,310] the challenge of participation was amongst participants confined to their wheelchairs, who were reliant on their family/friends to get them out of the house, who felt they could hardly breathe or make any basic movements, and did not believe that they were capable of doing any exercise (not exemplified by quote). Whilst, a participant in study by Arnold[304] refused to attend the programme in the summer as he felt much better in the summer months:

> "*I thought that's going to take two days out of my weeks in the summer- I'm not doing that*"

There were some participants who just did not consider their ill health to be poor or serious enough to warrant attending the programme.[114]

12. Lack of perceived benefit to participation in programme or research study

Almost half of the study participants in Taylor's study[114] did not perceive benefits from programme participation. It seemed that some interviewees expected a new treatment, perhaps new drugs with reassurance that it may help, shown in the quote below:

> *"I mean the thing is if someone goes to see you on this study thing, yeah? And you sit down there for half an hour and you talk and you tell and there must be something you can say "Well, here we are. Try that. That may help you."*

13. Lack of understanding of research study of SM support programme

Twelve of 39 participants in Taylor's study[114] lacked understanding of the research study and programme. Participants felt they were not given enough information about the study and medical jargon did not help. Participants felt they were being asked to be guinea pigs to test out drugs, illustrated below.

> *''I just thought it was a ... oh, what can I say ... one of these test programmes, do you know what I mean? Like a guinea pig programme.''*

14. Negative view of programme from experience and created by others

One participant[114] was put off from attending because of receiving negative feedback from a friend who did not gain any benefits from attendance:

> *''See, I've got a friend that's got this ... He's got very bad breathing. And I said to him the other day. And he said ''Ah, it's a waste of time. I was down there,'' he said. ''Waste of time,'' he said ''Then we's sitting there for half the day talking rubbish.'' So that didn't help me. I thought. ''Yeah,'' he said, ''That's all they done.''...''No,'' he said, ''I ain't going back there no more.''*

In some cases patients were reluctant to attend as they had negative experiences of exercise and research studies. Patients had a poor self-image or self-confidence related to exercise or patients did not enjoy their previous research experience and feared that the study may involve clinical tests (not exemplified by quote).

15. Prior commitments and competing demands

A participant in Arnold's study[304] was unable to commit to taking part–because of prior commitments which were considered more important and enjoyable:

> *"when the dates came through we were going on holiday and that was more important"*

> *"I would do it but not on Fridays 'cause I go to a community course. It's (i.e. the community course) great, we really enjoy it so I'm not going to miss that"*

Personal and professional obligations were barriers to attend COPD SM support programmes.[114,122,305] Fifteen participants in Taylor's study[114] gave competing demands as a reason for non-attendance. This reason was given amongst participants not wanting to attend or dropping out from the programme in Fischer's study.[305] Competing demands included caring for other family members, looking after pets, family summer holidays planned, disruption to home care routine and home services. Some others seemed too busy with the business of having a chronic condition and missed the course because of hospital appointments, hospital admissions and illness. Day times were inconvenient for some in full-time employment.

16. Burdensome journey (physical barrier)

Fischer[305] explored reasons for not attending and dropping out of programmes and did not necessarily differentiate between the two behaviours. Transport difficulties were commonly reported as a reason not to attend[122,305] and drop out of the programmes.[305] Many study participants[114,305,310] found travelling to the programme venue most burdensome. This was mostly experienced by people with restricted mobility or being housebound. Restrictions included use of oxygen and nebuliser regimes. The burdensome journey included the use of public transport, parking and even walking a long distance to get to the class once at the venue as stated by one individual:

> *''Charing Cross don't lay on transport (route) ... the ambulance picks up the wife and myself because my wife carries me portable oxygen with her ... But I, I definitely wouldn't be able to walk the stairs down to the train and I definitely wouldn't be able to walk from Hammersmith bus stop all the way round to where you pick up the bus to go to Charing Cross.''*

17. *Negative experience with health care staff in location of programme*

In one study[114] attending hospital for the programme was unpopular amongst some of the participants because of negative experiences with health care staff and so belief in the competency of health care staff was reduced (quote given does not justify this statement, hence quote not given here)

18. *Location of the programme*

Participants in Taylor's study[114] did not want to attend the hospital-based programme because the hospital was known to have MRSA colonisation previously and had received bad press. Another participant[305] did not want to attend because he described himself as a homebody and felt uncomfortable being away from home for such a long time (not exemplified by quotes).

19. *Seasonal weather*

There was also a concern amongst some participants[114] that seasonal weather could affect health status and exercise capacity (not exemplified by quotes).

20. *Referrals by health professionals – without explanation*

Two participants in Arnold's study[304] had refused participation because one did not know the medical referrer and in another case, their doctor was not convinced that the programme would be helpful:

> *"this may or may not help you"*

A patient in another study[305] declined participation as the physician mentioned the programme would be *"intensive"*.

(C) Reasons for dropping out of programmes

21. *Suffering an acute exacerbation*

One study[310] reported that when an individual suffers from an acute exacerbation it can make them weak which negatively affects their mood and motivation which includes dropping out from the programme. The statement does not exemplify dropout but the downward spiral experienced by a participant on experiencing an acute exacerbation:

> *"The pulmonary rehab is a miracle [...] because before I went there [...] my husband would say: 'Shall we go down and see John and Juliana?' and the thought of walking out that gate into the car, I would be absolutely gasping, [...] I made excuses not to go out and this is what happens, [...] the more you're housebound, the more depressed you get."*

22. Psychological limitations

One participant did not complete the programme as he seemed to suffer from depression owing to his condition and felt agitated and uncomfortable amongst a large group of people[122]:

> *"I didn't [want] to sit through too much because I tend to get a bit depressed and agitated and what have you...I don't like getting in with a lot of people..."*

23. Not ill enough

Three out of the seven participants in Sohanpal's study,[122] two of whom, were in employment did not consider themselves sufficiently affected by the disease to make attendance worthwhile. These participants were able to continue with most of their routine activities and did not to require any further help with their condition, illustrated by a quote below:

> *"...basically after 10 to 15 minutes I realized no I don't belong here [at the course], 'cos the people there [at the course] are worse than me...these people couldn't even walk up and down the street without having a...breather so I'm not like that..."*

24. No change in health status after attending one session

One patient suggested that patients were looking for miracles just after attending one session:[310]

> *"You get people coming in [...] just once and they really expect a miracle over night. And because nothing has happened they won't bother coming back anymore"*

25. Social isolation can reduce confidence

A feature commonly encountered amongst patients suffering from COPD is experiencing good and bad days. The author in one study reported that living alone led to five participants missing a few sessions and two dropped out of the programme entirely.[304] Those who missed a few sessions of the programme said:

> *"most of my days are like that, get up and feel I can't be bothered"*

> *"I just felt I couldn't go"*

Whilst participants who dropped out completely felt bad but could not continue to attend the programme because of lack of encouragement or lack of confidence:

> *"being on my own there is no-one to give me a bit of a push or encouragement"*

> *"for most people if there's someone around it gives them a little more confidence"*

(C1) Potential reasons for dropping out of programmes

Fischer's study[305] explored from participants possible reasons for dropping out of the programme.

26. Intensity of the programme

One popular reason that could lead to one dropping out of the programme as the intensity of the programme. Some participants felt that attending should not result in exhaustion as it would interfere with simple daily routines such as not being able to eat after training, illustrated by the quote below:

> *"The only reason I can think of is when I'm worn out when I come home. If it lasts...and you are exhausted for the whole evening and the next morning. That's not what it's supposed to be like. Sure, it can happen the first week, you can expect that. But not that you are too tired to eat after training."*

27. No improvements seen

Three participants who had not previously attended the programme were very clear that if they did not see any improvements for themselves halfway through the programme, they would dropout:

> *"Look, if I didn't notice any improvement _ I mean, after three weeks you can't tell- but when I'm halfway through the programme and I can't feel no difference, I would be wasting my time."*

28. Training with other participants

Eight patients in the study had concerns about training with other patients which could affect participation in these programmes:

> *"Well, some are only there for the fun instead of to get better. That's not what it's meant for, of course. It can be a nuisance when they're chattering for 5 or 10 minutes, sitting on a fitness machine, while in the mean time you could have used it. But you don't wanna send them away, of course."*

29. Lack of transport

The author[305] mentioned other factors that could become possible reasons for programme dropouts and suggestions on how to overcome them but they are not exemplified by verbatim quotes. Completing the programme would be difficult for patients who lived alone, had no car of their own, who were too ill to drive and who did not want to ask for help from others to drive them to the programme. Alternatives should be provided for these patients such as car loan, shared transport or financial compensation by healthcare insurance (not exemplified by quotes).

30. Psychosocial factors

According to Fischer[305] psychosocial factors such as homesickness, lack of support from staff and conflicts with other patients in the programme could result in patients dropping out of the programme (not exemplified by quotes).

Appendix 4.2 has documented some instances where there was a difference in the verbatim data interpretation to that of the primary study author and this was checked by the study supervisor.

The emergent themes were summarised into three main/overarching descriptive themes with 30 subthemes (Table 4.2)) related to reasons for:

(1) Attending with reasons for continuing and completing COPD SM support programmes;

(2) Not attending COPD SM support programmes;

(3) Reasons, or potential reasons, for dropping out of COPD SM support programmes

Thirty subthemes were mapped onto both the theoretical models (Box 4.1); four subthemes were not mapped onto either owing to limited primary data and lack of correspondence to

model constructs. In some cases subthemes were mapped onto more than one theoretical construct within the same model for example, subtheme *'14.Negative view of programme from experience and created by others'* was mapped onto the 'attitude' and the 'social influence' construct of the adapted ASE model; *'1.To help themselves – to improve health status'*, was mapped onto three separate constructs, the 'illness representations – controllability', the 'consequence' and the 'intervention representations' construct (Box 4.1). In addition, overlap between different model constructs was observed, for instance, the same subthemes that were mapped onto the 'attitude' construct of the adapted ASE model, were also mapped onto the 'intervention representations' construct of the SRM (Box 4.1).

Table 4.2 Summary list of overarching descriptive themes and subthemes

Studies of COPD SM support programmes		
(1) Reasons for attending with reasons for continuing and completing programmes	**(2) Reasons for not attending programmes**	**(3) Reasons or potential reasons, for dropping out of programmes**
1. To help themselves – to improve health status	10. Perceived exercise would worsen health	21. Suffering an acute exacerbation
2. Overcoming prior commitments and demands - to see improvements in health	11. Perception of health status	22. Psychological limitations
3. Gain control of condition	12. Lack of perceived benefit to participation in programme or research study	23. Not ill enough
4. Last chance to cope and remain independent	13. Lack of understanding of research study of PR programme	24. No change in health status after attending one session
5. Referrals by health care professionals - with explanation for referral	14. Negative view of programme from experience and created by others	25. Social isolation can reduce confidence
6. Previous positive experience of programme– social and emotional support from staff and other participants	15. Prior commitments and competing demands	26. Intensity of the programme**
7. To socialise	16. Burdensome journey	27. No improvements seen**
8. Altruism	17. Negative experience with health care staff in location of programme	28. Training with other participants**
9. Personal benefits and peer support*	18. Location of the programme	29. Lack of transport**
	19. Seasonal weather	30. Psychosocial factors**
	20. Referrals by health professionals – without explanation	
Key: SM – Self-management *Reasons for continuing and completing programme ** Potential reasons that could result in dropping out of programme		

Box 4.1 Mapping of descriptive themes and subthemes onto the theoretical models

Adapted ASE model	Themes with subthemes		
	Reasons for attending	**Reasons for not attending**	**Reasons for dropping out**
Distal determinants Demographics – educational level	n/a	n/a	n/a
Clinical – subjective symptoms	1. To help themselves to improve health status[#]	11. Perception of health status	21. Suffering an acute exacerbation 22. Psychological limitations 23. Not ill enough
Proximal socio cognitive determinants *Attitude* **– personal and general benefits from participating**	1. To help themselves to improve health status[#] 3. Gain control of condition 4. Last chance to cope and remain independent 6. Positive previous experience of programme 7. To socialise 9. Personal benefits and peer support* 8. Altruism	10. Perceived exercise would worsen health 12. Lack of perceived benefit to participation in research study 14. Negative view of programme from experience and created by others[#]	24. No change in health status after one session 26. Intensity of intervention** 27. No improvements seen** 28. Training with other participants**
Social influences	5. Referrals by HCPs – with explanation	14. Negative view of programme from experience and created by others[#] 20. Referrals by HCPs – without explanation	n/a
External or structural barriers	2. Overcoming commitments and demands	15. Prior commitments and competing demands 16. Burdensome journey 18. Location of the programme 19. Seasonal weather	29. Lack of transport**
INTENTION TO PARTICIPATE IN INTERVENTION	**Unmapped subthemes**		
		13. Lack of understanding of research study of programme[b]	25. Social isolation can reduce confidence[b]
		17. Negative experience with health care staff in location of programme[a]	30. Psychosocial factors**[a]

Key: ASE- Attitude-Social influence-External barriers; SM – self-management; * Reasons for continuing and completing programme; ** Potential reasons that could result in dropping out of programme; [#] Subtheme mapped more than once; [a] Insufficient information given in the primary studies; [b] Not within the model remit; n/a not applicable

Box 4.1 continued

The SRM	Themes with subthemes		
Illness threat	**Reasons for attending**	**Reasons for not attending**	**Reasons for dropping out**
Background influences Personal illness experience Medical and social communication	5. Referrals by HCPs – with explanation 6. Positive previous experience of programme[#]	14. Negative view of programme from experience and created by others[#] 18. Location of the programme – bad press 20. Referrals by HCPs – without explanation	21. Suffering an acute exacerbation 25. Social isolation can reduce confidence
Illness representations: **Disease identity**		11. Perception of health status	23. Not ill enough
Timeline	n/a	n/a	n/a
Controllability **Personal** **Treatment**	1. To help themselves – to improve health status[#] 3. Gain control of condition[#] 4. Last chance to cope and remain independent[#]	 12. Lack of perceived benefit to participation in research study[#]	
Consequences	1. To help themselves – to improve health status[#] 4. Last chance to cope and remain independent[#]	11. Perception of health status	22. Psychological limitations 23. Not ill enough
Intervention representations: **Purpose and benefits** **Necessity-Concerns** **COPING BEHAVIOUR – PREDICTING PARTICIPATION IN INTERVENTION** **APPRAISAL**	1. To help themselves – to improve health status[#] 3. Gain control of condition[#] 4. Last chance to cope and remain independent[#] 6. Positive previous experience of programme[#] 7. To socialise 9. Personal benefits and peer support* 2. Overcoming commitments and demands	10. Perceived exercise would worsen health 12. Lack of perceived benefit to participation in research study[#] 14. Negative view of programme from experience and created by others[#] 15. Prior commitments and competing demands 16. Burdensome journey 18. Location of the programme 19. Seasonal weather	24. No change in health status after one session 26. Intensity of the programme** 27. No improvements seen** 28. Training with other participants 29. Lack of transport**
	Unmapped subthemes		
	8. Altruism[b]	13. Lack of understanding of research study of programme[b]	30. Psychosocial factors**[a]
		17. Negative experience with health care staff in location of programme[a]	

Key: SRM – Self-Regulation model; SM – self-management; * Reasons for continuing and completing programme; ** Potential reasons that could result in dropping out of programme; [#] Subtheme mapped more than once; [a] Insufficient information given in the primary studies; [b] Not within the model remit; n/a – not applicable

4.3.3 Synthesis findings: Generation of analytical themes

The mapping revealed four key behavioural constructs that formed the analytical themes and explained participation (attendance, non-attendance, dropout) in COPD SM support programmes. These findings went beyond the findings of the included primary studies and explained patient participation beyond the previously reported socio-demographic and clinical factors. The key constructs were 'attitude' and 'social influence' from the adapted ASE model; 'intervention' and 'illness representations' from the SRM. The four analytical themes are described below.

4.3.3.1 Attitude

Attitude of attenders was that COPD SM support programmes[122,304,305,309] could help to improve their health and condition. Participants wanted to help themselves, and wanted to learn about their condition.[122,304] Some study participants wanted to gain control of their condition.[304,305,309] A few wanted to cope with the illness and remain independent.[309] Besides perceived health benefits, social benefits were important too.[122,304] Some participants saw COPD SM support programmes[122,304] as a reason to get out of the house, to socialise and meet others with the same illness. Two interviewees reported attending the programme for altruistic reasons.[122] In Arnold's study[304] a key reason given for continuing and completing the programme was social and health benefits. While, in Fischer's study[305] reasons given for programme attendance, among the previous attendees, included a positive past experience of the programme, particularly, staff supervision and peer support.

In contrast, an attitude among non-attenders was that SM support programmes was not beneficial particularly the exercise component would not improve health.[114] Some participants chose not to attend because they perceived the exercise as vigorous, strenuous and detrimental to their health. Several participants in Taylor's study[114] were more interested in research testing new drug treatments and not exercise. Furthermore, among interviewees, personal negative experience with exercise in the past and negative research experience were other reasons suggested for programme non-attendance.

Regarding dropout, a participant in one study[310] suggested that patients with COPD dropped out because they expected to see health improvements after just one programme session. Potential dropout reasons[305] were: inability to keep up with the intensity of the programme;

failing to notice any improvements in health halfway through the programme; and feeling uncomfortable whilst training with other participants.

4.3.3.2 Social Influences

Programme non-attendance was influenced by a lack of positive feedback from others or a lack of explanation given on the benefits of the programme. Several participants in Taylor's study[114] decided not to attend because their friends or family either had not found the programme useful or they did not think the programme would be useful. Another trusted source, health professionals, being unable to explain or advise participants about the benefits of the programme was associated with non-attendance.[304,305]

Conversely, the majority of attenders in Arnold's study[304] attended the programme because their doctor either explained how the programme could benefit them or they simply trusted the advice or suggestion to attend the programme.

4.3.3.3 Intervention representations

A positive perception/representation of COPD SM support programmes influenced attendance. Some participants perceived the programme would help them to learn about self-management;[122] the programme was perceived as a positive step to help oneself; some study participants believed that attending would help them to gain control of their condition.[304,305,309] Few participants saw the programme as their only hope of coping with the disease and remaining independent.[309] Perceived benefits from programme attendance in the past also influenced attendance.[305] In addition, almost all attenders in Fischer's study[305] perceived the programme as a necessity if they wanted to see improvements in their health and were not concerned about their possible conflicting obligations.

In contrast, the perceived negative benefits of exercise and previous negative experience with research and exercise in the past influenced non-attendance among several participants in Taylor's study.[114] Non-attendance in SM support programmes was also influenced by participants' perceived physical or practical barriers related to attendance such as, transport difficulties;[114,122,305,310] location (hospital) of the programme because of previous negative experiences with the hospital staff and bad press about the hospital;[114] seasonal weather

because it would affect health and exercise capacity;[114] and practical issues such as personal/ professional commitments.[114,122,305,310]

Patients' dropped out of the programmes because they did not perceive any health benefits after attending just one session.[310] Additionally, not gaining any benefits when one was halfway through the programme, the programme being too intensive and being uncomfortable while training with others in the group were cited as potential dropout reasons.[305] Lack of transport was also cited as a perceived concern by some study participants which could result in dropping out of the programme.[305]

4.3.3.4 Illness representations

The perceived increased severity of condition and its effect on ability to cope/self-manage, partake in social activities, be in control and remain independent prompted attendance by several participants in COPD SM support programmes.[122,304,305,309]

Among non-attenders, some participants felt they were too disabled to carry out any sort of activity or leave the house without support[122,310] or some perceived that improvements in their health were no longer possible.[114] One participant in Arnold's study[304] chose not to attend SM support because they felt better when they were offered the programme.

The perceived severity of symptoms also influenced patient dropout behaviour. Suffering an acute exacerbation often led participants to drop out of the programme as they needed time to recover.[310] A couple of participants dropped out because of depression associated with their condition.[122] Conversely, a couple of participants dropped out because they did not perceive themselves to be physically or psychologically affected by their condition.[122]

4.4 Discussion

The thematic 'framework' synthesis with use of theory, aimed to understand participation behaviour in group-based COPD SM support programmes and the findings have implications for improving attendance and completion in these programmes.

4.4.1 Summary findings

The application of theory helped in gaining an insight into the participation (attendance, non-attendance, dropout) behaviour of patients in COPD SM support programmes beyond the previously reported socio-demographics and clinical factors. The mapped subthemes yielded higher order constructs whereby, participation was influenced by an individual's attitude and perceived social influences; and intervention and illness representations.

Attitudes of wanting to help themselves, the perceived influence of HCPs, perceptions of the controllability of illness and perceived positive benefits of the COPD SM support programmes, including past experiences, influenced attendance behaviour. Non-attendance was influenced by an individual's negative attitude that improvement in their condition was no longer possible, perception that the programme would not benefit condition including from past experiences, perceived physical or practical concerns related to attendance and the perceived negativity of professionals and family/friends towards the programme. Dropout behaviour was influenced by an individual's attitude and intervention representations that the programme was not beneficial after attending a few sessions and perceived severity of symptoms.

4.4.2 Comparison with other literature

In agreement with recently published work[100,311] patient non-attendance was associated with some participants' perceived negative benefits of exercise. It has been explained previously that this could have arisen from the way information was delivered by professionals, or by patients' lacking understanding of information about the programme benefits.[311] Lack of clear recommendation or explanation about benefits of the programmes by professionals influenced non-attendance in this study. Lack of clear information and lack of referral has previously been reported to affect programme attendance.[100,124,218] Another social influence associated with non-attendance in this study was negative views of the programme given by family/friends.

In addition, the negative experiences with exercise and/or research in the past influenced non-attendance and positive past experience influenced attendance and completion of the programme. Within a behavioural context, the benefits gained from previous experience may have led to the formation of positive beliefs about the programme and these beliefs contributed to the appraisal of 'attending' the programme as positive. The positive appraisal

was retrieved[312] following invitation to attend which might have led to attendance and completion of the programme. Conversely, the reverse could have resulted in non-attendance. The physical or practical barriers cited previously[100,311 116] were described by non-attenders in this review. According to one study[100] this could be because health and/or the intervention may not be a priority for the study participants. Behaviourally, reporting of practical/physical barriers could mean that the individual was unsure of how the programme could help.[179] Another explanation might be that attribution of non-attendance to 'physical/practical barriers' may be more of a socially acceptable proxy than a reflection of personal circumstances, this requires further exploration.

The findings were compared with studies that utilised the 'SRM'[110,177] to predict patient attendance in rehabilitation. Similar to these studies' findings, patients' belief in self to control/cope with their condition and belief that the programme would help to control their condition influenced patient attendance in this study.

Regarding dropout while being unwell has been reported previously as a major reason for programme non-attendance and non-completion,[311] the perceived severity of symptoms influenced dropout behaviour in this study. In addition, participants' unmet expectations, particularly not observing any health benefit after attending one or a few programme sessions, was cited as a reason for potential dropout. Patients not knowing what to expect from the programme, or expecting to get cured prior to attendance, has been reported by one study[313] to affect programme non-completion.

4.4.3 Strengths and limitations

This qualitative synthesis with application of theory has helped to explain aspects of patient participation behaviour in COPD SM support programmes in response to the poor patient uptake in these programmes and the limited explanation for the poor uptake however, there were some study limitations.

At the time of the review only five studies of PR and one study of a COPD SM programme had explored reasons influencing patient participation qualitatively. The included studies were not underpinned by theory and none of the studies explored each aspect of patient participation (attendance, non-attendance, dropout) however, application of two theories to the studies' findings has made a contribution towards understanding the cognitions that may influence different aspects of patient participation behaviour.

The quality appraisal demonstrated that some aspects of methods reporting were insufficient in some studies e.g. limited verbatim data. This could affect the transferability of the findings in practice.[314] However, the study participants were the right people to answer the research questions[298] and in line with the review aim we were able to identify a breadth of reasons given for participation and/or completion in COPD SM support programmes. The inadequate data also prevented mapping of few of the subthemes (Box 4.1).

Both the 'best fit' theoretical models were able to explain patient participation to a considerable extent and our review findings were consistent with both these models. However, it was challenging to map an individual's view or beliefs into the distinct theoretical cognitive constructs; at times a reason given for participation was mapped onto more than one construct of the same framework. This suggests that an individual's cognitions are interlinked and help to inform an individual's decision making to perform certain behaviour.[315] In addition, using the 'best fit' approach described by Carroll[302] was limiting to some extent as the theories used in this study had been previously utilised and were not the newer/latest model versions. The 'ASE' model[14] that was developed in the 1980s now includes the 'stage of change' concept;[316] Leventhal's[8] 'Self-Regulation' model developed in the 1990s now includes new aspects of illness representations, 'coherence', 'cyclical timeline' and 'emotional representations'.[13] However, due to the limited primary data and subthemes being outside of the models remit it is unlikely the addition of the new constructs would have influenced overall outcomes.

4.5 Conclusions

This qualitative synthesis with application of theory is to our knowledge the first to explore the full range of patient participation behaviour (attendance, non-attendance and dropout) in SM support programmes among patients with COPD, and has helped to explain participation beyond the previously reported socio-demographic and clinical factors. The synthesis helped to identify a list of reasons that explained patient participation and application of theory helped to understand that participation behaviour was influenced by a participant's attitude and perceived social influence and their perceptions towards the illness and the intervention. As these psychosocial constructs are amenable to change[177,181,312] targeting these key constructs may help to improve uptake in COPD SM support programmes and improve health outcomes.

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4.6 Implications

Being the first review of its kind to explore participation behaviour among patients with COPD, we suggest further qualitative exploration, guided by theory, of patients' attitudes and perceptions towards their illness and COPD SM support programmes to help further understand the barriers to participation alongside professional and organisational barriers.[317] Assessment of patient perceptions towards their illness and treatment may help to identify eligible and suitable patients for the treatment and predict attendance in the treatment. In addition, studies[318,319] have suggested assessment of beliefs of patients with COPD during routine consultations; the beliefs need to be understood and acknowledged by health professionals so that the negative beliefs can be targeted and addressed by behaviour change interventions[177,180,318] and/or considered in the design of COPD SM support programmes.[320] One way to achieve this could be by adaptation of the illness[13] and intervention perception questionnaire[180] for COPD.

In practice, in order to influence attendance behaviour it is important to understand that an individual's attitudes to the intervention, particularly with a view to their beliefs about the benefits of the programme and sense of control over their condition, are critical. Non-attendance could be addressed particularly in relation to perceived physical/practical concerns related to programme attendance and exercise. Dropout behaviour could be managed by ensuring patients have appropriate expectations from the intervention prior to their attendance at the programme. Finally, the influence of others on participation behaviour has particular implications for HCPs understanding how much patients' value their advice and recommendations regarding their management. To help facilitate the latter, and for professionals to be positive and enthusiastic about COPD SM support programmes, provision of support and training for HCPs should be considered to help improve participation.[321]

The next two chapters lead into stage 2 of the study of developing and evaluating a complex intervention. Chapter V and VI explore from patient and professionals stakeholders reasons for non-participation in SM support programmes by patients with COPD; how participation may be improved in these programmes and how else patients with COPD could be supported with SM

Note: Stage 2 of the study comprises of a new qualitative primary study. Regarding the MRC *'developing a complex intervention'* phase, the qualitative study develops a theoretical understanding from stakeholders about how change (improvement of patient participation in COPD SM support interventions) can be achieved. The stakeholders in the study include patients with COPD and professionals involved in COPD management. The qualitative study is divided into two chapters, **Chapter V** presents findings, with respect to patient interviews and **Chapter VI** presents findings from interviews with experts.

The bigger qualitative study was referred to as the MY BREATH study – Manage Your Breathing for Better Health

Chapter V. Understanding reasons for poor participation in SM and PR programmes and how participation can be improved in these programmes – a qualitative study with COPD patients.

This chapter:

- in the introduction highlights the problem of patient participation and retention in studies of group-based PR and SM programmes (together referred to as COPD SM support programmes) (discussed in previous chapters) and explains the rationale for this qualitative study

- describes the methods

- presents the findings under emergent themes followed by the discussion, conclusion and implications

5.1 Introduction

The lack of reporting of participant flow data by studies of SM support shown in Chapter III could make it difficult to interpret the findings of the studies in practice and as a result, suitable patients may not get the opportunity to participate in SM support programmes. In this study, patient non-participation was defined as not taking part in a study of a SM intervention or the intervention. Chapter III also showed that some patients who were given the opportunity to participate in studies of SM support programmes refused participation, and about a third of the studies did not record/report reasons for patient non-participation. The need to understand the characteristics of 'refusers' or non-participants is vital[322] because the delivery of PR programmes (one of the most effective and cost-effective interventions in COPD)[323] including SM support for COPD patients, encompassed within the COPD care pathway http://www.networks.nhs.uk/nhs-networks/london-respiratory-network/key-documents/pulmonary-rehabilitation (accessed 3-7-13) has been regarded as essential for better health outcomes.

While five studies of PR and only one study of a COPD SM programme have explored the problem of poor patient participation, particularly the attendance, non-attendance and dropout aspects (Chapter IV) no studies of COPD SM programmes and only three studies of PR,[100,109,114] appear to have explored factors affecting participation or 'non-participation' from the patients' perspective. Furthermore, only a handful of studies,[100,109,324] have explored factors which might lower barriers to participation.

Due to the limited available evidence there is scope for further qualitative research to help gain a better understanding of what factors influence participation and retention in SM support programmes and how participation may be improved. The need for further research, particularly qualitative research, was raised in a recent study of patients' perceptions of participation in PR;[130] in addition, the need to develop strategies to encourage participation and attendance and engage patients in SM support programmes[19,47,100] has also been emphasised.

The aim of this study was to gain a better understanding from a patient stakeholders' perspective about: factors affecting patient participation in SM support programmes; factors that might encourage patient participation in these programmes; and how patients with COPD might be better supported in their self-management.

5.2 Research objectives

To explore, with people living with COPD using qualitative methods (individual interviews and focus groups) the following questions:

a) What are the reasons for poor uptake and completion of SM support programmes amongst patients with COPD?

b) What might be done to make an existing COPD SM programme more appealing and applicable to patients with varying levels of COPD severity (including changes to programme content and different modes of delivery)?

c) Whether different modes of SM delivery should be considered for patients with different degrees of airflow obstruction?

d) Which is the most suitable delivery method for patients with moderate to severe COPD to promote uptake and completion?

5.3 Research questions

The main results of the research will help to explain:

1)   Why people with COPD participate in, do not participate in, and fail to complete SM support programmes?

2)   What are the characteristics of people that attend and do not attend SM support programmes? (This might help to target programmes towards people who will gain benefits from programme attendance)

3)   Do people with varying levels of COPD severity want different things from SM support programmes?

5)   How should support programmes be delivered to people with different levels of severity, and by whom?

6)   How might we make an existing COPD SM programme more appealing, applicable and accessible for patients with moderate to severe COPD, or could we deliver SM support to these patients in an alternative way?

The findings of the study were intended to help either refine an existing COPD SM programme - with adoption of a new delivery method for patients with moderate to severe COPD, or to identify another way to provide SM support to patients with COPD.

5.4 Methods

5.4.1 Sampling and recruitment

Purposive sampling was conducted to obtain a diverse sample of men and women with COPD of varying age-groups and severity including housebound patients. The Medical Research Council (MRC) score was used to gauge severity of patients as it is the most practical means to assess disease severity in the COPD population.[325] The patients were recruited from a) participating Breathe Easy (BE) groups – these groups are voluntary lung support networks for people with respiratory conditions including COPD and are supported by the British Lung Foundation (BLF); and (b) Housebound patients from participating GP practices in two inner east London boroughs.

Participating BE groups were identified after liaising with the development officer at the BLF who explained the purpose of the study to a number of chairpersons of different BE groups across London. The chairpersons invited the study researcher to introduce the study to their members at one of their regular monthly meetings. Following the meeting, the researcher discussed the eligibility criteria with the chairpersons and handed out copies of the study material (invitation, information sheet and consent forms (Appendix 5.1, 5.2, 5.3)) to be distributed or posted to their members to invite them to the study. The reason for targeting BE groups was because people with COPD who attend these groups are typically targeted by SM support programmes and it was anticipated that they would be able to use their personal experience of the condition to shed light on why some people with COPD might not want to participate in, or would dropout from, these programmes. Housebound patients were invited into the study because COPD SM support programmes are usually conducted in the community in a group setting and may be inaccessible to house bound patients with severe COPD. These are the patients with the most frequent hospital admissions and it is possible that these patients have most to benefit from SM support programmes.[249] All the primary care practices in two inner east London boroughs were invited to take part in the study via an invitation letter (approximately n=94 letters were sent). Participating GP practices were given the study material to post to eligible housebound patients on behalf of the researcher. The plan was to recruit at least 10 housebound patients.

Interested potential participants contacted the researcher directly either by telephone or a postal reply slip attached to the study invitation letter in a pre-paid envelope.

The study inclusion criteria were:

- Adults aged over 35 with a diagnosis of COPD

- Willing to participate and fluent in English

The exclusion criteria were:

- Not fluent in English (as the COPD SM programme currently is delivered in English language)

- Unstable COPD and/or unstable co-morbidity

- Serious psychological illness

- Inability to give informed consent.

The interviews (either one-to-one or focus group) were arranged by the researcher at a time and place convenient to the study participants, which could be their home, Breathe Easy group venue, GP practice or at the host institution. As a token of appreciation for their time and contribution to the study, each participant was given a voucher worth £20.

The study was explained to participants over the phone and if they were agreeable an interview date was arranged and a consent form was sent to the participant. The participants could contact the researcher if they had questions or further queries.

5.4.2 Interview schedule

The semi-structured interview schedule (Appendix 5.4) was developed from discussion with the study team and from previous literature.[122] The interview questions were framed under the theoretical domains framework.[326] This theoretical framework has been previously utilised among health professionals to understand and explain implementation problems e.g. barriers and enablers to the implementation of evidence-based guidelines. However, due to the flexible nature of the framework only the domains relevant to this study were utilised. These constructs form a comprehensive coverage of possible influences on behaviour. Theoretical or health behaviour change constructs relevant to implementation research were synthesised into 14 domains: knowledge, skills, professional role and identity, beliefs about capabilities, optimism, beliefs about consequences, reinforcement, intention, goals, decision processes, environmental context and resources, social influences, emotion and behavioural regulation. So, the domains appropriate to conduct interviews with patients were used for example, within the 'Knowledge' domain the patient interviewees were asked, "How long have you been living with COPD?"; "How much understanding do you have about your condition?" Furthermore, where appropriate, the constructs of the Self-regulation model (SRM) and the Necessity-Concerns Framework (NCF) (applied in Chapter IV) were utilised as a conceptual guide to explain the study findings.

5.4.3 Interviews

A pilot interview was conducted with a patient advisor member of the doctoral study. The preamble for all interviews comprised of an introduction to the study and assurances as to confidentiality and anonymity and obtaining consent to record the interview. The interview would stop if the participant wished to rest, at the end of the interview the participant was thanked for their time and contribution and given a £20 voucher. Semi-structured face-to-face interviews explored, patients' views about their current COPD management, experience of attending either a PR or SM programme previously, reasons for attending or dropping out of the programmes and why other people with COPD might not participate in these programmes. If a participant had not attended a SM programme previously, a brief summary (comprising of one A4 sheet) of an existing COPD SM programme was presented (Appendix 5.5) and they were asked whether they would consider attending such a programme, why other people with COPD might not participate in/attend such a programme, what might help people to decide to participate in/attend such a SM programme, how else can patients be supported and what improvements to the programme should be made to improve attendance of the COPD SM programme in the future. Data saturation was achieved as no new themes emerged from the interviews; the aim was to interview as many male patients as possible and preferably those who had attended, invited but not attended or dropped out of the SM programme. The duration of interviews ranged from 30 minutes to 1 hour and 22 minutes, were audio-recorded, anonymised, transcribed and imported into Nvivo9 software for organisation and facilitation of data analysis.

5.4.4 Data analysis

Data analysis was conducted using a thematic framework approach.[327-329] This approach is inductive and grounded but also deductive as it used to answer a set of aims and objectives. The interviewer firstly read and re-read the transcribed data several times to become familiar with and get a sense of the data.

The second stage involved identifying a thematic framework where memos or notes of phrases from the data were made to get a general impression of the data. The framework also included a list of *a priori* issues or study research objectives. Coding was conducted line by line and the data were labelled with codes that captured meanings.

The third stage was indexing, where several repetitive codes emerged whilst sifting the data. Comparison of quotes was done both within and between the transcripts. There was no interpretation of the data at this stage. Initial categories or concepts began to develop where similar codes were grouped together to form analytical categories. A constant reference was made to the study aims when grouping data under the emerging concepts including issues that were raised by the participants.

Following this, data from all the transcripts was charted under emerging concepts or under the thematic framework giving a detailed account of views and experiences of the participants. The process of category formation requires constant comparison of data within a category with each other and, constant comparison of the data across categories. This is to ensure the interpretations remain grounded in the data.

The development of categories makes the data more meaningful, and more analytical. These categories were defined, shared and discussed with another experienced qualitative researcher who followed the same process on a sample of six transcripts chosen at random. This process of inter-rater reliability was done to ensure the researchers' own biases and preferences were discounted and the findings were not based on the subjective judgement of the single researcher.

The final stage of mapping and interpretation led to the development of themes. Here, in addition to making sense of individual quotes in this stage within the charts, it included looking at the relationship between the quotes and the links between the data as a whole to provide explanations for the findings and the overarching themes which were carried out with discussions between the interviewer and the qualitative researcher.

5.5 Ethical considerations

The study was approved by the National Research Ethics Service, Central London Research Ethics Committee (REC1) (11H0718/9). All study participants gave their written informed consent before the start of the interview.

5.6 Results

5.6.1 Sample characteristics

Eighty seven letters were sent out in total by chairpersons in all of the four participating London breathe easy groups and one participating GP practice out of approximately 94

practices. Forty one potential participants responded to the letter with 28 expressing an interest in the study, 22 potential participants were recruited and interviewed including the three housebound patients from the participating GP practice, one claimed to have asthma and not COPD. Six who had shown an interest to participate in the study were later not contactable or busy. Out of 13 potential participants who were not interested to take part in the study, five gave no reason, one was busy, two claimed to have asthma, one was caring for their partner, and four letters were returned to the researcher.

Individual face-to-face interviews were conducted with eighteen patients according to the preference and convenience of the participants, all interviews, except one, were carried out in the participant's home and for another the interview was conducted in a health centre. The remaining four participants were interviewed in pairs as they did not want to be interviewed on their own; hence one interview took place in a health centre and another in a community centre. Data saturation was achieved from the patient interviews as no new themes emerged as the interviews progressed. The sample characteristics are presented in Table 5.1.

Out of the 22 participants, the majority (n=18) were female; mean age was 74 years; six participants were housebound; 10 participants were diagnosed in hospital, nine participants by their GP, one participant was diagnosed in a chest clinic, one by nurses and one by both GP and hospital. The years to diagnosis ranged from 8 months-30 years; six participants were using oxygen; 14 lived alone; 20 were ex-smokers and two had never smoked previously; 20 participants had a MRC score of 3 and above. Nineteen participants had attended either a PR or a generic or a COPD-specific SM programme. Of the 13 participants who had attended PR, three had attended PR more than once, almost all had completed PR (two had missed a few PR sessions). Four participants had attended both PR and a SM programme with all four completing PR and three completing the SM programme, one participant had only attended (and completed) a SM programme and one participant who had attended PR three times had also attended and completed cardiac rehabilitation and a SM programme.

Table 5.1 Characteristics of the 22 patient interviewees

Patient interviewees										
Study ID	Age (years)	Sex	COPD diagnosis (years ago)	Housebound ?	Previous attendance in SM support programme (PR, SM, Education)	Completion of SM support programme	On oxygen?	Lives alone?	Smoker or Ex-smoker	MRC Dyspnoea breathlessness scale (NICE 2007)
PP1 pilot interview	not given	Female	8	No	PR	Completed	No	Yes	Ex-smoker	3
PP2	77	Female	6	No	PR	Completed	No	Yes	Ex-smoker	4
PP3	83	Female	4	No	PR	Completed	No	No	Never smoked	2
PP4	76	Male	5	No	PR thrice	Completed	No	Yes	Ex-smoker	4
PP5	82	Female	2.5	No	PR and COPD-EPP	Completed PR and EPP	No	Yes	Ex-smoker	3
PP6	79	Female	9	No	Breathing classes	Completed	No	Yes	Ex-smoker	3
PP7	80	Male	30	No	PR possibly twice	Completed	Yes	No	Ex-smoker	3
PP8	62	Female	16 months	No	PR	Completed	No	Yes	Ex-smoker	4
PP9	65	Female	4-5	No	Exercise course and COPD EPP	Completed PR and EPP	No	No	Never smoked but where worked, people smoked	2
PP10	68	Female	8	No	PR	Completed	No	No	Ex-smoker	3
PP11	62	Female	2	Yes	PR	Completed	No	No	Ex-smoker	4
PP12	73	Male	7	Yes	PR thrice, CR and generic EPP	Completed except the last PR programme	Yes	No	Ex-smoker	5
PP13	79	Male	2.5	No	PR	Completed except missed one session	No	Yes	Ex-smoker	3
PP14	79	Female	6-7	No	PR	Completed	Yes	No	Ex-smoker	3
PP15	79	Female	6	No	PR	Completed	No	Yes	Ex-smoker	3
PP16	73	Female	18 months	No	SM programme	Completed	No	Yes	Ex-smoker	3

PP17	76	Female	4-5	No	PR	Unable to complete as missed two sessions	No	Yes	Ex-smoker	3
PP18	69	Female	5	Yes	PR and SM programme	Completed PR, SM programme - dropped out	Yes	Yes	Ex-smoker	4
PP19	63	Female	9	No	PR and EPP	Completed PR and EPP	No	No	Ex-smoker	3
PP20	91	Female	20	Yes	Does not remember	N/A	Yes	Yes	Ex-smoker	4/5
PP21	61	Female	4-5	Yes	No	N/A	Yes	Yes	Ex-smoker	4
PP22	86	Female	1.5	Yes	No	N/A	No	Yes	Ex-smoker	3

Key:

MRC – Medical Research Council; COPD- chronic obstructive pulmonary disease; GP – general practitioner; PR – pulmonary rehabilitation, EPP – expert patients programme; SM – self-management; CR – cardiac rehabilitation N/A – not applicable

5.6.2 Emergent themes and subthemes

The study findings comprised of a detailed account of views and experiences of people living and adapting with COPD and who mostly had previous experience of participation in SM support programmes. The findings are presented under emergent thematic categories or first order themes (Table 5.2) followed by overarching themes or second order themes. The thematic categories comprised findings that relate directly to the research objectives of this study e.g. why people with COPD do not participate in SM support programmes, and findings that informed the research topic but were not directly related to the research objectives e.g. participants' own reasons for attending SM support programmes. The data within and between the emergent categories were examined for relationships and patterns that provided explanations for the findings, these explanations grounded in the data were grouped to form six overarching themes described in the next section.

Table 5.2 List of emergent thematic categories

Findings that were directly related to study research objectives.	Findings that informed the research topic but were not directly related to study research objectives. Participants' own reasons for:
(1) Factors that might affect participation in COPD SM support programmes - Patient characteristics e.g. lack initiative, do not want to discuss illness - Patients' cannot be bothered owing to physical, psychological and emotional limitations leading to: ---depression and lack of motivation ---reluctance to do or learn anything ---frightened/anxious to go to programme alone ---lacking confidence - Patients' negative views about the programme --- programme is about smoking cessation --- exercise/self-help not useful or beneficial - Programme organisational issues ---insufficient information about the programme ---nearby venues closing down - Physical or practical barriers ---cost of transport - Awareness about the programme - Gender differences	(4) Understanding about COPD and its management - Knowledge and understanding of condition - Confidence to manage - Control of condition
(2) Suggestions for improving participation in COPD SM support programmes - Motivation and encouragement e.g. promotion of programme benefits via home visit, invite to trial session, allow family members to attend - Support with accepting condition - Building confidence - Creating awareness of COPD and SM support programmes and its benefits e.g. adverts, involve professional staff to discuss benefits, - Improvements in health system and programme organisational factors (see point (3) below).	(5) Attending and adhering to SM support programmes - To try and see health improvements or attempt to take control of condition e.g. to learn forgotten tips/skills - Recommendation to attend - Altruism
(3) Making SM support programme more applicable and appealing to improving uptake - Improving organisational issues such as, --- Invitation: Informing patients about the benefits of the programme face-to-face preferably instead of sending an impersonal letter ---Waiting time: between invitation and attendance should be no more than two to four weeks; ---Venue: needs to accessible, comfortable and inviting - Improving structure of the programme such as, ---Time/length of session: e.g. consider patients' medication needs, avoid rush hour times and avoid clashes with PR or Breathe Easy sessions; ---Content: e.g. assess patient expectations, include talks by experts, the topic on 'depression and COPD' is important and talk on 'living wills' should be omitted, allow patients to exercise at own pace, have a relaxation time ---At the end of the programme refer patients to Breathe easy ---Facilitators should be well trained	(6) Dropping out of programmes including reasons that might have affected dropout behaviour in others - Poor facilitation skills or insufficient support from programme staff - Physical factors e.g. location of programme - Lack of perceived benefit/unmet expectations - Illness
(4) Other ways to support people with COPD with SM	(7) Wanting to re-attend programmes again (or not)

who cannot or do not want to access group-based programmes	- invite to attend programme each year - programme completion boosted confidence to re-attend - unable to or did not want to exercise alone - to keep up with learnt and forgotten skills - desire to be followed up - nothing more to learn

5.6.2.1 Overarching themes

Six overarching themes were generated that helped to address the research objectives.

Patient non-participation were explained by:

1) Resignation/Denial

2) Beliefs about health/illness and treatment beliefs

3) Programme organisational issues

Patient participation could be facilitated by:

4) Motivation and encouragement

5) Promotion of programme benefits

6) Organisational improvements

Figure 5.1 illustrates within the patient participation definitions (from systematic review Chapter III) the overarching themes.

Figure 5.1 Illustration of barriers to patient participation and facilitators to improve participation in COPD SM support programmes

Illustration of patient participation definitions

STUDY

Non-attenders

Intervention dropouts

Study dropouts

Eligible patients

Study participants

Attenders

Intervention completers

Study completers

Study non-participants

INTERVENTION

Participation could be influenced by people of COPD:
- being resigned to living with their condition or in denial of condition;
- negative illness and treatment beliefs; and
- programme organisational issues

It follows that participation and completion of SM support programme could be improved by:
- provision of motivation and encouragement
- promotion and discussion of programme benefits; and
- programme organisational improvements

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(1) Resignation/Denial

The study participants described the type of patients with COPD who participate and do not participate in COPD SM support programmes. The former type, fought or pushed for things they needed to help their condition, they were motivated, proactive and used initiative to seek health improvements. These characteristics were reflected in the participants' own reasons for attending SM support programmes, which were: to live, to adapt, to keep themselves as well as possible and not be a burden.

> *PP18:...You know, exercising, of course you are, you're going to improve your whole wellbeing...That's the way I look at it, but then again, that's only my point of view. Because I don't want to die!...*

In contrast, the non-participants were mentioned as people who might not be willing to help themselves, they perhaps felt they were entitled to be a burden and wanted to seek care only from a HCP. These people might have become resigned to their situation either because they felt their condition was not recognised by others or because they could not do anything to help themselves and so were not interested in seeking help or learning anything new. Discussing the illness might also be uncomfortable for this group of people as they might have not accepted their illness, accepting the illness might be frightening for them.

> *PP21: I think perhaps it could be something to do with the more you know, the more frightened you get, you know...some people don't want to think about it, because it's almost like acceptance there's something wrong with them.*
>
> *PP8: Feel that they are entitled to be a burden; that this thing (COPD) has happened, they're in a terrible state. There's nothing to be done about it. It's not fair.*
>
> *PP12: Well, as a disease, COPD, hasn't been ... it's not very ... well known amongst the common people and the medical (profession). It's not had the publicity like cancer gets or crippling diseases. I mean, if you saw me just sitting here, you wouldn't think I was disabled, would you? Believe you me, I am! So that kind of thing. I mean, people don't think you're disabled.*

(2) Beliefs about health/illness and treatment beliefs

Participation might be affected by patients' negative beliefs about their condition such as being incurable or the belief that nothing more could be done. The physical, psychological and emotional consequences of living with COPD and associating symptoms with COPD might lead patients to become reluctant to try anything new, specifically any physical activity, patients might lose motivation, and they would be frightened or have low self-confidence to go somewhere that was new. These latter effects were mostly stated and attributed more to people who lived alone because of participants' own experience of loss of motivation, depression or wanting to give up at some point in their illness journey in the past however, they were able to get through as they had support and they sought the help they needed. In addition, despite previous programme attendance and due to the unpredictable nature of their condition some participants still struggled to say that they were hundred per cent confident in managing their condition and being in control of the condition was still perceived as difficult by many participants.

> **PP9:** ...I think some of them have got quite bad chests, but I don't know, perhaps they've got to the age where they can't be bothered, you know? Perhaps that's what it is.....Perhaps they think, well, you're never going to be cured, because your lungs are not any much good with that.

> **PP19:** I suppose when you're really, really ill, like in hospital, you're so fed up with it, it's very easy to say, oh, I can't be bothered!...Not everybody is very good at seeking that kind of help; I think the stigma attached to mental health is still a stigma!...it took me a long time to get over it (my depression). And i'm still on medication, but I sought the help I needed to get me through it and help me...

> **PP11:** ...I mean, before I got struck down with this (condition), I was really outgoing, ... and I was a very strong person, yeah? But to go somewhere that is very strange and on your own, a lot of people would not be able to hack that; they'd be frightened.....Well, to actually be sitting and to actually go and do something on your own, yeah! ...You know, it would be pretty scary,...

Negative beliefs about SM support programmes could also affect participation. Patients may have not understood or seen the value in carrying out self-help behaviours such as exercise. Patients who were smoking and were not ready to quit may have perceived the programme as preaching about smoking cessation which might have provoked reluctance to hear about

smoking cessation. Patients might also not consider the programmes important enough in their list of priorities and instead might be more concerned about the weather or cost of travel that could affect participation. In comparison, the participants' own reasons for attending and adhering to the programmes included perceived programme benefits or perceived controllability of their condition.

> **PP20:** *...It's no good doing exercises, because you do them for a little while and then you leave it again, or you will forget again.*

> **PP13:** *...So you should talk to the people who have the long term condition already, ... and they will tell you that other people will try to stop them from smoking, because it could help. And they (who are smoking) keep away from him or her, because they don't want to hear your view, because they want to still smoke!....then by talking about COPD, you put me off smoking. ....you don't tell me not to smoke, but you're telling me how it would affect me when I smoke. So I listen to you and I don't want to hear!...Don't want to listen to it, I don't want to be scared....*

> **PP20:** *No, because it costs money...I'd have to have a minicab there and I'd have to have a minicab back, and I just cannot afford it. No.*

An alternative view was that perhaps patients who smoke feel guilty and stigmatised and unworthy of help.

Another view was that it was not that patients might not want to participate in the programmes but they might not know about the SM support programmes

> **PP1:** *The biggest problem is not so much making people come as making them aware. Because I don't think people sit there going, "Oh, I'm not going to do that." They sit there and go, "Oh, I wish there was something, but I don't know what!" I'm sure that's the biggest problem, they're just not knowing (that these programmes exist)!*

(3) Programme organisational issues

Besides patient/personal factors, several programme organisational issues were suggested that could affect participation in SM support programmes, they were: prolonged waiting times to attend the programme, unmotivated patients might not make an appointment for PR assessment, lack of accessible venues or nearby venues closing down.

PP11: I think maybe if it (programme) wasn't made quite so official, you know? You get a letter and then they say that there's a huge ... there's a waiting list, and I think that can make you go, oh, I can't be bothered then!....I think it was a couple of months! ....I think the biggest barrier is the way that you communicate. Yeah. I think that that is the crucial part.

PP2: ...there's not enough of them (of PR programmes), not enough ... you know?

(4) Motivation and encouragement

To improve patient participation the participants' suggested that patients may need to be supported with accepting their condition, reassured that they can do things to take control; COPD and its consequences need to be recognised and acknowledged by the general public including HCPs; patients may need to believe they are worth something by encouraging them and building their confidence to achieve things important to them. Patients might be encouraged to participate in the programme by informing them about what the programme entails – this could be done at their home or GP practice; by showing them improvement seen in others; by inviting them to try out some sessions either at home or at the programme venue, without any pressure of commitment. Patients might also be encouraged and have the confidence to participate if their support network could also be involved i.e. they could bring a family member, friend or a carer to the programme. These suggestions may also help to address the psychological and emotional consequences of living with COPD.

PP10:...I'm sure you know, it's for people to know that they're worth something as well...people's sense of worth, you know, build their confidence up. ...I think maybe people need to be encouraged in the things that they do do well.

PP8: ...I think if you got the recognition, it would be a motivating factor for me to go along (to the programme)...Recognition of your own fear, panic, depression, anxiety.

PP6: Well, if there's someone ...someone to do with COPD, and they know that someone else has got it at home and they're on their own, maybe it could give them a little bit of support if they were to go round and tell them about this class....And maybe if possible go with them. You know, like you get a carer?....And go with them for the first time, just to let them see what it's like, and then they wouldn't be so frightened or nervous, so they'd most probably enjoy it...Yeah, maybe I think it would be quite a good idea just maybe once a week

that they (carer) could help that person to go to even just one class. And once they've seen what it's like, well, if they liked it, they could go on their own...

(5) Promotion of programme benefits

Patients might consider seeking help including participation if they perceived health improvements could be attained from participation in the programmes. This could be possible by, if in addition to advertising the programmes though leaflets and posters in centres that patients frequented e.g. GP practice, pharmacy, hospital, day centre, church, Breathe Easy, the persons working at these centres who knew the patients best, including their families and their situation, could be involved in discussing the benefits of the programmes with patients. Use of optimistic phrases to help patient believe in the benefits of the SM support programmes was also suggested such as, *'strengthen'*, *'improve'*, *'gentle exercise'*, *'you'll get fit'*.

PP4: Well, I think they (patients with COPD) should be convinced that it (SM programme) is going to be useful...someone has got to help them. The only thing I can think of is GP, you know? Or a friend or a parent, or a partner or whatever it is; you know, there's got to be somebody who is close to them...Who knows them and knows their situation...Well, all you've got to do is tell them that it's good for them and they'll get better...Or it will improve their situation, improve their well being ...

PP5: Maybe in day centres as well, you know? Having leaflets in day centres and having a big one on the wall and maybe having people who run the day centres could maybe have a discussion about different things that's going, and discuss: Look, we've got this so and so plan, if you'd like to be involved. ......Because they (patients with COPD) would think, oh, well, he (staff at day centre) arranges all these things for us, and does everything for us, and we enjoy them, so he knows what he's talking about...!

PP2:...Yeah, because when you first get it (the condition) and you go to these (programmes), it would help you to manage it (the condition) a bit more better...

One participant also pointed out that it was important for HCPs to know about the programmes and believe in the programme benefits for their patients.

A different view by several participants was that despite all efforts to encourage and promote patient participation it was up to the individual to decide to take part in the programme.

Best/Alternative way to support patients with COPD with their self-management

Furthermore, the views of participants were varied or inconsistent when it came to suggesting alternative ways to support patients with COPD with their SM. Most participants suggested group-based programmes instead of delivery of the SM programme to patients with COPD in their home, face-to-face or by phone or through the internet. This was mainly owing to their positive experience and perceived benefits of group-based programmes and lack of interest or lack of technology use. Specifically, regarding housebound patients some patients felt it was important to provide support to them at home while others believed delivery of the programme to housebound patients would not be cost-effective to the NHS and hence would not be sustainable and so felt a better option would be to identify housebound patients, support them individually first till they felt ready and comfortable to attend the programme.

PP1: ...I wouldn't suggest a one to one, because I don't think that would work. ...Because it would cost an awful lot of money for one person to go to one person's home, and do and hour or so. You know, the funding for that would be so high that no-one's going to want to carry on; they'll do it for a while and then go, we can't afford that. ...And also part of the self-management thing is to do with being with people. A lot of their problems are, they're indoors, very lonely and if you keep them indoors, they're just going to get worse. they need to come out. Even if they are housebound, they need to come out.

PP10: In the hospital when they're (people with COPD are) being released.....I'm sure the one to one has got to be (there)... or maybe ... at our GP practice,... And that is the way to do it though. ....I'm sure the more the personal (the better) ...

PP9: ... Unless, like you have a one to one around their house and spoke to them. By speaking to someone like me, perhaps, and then you make them feel more relaxed and it would help them if they went to the group; perhaps something like that.

For patients with COPD in general, two non-technological options had been suggested for delivery of the SM programme and they included: have a person who specialises in COPD based in the GP practice and who patients could access for more information instead of being

given information in the hospital or deliver the content of the SM programme in monthly Breathe Easy meetings.

(6) Programme organisational improvements

Suggestions given to improve the organisational and structural aspects of the COPD specific SM programme could be applied to other SM support programmes relevant for COPD patients to help improve participation and retention. Improvements were suggested for the mode of patient invitation and provision of information about the programme to help patients believe in the benefits or importance of the programme. In addition, suggestions were given to change structural aspects of the programme to help improve participation for example, use trained staff, introduce talks by several experts, reduce waiting time between invitation and attendance to two to four weeks, hold the programme outside of rush hour times, keep in mind that concentration mainly lasts an hour or two, include light exercise with music, refer patients to PR or Breathe Easy at the end of the programme.

> **PP3:**... *it all needs to go ahead quickly. Well, two weeks or something like that; not months, because I think people do lose interest, like "Oh, I don't think it's going to be much good," or something like that, you know.*
>
> **PP8:** *... I'm wondering actually ... If the doctor actually invited you to go in and have a chat about this, that might work better than the doctor saying, "Here's the programme that you can do if you want to." ...You need the help of a good psychologist....To understand that key, if there is one, to make people work very hard for a relatively small reward.*
>
> **PP10:** *Well, it could be exercises that are good for you with a bit of music and make it a bit of fun, half an hour. You know?....And also you don't need equipment for it....Well, this they could do, maybe in the middle of a session, say the odd half hour and then a cup of tea and that.*

A number of suggestions had been put forward for improvements to the PR programme as well and they included: relaxation sessions, assess expectations and more discussion time and allow people with severe COPD to carry out exercises at their own pace.

5.7 Discussion

5.7.1 Summary findings

This study is the first to provide an insight from a COPD sample of sufficient size to result in data saturation with a mixed prior experience of attending SM support programmes about:

(1) Factors that might lead to patient non-participation in such programmes.

(2) Suggestions to improve patient participation in these group-based programmes and views on alternative ways of supporting SM in these patients.

(1) Factors that might lead to patient non-participation

The participants' characterised people who did not participate in COPD SM support programmes for example, as those who were not ready to help themselves, they might have not accepted their condition or they might have become resigned to their condition. In contrast, those who participated were for example, proactive, used own initiative, ready to help themselves; these characteristics were noted among the interviewees.

From participants' own experience of living and learning to adapt and managing their condition and its consequences over time they felt patient non-participation could also be due to negative perceptions about their illness for example, condition is incurable, perceived physical, psychological and emotional limitations (particularly those who might be living alone), this may make patients lose motivation, confidence and reluctant to try anything new. And ~~the~~ negative perceptions about SM support programmes for example, the programme is only about smoking cessation, exercise is not useful. Furthermore, non-participants might be more concerned about the practical/physical barriers related to attendance e.g. competing priorities, cost of transport. Despite previous attendance in SM support programmes, many participants were not hundred per cent confident or in control of their condition due to its' unpredictable nature. This highlights the difficulty or the constant work that patients with COPD have to do to manage their condition daily; however, most participants were able to perform SM strategies which they had learnt from attending PR and so, patients who do not participate or attend SM support programmes may be more likely to experience difficulty with SM. A different view given about non-participation was that patients might be unaware of SM support programmes. Outside of patient factors, some programme organisational issues were also proposed that could affect patient participation such as, long waiting time

between invitation and attendance in programme, lack of proper communication about the programme, nearby programme venues closing down.

Some reasons given for why patients might have dropped out of SM support programmes included: poor facilitation skills of programme staff or insufficient support or attention paid to patients, inappropriate programme venue, lacked perceived benefits of the programme, unmet expectations, other programme attendees not serious about the programme and illness.

(2) Suggestions to improve patient participation

Patient participation in COPD SM support programmes might improve if the barriers mentioned above could be addressed by the following proposed improvements: provision of patient motivation and encouragement by informing about the programme and its benefits using a personalised approach, provision of support to accept condition and reassurance that they can learn to take control, build sense of worth and confidence that things important to them can be achieved and recognition of the condition and its disabling nature by the wider public including health professionals. These above suggestions were also proposed by some of the participants for encouraging housebound patients to attend the programmes; ~~as~~ they believed group-based programmes were still better for these patients in comparison to ~~using~~ a technological approach or an individual approach as it would be costly and unsustainable. A wider promotion of SM support programmes in the form of leaflets/adverts in several locations such as GP surgeries, day surgeries, hospitals, BE support centres, pharmacies and even church was suggested plus involving staff at these locations including family to communicate the programme benefits to patients to help improve participation. Lastly, several organisational improvements had been suggested for COPD SM support programmes to help improve participation and retention (see Table 5.2).

Several participants had also pointed out that despite all efforts to improve patient participation in SM support programmes some patients might still not want to participate in the programme and the ultimate decision would rest on the individual.

5.7.2 Comparison with other literature

(1) Factors that might lead to patient non-participation

The study findings with regard to resignation of living with COPD or in denial of COPD to affect patient participation in COPD SM support programmes can be explained by the Corbin

and Strauss[1] sociological perspective of illness trajectory that comprises of three lines of work ('illness work', 'everyday life work', 'biographical work') that are necessary for managing chronic illness. The 'illness-related' work has been used previously to explain health care utilisation among patients with chronic disease[166] (described in Chapter II, Box 2.2) Within the illness trajectory, Corbin and Strauss[1] have put forward that for an individual with chronic disease to live, there needs to be a balance between three types of work, management of day to day illness, carrying out routine daily activities and the biography of the individual, however, the struggle to achieve this balance is not easy and the state of equilibrium is prone to instability because of several consequences. One consequence includes 'conditional motivation'. Motivation for a person with chronic illness depends on having a trajectory scheme – knowing what lies ahead to carry out illness trajectory work; a biographical scheme – one must wish to live which would mean the individual must come to terms with their illness, their limitations and potential outcomes of their illness; hope – that the individual can carry out tasks and can attain something. Without hope the previous two conditions would be useless; and commitment – to carry out the trajectory and the biographical scheme.[1]. However, Corbin and Strauss stated that for an individual to remain motivated there needs to be some pay-off.

Thus, patients with COPD who have resigned to their illness and cannot see that they can do something to manage their condition, those who have not come to terms to their illness or its limitations or do not have the confidence that they can achieve things or gain benefits then these patients might be more likely to lose motivation to move forward which might lead to non-participation in self-care, including in SM support interventions. Resignation to live with the illness has not been reported previously to affect participation in SM support programmes but this attribute has been recognised among patients living with advanced COPD who may have accepted COPD as a 'way of life' where patients do not actively seek information or would 'rather not know'.[330] SM support staff have previously mentioned that patients who lack readiness to take responsibility[122] or accept illness[313] would find it harder to change behaviour and hence may make a decision not to participate in SM support however, SM support programmes may not be appropriate initially for these patients until they come to terms with their illness and feel that it can be managed. In contrast, the study findings suggested that people who do participate in these programmes would be those who are ready to help themselves, are proactive, use initiative to get what they need, they want to live and

learn to adapt and believe that they can achieve health improvements. This description was reflected in the participants' reasons for attending SM support programmes and within the sociological context one could say that these patients are motivated and may be more likely to achieve a relative equilibrium necessary for trajectory management.[1] While, within a policy context – these individuals would be referred as 'activated' patients who are taking responsibility for their health by asking questions, seeking explanations, stating preferences, and expecting to be heard (described in Chapter II).

A patient with COPD may also become resigned to their situation due to the lack of recognition of COPD and its disabling nature by the wider public including HCPs which could inhibit help seeking including participation in SM support programmes. Halding[308] reported that patients with COPD, having non-supportive consultations with HCPs and their needs receiving little attention as a result of smoking, end up concealing their condition and lose out on support – 'they withdraw into an exile in everyday life to maintain dignity'.[308]

This study further suggested that individuals with negative health/illness beliefs and treatment beliefs (via the SRM, SRM-NCF) within the wider illness trajectory might further affect participation. In comparison to a previous study[109] that suggested perceived uncontrollability of the condition, perceived 'incurability' of the condition was suggested in this study to affect participation. In addition, the experience of physical, psychological and emotional limitations as a result of living with COPD or negative illness perceptions (increased perceived symptoms to COPD or 'disease identity', increased perceived 'consequences' decreased 'personal controllability') and negative 'emotional perceptions' might lead an individual to become reluctant to be involved in anything new or any physical activity. Also individuals may, become depressed and lose motivation, and become frightened and have reduced self-confidence to leave their home and go to a new place and sit with strangers including the fear of getting breathless when they are outside could affect participation. These factors were suggested more for people who might be living alone because the participants through their own experience, had battled through these situations e.g. depression, coming to terms with illness, being unmotivated but they had learnt or were still learning to adapt and manage their condition with the help of support and/or seeking help.

These findings are supported by other studies which have reported that patients with COPD who have led sedentary lifestyles will find it harder to become more active;[313] Inactivity due

to loss of motivation could be seen more in patients who live alone as they may more likely perceive their health as negative and disabling[82] and hence might consider 'giving in' to their condition and limitations as opposed to 'keeping up' with their condition.[331] This can affect engagement in complex treatments[32] which could include participation in SM support programmes. While the fear of exercise or the belief that exercise could be harmful have been reported to affect participation in PR in previous studies.[100,116] This study identified that patients' might undergo fear, panic, anxiety or nervousness when going to a new place delivering SM support and meeting strangers. These emotional consequences have been commonly reported in studies in relation to patients living with COPD.[32]

The lack of perceived benefits from exercise previously reported in studies[100,114] was also suggested as a possible reason to affect participation including not seeing the value of self-help in this study. In addition, the stigma of smoking that can influence patient participation reported previously[100] and the perception that the programme was preaching about smoking cessation could also affect participation among patients not yet ready to quit. Patients' lack of perceived benefit from exercise has been explained as possibly arising from insufficient information given about PR[100] and patients' lack of interest in quitting could be because of insufficient or inappropriate advice given to patients with COPD about lifestyle modifications that are necessary for them to adhere to for the long term for their illness management.[332]

Participants in this study also suggested that some physical/practical barriers could be perceived as 'concerns' by patients with COPD in relation to participation and they were: ease of access, cost of transport and other prior obligations or priorities and in light of these the programme may not be perceived 'necessary' or important. Physical/practical barriers have been previously reported to affect PR uptake.[100,114]

In this study, some organisational issues such as insufficient communication about the programme, not enough centres to provide PR or nearby centres closing down were suggested as issues that could affect participation. The insufficient provision of information about PR has been reported previously to affect patient uptake.[100,114]

Another finding reported in this study to affect patient participation was that patients may not be aware about SM support programmes. Patient stakeholders in a previous study[313] had also mentioned that no information was given to them about PR until their condition worsened and some felt that the knowledge of GPs about PR was limited. The lack of awareness or lack of provision of information about SM support programmes is indeed a missed opportunity for suitable and eligible patients with COPD to consider participation.

(2) Suggestions to improve patient participation

To improve patient participation in SM support programmes, first patients may need to be supported to accept their condition and educated to take control of their condition. A study[313] suggested that only through accepting the condition can an individual recognise their needs and can think about fulfilling those needs; this may also help to prevent patient resignation or going into a downward spiral.[1] This provision of support would be usefully delivered prior to patients attending the programme including when they attend the programme which was previously suggested[333] as this may increase the likelihood of more patients considering participation in the programme. In addition to assessing patient's personal motivation to change and goals[324] this study proposed to improve participation, patients may need to be motivated and encouraged by building their confidence in things that are important to them and goals that they can achieve so they feel a 'sense of worth' and that they are still capable of doing things to help themselves. This may be appropriate when a patient is in the earlier stages of the disease for better management of their condition.[1] In one study[313] some HCPs had mentioned that it would be useful to know whether a patient with COPD was self-motivated however, this would only work if health professionals allowed patients to participate (described in Chapter II), i.e. become involved, or to engage them as partners in their care.[47,324]

Another way proposed to encourage patient participation in this study was by informing patients about the programmes either face-to-face by a GP, SM support staff in a GP practice, home visit by persons who know about COPD or even via a DVD and showing how it may have benefitted others; by holding a few sessions in a patient's home or inviting them to a trial session without any pressure to commit and by allowing patients to bring a family member, friend or carer to at least the first session of the programme was mentioned by many participants. Involving the patient's support network might give patient the confidence or may help to allay any fear or nervousness they might associate with leaving the house and going to a new place and sitting with strangers. Patients who live alone have been linked with becoming socially isolated[308] and becoming depressed[334] and this was recognised by the participants in this study and so, the provision of motivation and encouragement in this study may help to alleviate depression and/or anxiety in this group of patients. A study[334] identified that patients with COPD who live alone and who have not participated in exercise previously

need additional support in treating depression and would benefit from motivational interview tailored to exercise and referral to PR to increase the likelihood of participation. Use of peer support and education from people with COPD[100] and asking patient to attend a trial session[335] have been suggested previously to improve PR uptake. The proposed suggestions of motivation and encouragement including provision of support to accept their condition would fulfil the criteria that patients with chronic disease have mentioned to participate in their care and which could include participation in SM interventions (discussed in Chapter II); the criteria included to be informed/to have knowledge, to be confident in one's own ability, to comprehend information about disease and its treatment and to seek and maintain a sense of control.[188]

A wider promotion of programmes and their benefits was also suggested by the study participants alongside creating awareness of COPD among the wider public including the medical profession so patients can consider seeking help which could include participation in SM support programmes. Creating awareness about COPD among family members of COPD patients[333] and anticipating patient's concern, acknowledging and normalising them[109] has been reported previously to help improve uptake.[109] A suggestion given to promote awareness through adverts/leaflets suggested in this study was also reported previously;[336] the participants' proposed that in addition to placing leaflets and posters in locations such as GP practices, day centres, Breathe Easy centres, pharmacies, the staff (trusted by patients) working at these centres including the patient's family could be involved to discuss the programme and benefits with patients which may increase the likelihood of participation. This approach may prove valuable for a patient as they could then discuss their interest in the programme with the health professional when they perceived it as necessary instead of waiting to be referred. This proactive role by the patient would further fulfil two requirements deemed important according to policy initiatives[337] for a patient living with a chronic disease, active patient involvement and self-management. Furthermore, so far, respiratory consultants or physiotherapists have been mostly reported to influence participation in PR[311] and hence it may be useful if that role could be adopted more by GPs to help improve participation however this would be facilitated if GPs were made more aware about SM support programmes and believed in the benefits for their patients – this was also deemed important by a few participants in this study. Several participants also suggested that it should be recognised that despite all efforts to improve patient participation in SM support

programmes, some patients may still not want to participate and the decision would rest on the individual.

This study appears to be the first to explore whether the SM programme could be delivered to patients on a one-to-one basis who cannot or do not want to attend group-based programmes e.g. housebound patients. However, most of the study participants felt that group-based programmes was still the best way to offer SM support instead of using an individual approach or technology (including phone calls). This finding was mostly based the participants' preference and the perceived benefits of group-based programmes, most either disliked, did not know how to use or were disinterested in technology.

An individual approach and provision of support to housebound patients was deemed important e.g. through use of community nurses who already visited patients in their home as part of their service provision but some participants felt this form of support would be too expensive for the NHS and hence not sustainable. These participants felt that a better use of resources could be to identify and provide one-to-one support to housebound patients till they felt ready or comfortable to attend group-based programmes – this suggests that the approaches suggested above to improve participation in SM support programmes: e.g. motivation and encouragement and promotion of programme benefits may also be beneficial for these housebound patients to consider participation in SM support. However, the needs of housebound patients may benefit from further exploration.

Moore[100] has suggested the development of home-based services e.g. via DVD for patients with COPD who do not find it feasible to attend PR in a group however, based on the study findings the latter might not be the best option. One study[338] had explored barriers to adoption of telehealth services amongst patients with chronic disease including COPD and the findings, patients' being uncomfortable or did not know how to use technology and would have preferred to speak to someone in person support the findings of this study. The literature is inconsistent about the place of internet among patients with chronic disease for example one study[337] reported that some patients with chronic illness might find internet interactions most relevant soon after diagnosis and perhaps place less value in them for long term management of their chronic condition while, another study[333] has reported that patients may like to receive written information on paper in the earlier stages of the disease than read information on the internet, these issues may benefit from further exploration. Two non-technological options had been offered by a few participants and they included have a

person/specialist based in a GP practice that patients could regularly access for COPD-related queries and deliver sections of the COPD SM programme in Breathe Easy meetings.

Besides focusing on the patient, improvements to the organisational aspects of the SM programme might also help to improve patient participation. The improvements suggested in this study (section 5.7.1) can be added to the previous evidence suggested for SM[122] and PR programmes[100,114] or applied to programmes that might be being developed or re-designed to improve patient participation.

5.7.3 Strengths and limitations of the study

This study is believed to be the first of its kind to explore factors affecting participation in SM support programmes by patients with COPD, how participation might be improved in these programmes and how patients with COPD might be best supported with their SM from the patient stakeholders' perspectives. However, there were some study limitations.

Firstly, most study participants had previously attended a SM support programme and so, their views might not be transferable to patients with COPD who have not been exposed to these programmes. However, these participants were purposefully selected to give an insight into patients' reluctance to participate in SM support programmes because they had the same condition and they were familiar with the research topic of patient non-participation. The participants themselves, were mostly elderly and suffering from moderate to severe COPD and were a true representation of a patient living with moderate to severe COPD and their reasons for non-participation were based on their own difficult experiences of living and coping with COPD and how these experiences could impact on participation in SM support programmes. These reasons might have been difficult to obtain from non-participants as this would have required self-critical insight and they might have been reluctant or uncomfortable or embarrassed to discuss these reasons; in addition, these patients may have been difficult to recruit in the study due to their non-participation.[93,122]

Secondly, the majority of the participants were female even though the prevalence of COPD is commoner among males, and so the findings may not be transferable to male patients with COPD. The issue of gender and participation was explored in this study and the findings presented in the descriptive themes could be used as a starting point for further exploration of non-participation among male COPD patients.

Thirdly, only three out of a target of 10 housebound patients (one of whom claimed to have asthma and not COPD) were recruited from a single participating GP practice out of the possible 94 practices that were invited to participate in this qualitative study. The best way to recruit housebound patients or patients with advanced COPD in a research study is by having their clinician introduce the study,[94] within primary care or hospital[78] however, this approach was unsuccessful for this study. One study[33] has suggested that housebound patients may have difficulties responding to a letter of invitation which can result in high non-response rates however, in this case, patients were not even given an opportunity to respond to a letter as 93/94 GP practices did not take part in the study. Unlike this study, a qualitative study by White[93] was able to recruit their target number of housebound patients from a large number of GP practices and this could be because the recruitment was carried out by a local GP and suitable patients were identified from the disease register. Despite the poor recruitment three more housebound patients were recruited from the participating Breathe Easy groups and valuable insight was obtained from these participants on the research topic.

Fourthly, although, the participants were the appropriate group of people to suggest improvements for patient participation in SM support programmes and how patients might be best supported with their SM their preferences for group-based programmes and dislike or disinterest in technology might have biased the findings. Another way to better support patients with their SM needs further exploration from patients not exposed to SM support programmes to identify their preferences for SM support. Conducting serial 'snapshot' interviews would be useful to capture patients' preferences in a future study.[339]

Lastly, the study was also aware of the researcher's attitude in influencing design, data collection and analysis of qualitative themes and used an expert in qualitative research and the lay patient advisory group to obtain a balanced interpretation of the collected data.[339]

5.8 Conclusions

This study is believed to be the first of its kind to explore from COPD patient stakeholders factors that could affect participation in SM support programmes by COPD patients, how participation might be improved in these programmes and how might patients be supported with their SM in a non-group setting. The findings have contributed to the limited evidence base that exists on this research topic deemed necessary to explore.[47,130]

Participation in SM support programmes might be affected by patients with COPD (1) being resigned to their illness either because they may feel there is nothing they can do to help

themselves or the lack of recognition of their illness and its disabling nature, being in denial of their illness and so they may be not ready to help themselves and might feel entitled to be a burden; (2) negative illness beliefs e.g. the perceived incurability of condition, perceived physical, psychological and emotional consequences might lead patients to become reluctant to be interested in anything, particularly physical activities, become depressed, fearful, lose motivation, and lose the self-confidence to go out to a new programme and be among strangers; (3) Negative treatment beliefs e.g. perceived programme to be about smoking cessation, might not see the benefit of self-help or exercise or might not perceive exercise as important or necessary and may perceive increased physical/practical concerns related to participation or lack awareness about the programmes; and (4) programme organisational issues.

The following reasons might predispose patients to drop out of SM support programmes: poor facilitation skills of programme staff or insufficient support or attention paid to patients, inappropriate programme venue, lacked perceived benefits of programme, unmet expectations, other programme attendees not serious about the programme and illness.

The following suggestions might help to improve patient participation in SM support programmes: (1) provision of motivation and encouragement to build patient self-confidence and self-worth, provision of support with accepting condition, recognition of COPD among the general public including the medical profession and involving patients and their support network to see the programme benefits; (2) wider promotion of programmes and discussion about the programme and its benefits particularly addressing beliefs about physical activity or exercise by health professionals involved in provision of COPD care and including family; and (3) improvements to organisational aspects of the programme. Provision of group-based programmes was felt appropriate even for housebound patients in comparison to the individual approach or use of technology; better use of resources was suggested to provide individual support initially to housebound patients till they felt comfortable to attend group-based programmes.

5.9 Implications

The study findings suggested that if professionals support patients to accept their condition, provide motivation and encouragement and discuss the programme benefits then that might help with addressing some of the patient barriers to participation and improve participation.

In addition, creating awareness of COPD among the general public including health professionals and programme organisational improvements may further boost participation.

This means that to address the patient factors HCPs might have to facilitate a partnership/patient-centred care approach[55] and assess within the patient's illness journey their beliefs about the illness and its treatment but also if they have hope and can commit to managing their condition.[1] If patients' can comprehend information about their condition and its management, are confident in their ability to manage their condition and recognise that they need to help themselves[188] then they might be more likely to self-manage their condition which could include participation in SM support programmes. Providing training to professionals in patient engagement[340] may help them to support their patients and their needs. Along with education and an emphasis on the complementary nature of SM support programmes to medical management among non-pulmonary professionals,[30] COPD and its disabling nature also needs much recognition among the larger public including the medical profession so patients with COPD can seek the help they need and prevent the downward spiral of resignation, loss of motivation and thus non-participation.

This qualitative study continues into the next chapter which presents and discusses findings from interviews with experts' (both lay and HCPs) involved in COPD management and self-management about patient reasons for non-participation in SM support programmes. It considers how participation might be improved including how patients with COPD might be better supported with their SM.

Chapter VI. Understanding reasons for poor participation in SM and PR programmes and how participation can be improved in these programmes – a qualitative study with experts

- This chapter continues from the previous Chapter V and so the research objectives and the research questions are the same; the data analysis and ethics consideration section will not be repeated. The focus of this chapter is to present findings from interviews with experts.

- The chapter begins with a brief introduction followed by the methods with sections on sampling and recruitment, interview schedule and interviews; next, the study findings will be presented followed by the discussion, conclusion and implications.

6.1 Introduction

The previous chapter IV and V have already established the limited number of qualitative studies that have explored the problem of participation and retention in COPD SM support programmes from the patients' perspective. Efforts to understand this problem from the perspectives of lay or health care professionals (HCPs) (referred to as experts in this study) are meagre.

The only one well documented[124,218] reason for patient non-participation in PR has been explored qualitatively among HCPs particularly, the poor or inadequate patient referral of eligible COPD patients to PR. One UK study[116] and a recent Australian study[218] explored the barriers and facilitators to PR referral of COPD patients among primary care professionals. No studies have explored factors affecting participation specifically in COPD SM programmes among HCPs except, one study[122] that explored how participation could be improved in a COPD SM programme among lay tutors that delivered the intervention.

The aim of this study was to gain a better understanding of factors affecting patient participation in SM support programmes; factors that might encourage patient participation in these programmes; and how might COPD patients be better supported with their SM from experts involved and/or interested in management of COPD patients and SM.

6.2 Research objectives

To explore, from experts (lay and health care professionals) involved and/or interested in COPD management and self-management using qualitative methods (individual interviews) the following questions:

a) what are reasons for poor uptake and completion of SM support programmes amongst patients with COPD?

b) what might be done to make an existing COPD SM programme more appealing and applicable to patients with varying levels of COPD severity (including changes to programme content and different modes of delivery)?

c) whether different modes of SM delivery should be considered for patients with different degrees of airflow obstruction?

d) which is the most suitable delivery method for patients with moderate to severe COPD to promote uptake and completion?

6.3 Research questions

The main results of the research will help to explain:

1)   Why people with COPD participate in, do not participate in, or fail to complete SM support programmes?

2)   What are the characteristics of people that attend and do not attend SM support programmes? (This might help to target programmes towards people who will gain benefits from programme attendance)

3)   Do people with varying levels of COPD severity want different things from SM support programmes?

5)   How should support programmes be delivered to people with different levels of severity, and by whom?

4)   How might we make an existing COPD SM programme more appealing, applicable and accessible for patients with moderate to severe COPD, or could we deliver SM support to these patients in an alternative way?

The findings of the study were intended to help either refine an existing COPD SM programme – with the adoption of a new delivery method for patients with moderate to severe COPD, or to identify another way to provide SM support to patients with COPD and test the new intervention in a small exploratory study (Chapter VII)

6.4 Methods

6.4.1 Sampling and recruitment

Key personnel were purposively identified and approached following reading the literature; attending a two day workshop in east London on COPD that was aimed at HCPs; and discussion with the study supervisor.

The potential participants were to include:

•   People that develop self-management programmes, including COPD self-management programmes

•   People that deliver self-management programmes, including COPD self-management programmes

•   Physiotherapists that deliver pulmonary rehabilitation programmes (in hospital, out-patients and/or at home),

- Health care staff and/or researchers involved and interested in promoting SM for chronic conditions including COPD in the community.

The potential participants were invited to participate in this study via an invitation letter (Appendix 6.1) and an information sheet (Appendix 6.2) which was either posted or emailed. The potential participants were sent one reminder email if no response was received. Interested potential participants contacted the researcher directly either by telephone, email or a postal reply slip attached to the study invitation letter in a pre-paid envelope.

The interviews were arranged by the researcher at a time and place convenient to the participants, which could be their home, place of work or at the host institution. As a token of appreciation for their time and contribution to the study, each participant was given a voucher worth £20.

If the participants (who will be referred to as 'experts') were agreeable an interview date was arranged and a consent form (Appendix 6.3) was sent to the participant. The participants could contact the researcher for further queries.

6.4.2 Interview schedule

Similar to Chapter V, the semi-structured interview schedule (Appendix 6.4) was developed from discussion with the study team and from previous literature[122] and the questions were framed under the theoretical domains framework.[326] The theoretical domains appropriate to conduct the interviews with experts were used for example, within the 'Social influences', 'Emotion', 'Environmental context', 'Memory' domains the experts were asked, "In your experience what could the reasons be for non-participation by patients with COPD?".

6.4.3 Interviews

Pilot interviews were conducted with two HCPs. The preamble for all interviews comprised of study introduction, confidentiality, anonymity and permission to record the interview. The interview would stop if the expert needed to resume their work, and at the end of the interview the expert was thanked for their time and contribution and given a £20 voucher. Semi-structured face-to-face interviews explored, experts' views about their experience of involvement in SM generally or specific to COPD patients, whether there was a problem of patient participation in SM support programmes and if yes, what were the barriers to participation, how participation might be improved in these programmes (a brief summary (comprising of one A4 sheet) of an existing COPD SM programme was presented (Appendix

5.5) and how patients with COPD, who do not or cannot participate in SM support programmes, might be supported with their SM. Data saturation was achieved as no new themes emerged from the interviews. The duration of interviews ranged from an hour to an hour and a half, were audio-recorded, anonymised, transcribed and imported into Nvivo9 software for organisation and data analysis.

6.4.4 Data analysis

See chapter V (section 5.4.4).

6.5 Ethical considerations

See chapter V (section 5.5)

6.6 Results

6.6.1 Sample characteristics

In all 16 interviews (including two pilot interviews) were conducted. Following the two pilot interviews 19 experts were approached and 12 agreed to participate. Of those who did not participate two no longer worked where the invitation letter was sent and five did not reply. In addition to the 12 experts, two experts who had been identified initially as collaborators in the development or refinement of the COPD-specific SM programme for COPD patients (original study research objective, section 1.1.3) also agreed to take part in the study. So, out of the 16 recruited experts, two developed and delivered SM programmes one of whom was a health professional, three were lay tutors who delivered SM programmes, one was a policy director and three were researchers, one of whom was a health professional who evaluated SM programmes, one health professional delivered PR and of the six remaining experts, two were health psychologists, two were GPs and two were respiratory consultants within an interest in COPD management and/or SM (Table 6.1).

Table 6.1 List of the expert interviewees

No	Study ID	Title
1.	EP1 – pilot interview	Health psychologist
2.	EP2 – pilot interview	GP
3.	EP3	Development of SM programme and delivery
4.	EP4	Physiotherapist
5.	EP5	Policy director and evaluation of SM programme
6.	EP6	Delivery of COPD SM programme
7	EP7	Researcher
8.	EP8	Health psychologist
9.	EP9	Delivery of SM programmes including condition-specific (diabetes and COPD) programmes
10.	EP10	Respiratory consultant
11.	EP11	Delivery of generic EPP and COPD SM programme
12.	EP12	GP with special interest in COPD
13.	EP13	Respiratory consultant
14.	EP14	Health professional/Development of SM programme/COPD SM programme and delivery
15	EP15	Health professional/Researcher
16	EP16	Researcher
Key: GP –general practitioner; SM – self-management; EPP – expert patient programme; COPD – chronic obstructive pulmonary disease		

6.6.2 Emergent themes and subthemes

The study findings comprised of a detailed account of the views of experts who belonged to different levels of the health care system and who were involved in the management and/or SM of patients with COPD.

Section 6.6.2.1 describes the emergent overarching themes with subthemes. Additional quotes that support the study findings have been placed in Appendix 6.5. Within the patient participation definitions, Figure 6.1 illustrates factors that may affect patient participation and retention in COPD SM support programmes and Figure 6.2 illustrates suggestions that might help to improve patient participation and retention in these programmes.

Figure 6.1 Illustration of factors affecting patient participation and retention in COPD SM support programmes

6.6.2.1 (3A) Patient factors

- unmet expectations/wrong expectations from the programme
- instability of the illness or not ill enough
- group dynamic not working
- physical or practical barriers

6.6.2.1 (3B) Programme organisation factors

- inadequate facilitation skills
- uncomfortable with discussing the 'living wills' section

6.6.2.1 (2A) Patient factors

- ✓ do not want or not ready to change behaviour
- ✓ not accepted condition or taking a long time to accept
- ✓ illness and its consequences can lead to lack of confidence to go out
- ✓ lack understanding or negative beliefs about the illness and the programmes
- ✓ physical or practical barriers e.g. competing commitments

6.6.2.1 (2B) Health system factors

- ✓ lack of support from primary care/lack of integration of SM
- ✓ lack of understanding about the role of SM/programmes among professionals
- ✓ inefficient health system e.g. insufficient training for primary care professionals, lack of communication between different health service levels
- ✓ right patients not being recruited

6.6.2.1 (2C) Programme organisation factors

- ✓ staff unable to explain the programme and its benefits to patients over the telephone
- ✓ long duration of the programme
- ✓ absence of a rolling programme

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Figure 6.2 Suggestions that might improve patient participation and retention in COPD SM support programmes

Health system improvements to improve patient participation

Provision of training and support for health care professionals

Integration of SM into the COPD care pathway

Promotion of benefits of SM and the programmes

Identify the right patients for the programme e.g.at diagnosis or via the patient activation measure

Build relationships with patients and identify what patients value and if they might be ready to self-manage or to participate in self-management support programme

Carry out 'pre-work' to support patients as per their needs e.g. support with accepting condition, discussion of programme benefits

Use professionals enthusiastic about self-management and the programmes to refer patients

Pitch patient invite and information about the programme at the right level of the patient, assess and address expectations and logistical difficulties

Illustration of patient participation definitions

Organisational improvements for COPD SM programme

To improve participation

- offer flexible programme e.g. at different times, locations

- ensure convenient journey and comfortable venue

- programme sessions need to keep patients engaged

To improve retention

- Improve facilitation skills

- Involve health care professionals to deliver the disease-specific elements of the programme

- Include in content e.g. exercise, session of depression and COPD to remain, ask preference of patients prior to discussion of the 'living wills' section, cover the 'what is COPD?' section with patient prior to their attendance in the programme

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6.6.2.1 Emergent overarching themes

The experts' level of engagement in SM was varied perhaps due their professional role, and this helped to get a greater understanding from experts about the importance of SM and how much SM was embedded in the care of patients with COPD. Some experts were involved in the development, delivery and/or evaluation of group-based SM programmes or delivery of individual support to patients. These experts believed that SM programmes were about engaging patients in their care to reduce hospital admission and improve patient outcomes – in line with policy initiatives. A few experts felt that SM education was not delivered in PR as intended by the policy guidelines[41] while, some experts believed that the educational content delivered in PR or during supported discharged all was part of SM. Based on this it seemed that COPD patients might only be able to access SM support through SM programmes.

Nonetheless, non-participation and poor retention in PR and SM programmes was acknowledged by all experts and explained under five overarching themes:

(1) Challenges of delivery of SM support programmes – this theme was not directly related to the research objectives of this study but informed the findings that explained how participation might be improved;

(2) Reasons for patient non-participation in COPD SM support programmes;

(3) Reasons for patient dropout;

(4) Suggestions proposed to improve patient participation and retention (similar to the previous chapter were mostly suggested for the COPD-specific SM programme but the findings could again be applicable to programmes in development or refinement to help improve participation); and

(5) Supporting patients with their SM in a non-group setting.

(1) Challenges of delivery of SM support programmes

Several challenges in the recent delivery of SM support programmes were expressed that included patients' not knowing anything about COPD until they came to the programme. This lack of knowledge made them angry and reluctant to learn anything or they felt they were going to be told to stop smoking; patients' agreed to participate but then did not attend the programme which was frustrating for the experts and created organisational difficulties e.g.

an interviewee (SM tutor who did not have COPD) was asked to facilitate a COPD SM programme which they found difficult because of insufficient understanding about COPD.

EP4: Quite a few in the (PR) class I run don't even know what COPD is, aren't really sure about the condition and how it affects their lungs. So a lot of them ask about that and ask whether actually it's going to get worse or can it get better sometimes...(on further probing why patients do not know what COPD is when they attend programmes)... I often wonder whether it's explained properly when they're diagnosed, or sometimes whether it is formally diagnosed, or whether people (HCP) see smoking history or cough, or shortness of breath, and they might just put the two and two together, without really explaining what the condition is.

EP3: ... And someone else came to a course ... and she was like, "I'm not giving up smoking!" and the tutor just went, "Well, we're not asking you to give up smoking; this isn't what it's about!"..."If you want to give up smoking, you can go to a smoking place rather than here, because this is about self-management."...And I think two weeks later she went off and joined a non-smoking group!

EP9:...So we (including the interviewee) aren't aware of what COPD entails; we're only aware of our specific condition... I don't know if it's to do with money. ... with all the change around and turnaround that they're having at the moment, with all the staff that they've got rid of ...So the first week we would have a drawing of the chest and the lungs, and how COPD might occur. And this is what I found very difficult, because I really felt that at this point, it would have been much more sensible to have a health professional on board...

i) Uncertainty about the future delivery of SM programmes

Despite these challenges, the experts who delivered SM support programmes in practice felt it was important to deliver these programmes to patients with COPD because patients who attended and adhered to these programme had gained benefits. However, several experts who did not deliver the programmes were unsure/uncertain because they felt a class-room based approach may not be the best way to support patients with cognitive issues, it might not change beliefs or because patient-based positive outcomes had not translated into cost savings for the health services.

EP11: Really for any patient, it doesn't matter who you're delivering for, you see enormous benefit. If they stick out the course, if they stay with the course and attend most of the

sessions, it really does help them. It helps them start to realise they can help themselves more, and that actually they don't have to be dependent on everyone else. It helps them realise they can do things again, ... also partly accepting their condition more; they see people around them with similar problems, so they're not alone, which is an enormous help to them, they find...

EP10: *Yes, and I think also these patients are elderly, they have other medical problems. We know about psychological co-morbidity, we know about cognitive issues, so I don't know how much sitting in a room listening to somebody talking and pointing at a board, whether that's the right way, whether that's how they want to find out about things, whether there are different ways they want to find out about things. But I don't think we know the answer to that.*

EP15: *...Not very powerful effects on real end outcomes that are of importance to health systems that were, for example, trying to decide should we offer this programme. I do think absolutely patients love it. I mean, it's really fascinating that it doesn't have a stronger effect on some of these medical outcomes that are subjective! You know, you would think, well, if they really like it, then maybe their health status would go up too, but it just doesn't seem to happen....my gut is that it's just I think the reasons to be in the programme are not so much to change outcomes that are going to be of interest to doctors and to health systems... the value of the programme is probably in mostly non-medical terms.*

One expert mentioned that delivering a clinician programme and a SM programme with service improvement would be beneficial all-round

(2) Reasons for patient non-participation in COPD SM support programmes

All experts agreed that participation in SM support programmes by COPD patients was indeed a problem. A few experts had mentioned that as a result of poor uptake they knew of some centres that had been closed down. Several experts acknowledged that these programme would always be unsuitable for some patients owing to their personalities or motivations and mentioned that it would be difficult to engage patients to take part or attend these programmes who might be unengaged, unmotivated or uninterested in SM.

The reasons for patient non-participation were expressed at the level of patients; health system and organisational factors.

(2A) Patient-related factors

The following patient-related explanations given by the experts for non-participation matched those that were given by the patient stakeholders under the theme 'resignation or denial' (in Chapter V, section 5.6.2.3).

i) Patient characteristics

Some explanations given for non-participation were that patients' might find changing behaviour difficult, they might not understand why self-care is important for them or they might not want or be ready to self-manage or because they have always been told what to do or offered solutions instead of being asked to present solutions. In addition, non-participants perhaps might not want to make things better for themselves, some might have accepted their condition but they do not ask or want to seek help or some just take time to accept their condition or perhaps feel judged because of their smoking. In comparison, patients who participated in SM support programmes were those who wanted to learn about their condition and management, they have accepted their condition and are already engaged with the services.

EP8:...It's really difficult to change your behaviour, and I think sometimes we come to work and we think, why aren't these people doing what we know is good for them! And then you knock off at 5 o'clock and go and have a bottle of wine, a kebab and, you know, loads of unhealthy behaviours!!! ... We all have things that we just can't give up and we just have to learn that your patients are just the same as you... And if somebody has smoked 50 cigarettes a day for 50 years, it's not going to be easy to just stop smoking, because probably that's the time when they're really going to need a cigarette!

EP12: I know some people are able to get to that kind of service whatever the obstacles that lie before them, they will get help, they'll ask somebody, they will get there by wheelchair, they'll crawl!...And there are some people who need a lot of encouragement and support to avail the services, even if they are able bodied and otherwise fit to do so....So that suggests that there are important psychological differences between these people.

EP13: ...As I say, a lot of people just accept it; it's just I'm a smoker, I'm still

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ii) Symptomatic nature of COPD and its consequences

Many experts suggested that patients' might not want to join a group because of their illness/comorbidities and due to psychological or emotional limitations. Specifically, patients' might be fearful of the unknown, they might not want to discuss their illness with strangers, they may be depressed or lack confidence to go out if they live alone and in some cases the anticipation of attending the programme may make patients anxious or they might remember previous anxiety attacks. The symptomatic nature of COPD and its limitations might also make patients feel ashamed because they are dependent on others, they might be embarrassed e.g. coughing, about using oxygen in public and these limitations might not be acknowledged.

EP2: *My main perceptions? Fear of a group, if they know it's a group. Fear of the unknown, that it's not a normal one-to-one encounter, but you step into a different role. Fear of exposing yourself.*

EP1: *I mean, I think there's a number of people who possibly don't come on these courses because they don't really know and they're a bit worried, especially if they've had a condition for a number of years. They get to a point where they're a bit worried to admit they've really no idea what their condition is. ..And they're worried that if they came on a course they might be shown up for that*

EP9: *I think it's the thing with lots of conditions; you get up in the morning, you don't really feel well. I mean, nobody is happy with living with their condition, but a lot of people aren't comfortable either. And so you might feel embarrassed about breathing like that, because initially it could just be excessive coughing that you're getting, so you're embarrassed about being in an environment where you're just continuously coughing.*

iii) Lack understanding about COPD and the programmes

The experts' mentioned that patients' might not want to participate because they might have no understanding of their condition or they might believe they are not going to get better, they might not understand how the programme or exercise would be beneficial to them

EP3: *Or it's not for them...like, I think with COPD, there are people that have become a victim of it (the condition), quite often....And so it takes quite a lot of work to think about ... they've already got this self-belief that if they exercise they'll become puffed, so they don't exercise.*

EP13: *Oh, absolutely! I think that's a big barrier, if they have poor understanding about what have I actually got and why am I breathless, and what slows me down.*

EP6: *In I*** we've had like eighteen register, ten turn up and three complete, maybe, or four complete. I would say the biggest reason is that people think, well, I've got this, it's not going to get any better, so there's no point in learning anything how to deal with it.*

iv) Physical or practical barriers related to participation

Several physical or practical barriers were suggested that could affect patient participation. They were: inconvenient times, difficulties getting to the venue, practicalities of carrying oxygen to the venue, comorbidities that could make it difficult for a patient to sit for a couple of hours at a time and competing commitments

EP11: *...A lot of them (patients) struggle with the travelling; actually getting there, the journey is just too much, or it's public transport. I often think that's an area that would help; we've regularly had requests, "Can you help us get there?" and people haven't, so as a result they didn't go, or they gave up very quickly.... or they haven't got the money to pay for a taxi. Or they have to organise it themselves.*

EP7: *Generally, it's (a) getting to the venues, and certainly for people with mobility and disability issues, you know, car parking is a huge problem. You know, if they can't park, even if there's free car-parking, and sometimes there's not, if there's no car parking spaces right by the venue, you know, to ask people to walk round the other side of the building, that's going to put people off.*

The patient-related factors mentioned here for patient non-participation match the reasons that were suggested by the patient stakeholders.

v) Gender differences

Gender differences were also explored and according to some experts there was not much variation in attendance amongst men and women except that men perhaps might not consider

participation because they are not joiners like women – a natural social difference or perhaps men might feel that being men they are not supposed to ask for help even though they might find it hard to adjust to their illness

EP12: *Well, men aren't joiners in the way that women are. Men are less social than women. Men are less likely to make casual conversation, they're less good at gossiping, they're less good at sharing than women. There's not a tradition of chat and gossip between men, it's not so good, not so old as it is between women, although that's changing. So there's probably a natural social difference, which is learnt probably.*

EP8: *And I think loss is a big thing; so people not being able to do what they used to do, or cope how they used to do. So a lot of men who were maybe dockers or manual workers who have always coped with things by going to work or by going to the pub, or going out with their mates, by smoking, and suddenly because of their physical limitations, they can't cope in any of those ways. So they just feel a whole sense of uselessness, a loss of role, and depression, inability to adjust to the illness...And men as well; I think sometimes men are sometimes a bit reluctant to go to the groups.*

(2B) Health system-related factors

Various health system factors were suggested that might affect patient participation and they included the following:

i) Lack of integration of SM in routine care

Some experts, who had delivered SM programmes previously, mentioned that problems in patient participation or recruitment had occurred because they lacked the support of participating primary care trusts and/or GPs despite the SM programme being commissioned by them. They explained SM or SM programmes might not have been a priority for health professionals possibly because of time constraints, not being involved in the programmes or about patient progress or the lack of integration of SM in primary care

EP14: *It (recruitment) is a lot of work, and in fact what we've done because we're concentrating on the practices, part of the work that they have to do is they have to do the telephone calls; you know, that's their responsibility...We generate the letters and send them out, but the telephone contact has to come from the general practice, because we don't have the facilities to do that....*

EP5: *...The simplest way to put that is a lot of programmes are run off-centre from core health services and what have you, they're not really linked into the care pathway, they're not really linked on what the clinician is doing and so forth, so therefore recruitment to them (the programmes) is problematic...*

ii) Lack of understanding about SM and programmes among health professionals

Health professionals' might not understand the role of SM or SM programmes which might make it difficult for them to embed SM in practice or the insufficient evidence of benefit for SM might make them reluctant to change their practice including referral to the programmes.

EP1: *... perhaps we don't spend a lot of time helping other people (clinicians) understand it. Because I know when I was training up, a nurse specialist facilitated the self-management programmes we ran, ... we... thought of as self-management, and what the health care professionals we were training thought of as self-management, were quite different...(on further probing)...Because I still think that when I talk about self-management, I talk about, you know, an approach which is very facilitatory, getting patients to be solving problems themselves. Whereas I think the health care professionals were talking about it, but still taking a very didactic approach.*

EP16: *I think they (GP) didn't understand it. ...and they hated the term 'expert patient' – that was an absolute anathema to a lot of people, patients and clinicians...I think they had this sort of vision that someone out there was doing things and telling things to their patients that weren't safe, that they weren't in control of them, that they didn't know about.*

EP2: *...I think from my experience it has to do a lot with the culture of the practice; whether you've got a more traditional paternalistic model, whether you've got a more bio psycho-social model, which embraces all this and in some practices, you will have a lot of referrals for self-management; in others, none.*

iii) Inefficient health system

Inefficient workings of the health system were also suggested to affect patient participation in SM support programmes. They were: primary care staff might lack training to provide information about the programmes, lack of communication or sharing of information about patient care between primary and secondary care and administrative problems such as referrals getting lost or not reaching patients.

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> **EP10:** *Well, it's just the system, isn't it, because they still don't talk to each other, you know? GP records and hospital electronic records don't mesh. ...There are people working in silos and nobody knows what everyone else is doing! I think it's just a vastly complex, inefficient lumbering system. Simply just getting us all to talk together and share information effectively is hugely challenging! ...But that is changing; you know, social care is now coming into the mix.*

> **EP4:** *...So quite often the (PR) referral goes off and they (patients) don't really know anything about it. A lot of people we ring up and say, "Would you like an assessment?" they haven't got a clue that a referral has even gone off!... we have been into GP practices and done lots of education sessions about what our service entails...But whether it's just that the GPs are always changing, there's locums and everything going through, so maybe we don't always maybe catch everybody...*

iv) Right patients might not be recruited

Some experts mentioned that in previous SM programmes the appropriate patients may have not been targeted which could have affected patient participation. For example, targeting patients with no understanding about their condition, not asking patients if they would find the programme useful and research studies might have used too wide or a narrow inclusion criteria.

> **EP1:** *And kind of applying a general everyone is offered this, that might be why we're coming up with some problems.*

> **EP8:** *barrier Yeah. I think it (COPD) is a really poorly understood condition...And I think something really telling happened the other day when I was in a patient's house and she (partner of COPD patient) said, "Yeah, he didn't tell anybody that he's HI ... COPD!" And I said, "Were you going to say HIV?" And she said, "Yeah!" So to her it was just another illness with letters...And it's really because this man has never told anyone that he's got COPD, and he's someone that we're trying to get into group programmes, but for him it's so shaming, that he said that he has asthma...*

(2C) Off-putting programme organisational factors

Several programme organisational issues were mentioned that might have been off-putting to patients thus affecting patient participation. They included: place of patient assessment being different to the programme venue, programme staff who were unable to explain the service

over the telephone, the person who invited patient to the programme not being present at the programme, patients who might get tired or might not be able to concentrate for three hours and absence of a rolling programme.

> **EP4:** *...we have our assessments in a different place to where we run the programmes....Which often patients find it difficult to get to. It's in a hospital setting so maybe that puts some of them off...and sometimes they've only had a phone call from us, and then a letter with some questionnaires, to come along. So, it's quite difficult to explain the service and why it might be helpful on the phone.*

> **EP6:** *And I think with a lot of courses, you can get the contract manager to phone and say something, but people will then warm to that person over the phone. And then they'll say, "So are you going to be there?" and then you have go, "No, actually, sorry, I'm not! I'm going to be sat in behind the desk or ...!" You know?...And then people go, "Oh, well, I'm not coming then."*

(3) Reasons for patient dropout

(3A) Patient-related factors

The following patient dropout reasons were suggested by several experts: patients' might have lacked understanding about the programme, they had unmet expectations (e.g. not cured or treated or no health improvements seen following attendance at one or two sessions), or patients' lacked understanding that the programme was about SM for the long-term or lacked perceived benefits. Other reasons included suffering acute exacerbations or not ill enough; and the group dynamic not working e.g. younger or less ill patients could not relate to patients who were older or more severe

> **EP6:** *... a lot of people get completely the wrong end of the stick, don't read the literature and what it's saying, they think they're going to get a cure by going to this!...You know, and then when they come on the first week they realise that actually, no, it's not for them...they don't really understand the self-management aspect of it. They think that someone's (doctor is) going to come and it will be a lot more medical than it is.*

> **EP11:** *And also it's introducing things specific to a person's condition; so with COPD, there's a lot of specific COPD things. You do find with quite a lot of people coming on the courses, they think they're coming on something to help their specific condition, and that's one of the reasons some people leave, because they see it and think, well, this is nothing to do with my condition, so they leave..... And reality is, it is*

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> *going to help you, it's just that you have in your mind that you need something specific to that.*

EP13: *...Their condition is very variable, so they have exacerbations and drop-out, so there's not the stability you might have with other chronic conditions, you know?*

EP9: *... I had one particular gentleman, who was on the angry course; he was living with COPD and he was really worried about his condition because he was saying, "I don't know who to talk to. I've got this, I've got that. Blah, blah, blah!" And he was really enjoying the first week that we had delivered, but because of this psychologist (another attendee) who wouldn't stop talking and asking questions ...During the programme he walked out...*

A few experts also suggested that prior commitments such as hospital appointments for other comorbidities, holiday plans; problem related to transport or the lack of support from others to help patient to get to the programme

(3B) Organisational factors

Some experts cited the following organisational factors that could have led patients to drop out of the SM programme: the first session of the programme might have been uncomfortable for patients because there is a lot to take in, the set-up of the programme seemed to be like alcoholics anonymous, classroom-based, poor facilitation skills or the 'living wills' section of the programme might have been upsetting for patients.

EP11: *It's quite hard that first session in that it's a lot of talking, and whether that's off-putting or not, I don't know...I'm not sure how much they take in as they're talking because it's heavy stuff like, this is what you've got to do in self-management.*

EP7: *Yeah. And then there's all the other issues around sometimes the way the course is delivered. If they get a sense that the tutors are ... often this is a common criticism and sometimes it's a reason for dropping out, that tutors are reading from the manuals. And, "We've got our own course book. What's the point of me going along to the course and listening to someone read from that; I could have read it myself!"*

(4) Suggestions proposed to improve patient participation and retention in SM support programmes

Several improvements were cited for the health system and organisational aspects of the SM programme to improve patient participation and improvements to the organisational aspects of the SM programme were suggested to improve patient retention.

(4A) Health system improvements

i) Identify the right patients and offer the right programme

Some experts proposed targeting a type of patient such as, symptomatic patients, patients with mild, moderate and severe COPD, recently diagnosed patients and younger patients in their forties for group-based PR/SM programmes; programmes should be targeted at the right time for patients; and use of the patient activation measure (PAM) to ensure consistency among professionals to identify the type of support the patient may need.

> **EP12:** *...if you're not symptomatic, then it's not an issue and you probably shouldn't be getting it at the moment, apart from smoking cessation.*
>
> **EP9:** *... I was just thinking, it is so important to catch them at that right time and... if their mindset is that I'm being looked after because I've been given X amount of medication and that's how it's going to have to be, you can't force them to do something they don't want to do.*
>
> **EP6:** *It (PAM) should be used ... And then if they're (patients' are) saying, if they're very confident that they can manage everything ... at the end of it, then just turn round and say, "Well, do you know what, I really don't think that you'll benefit from attending this course. ...And then to them other people you can say, "Well, judging on the fact that you've said you're not confident with that, I think that it would be a really good idea for you to come along." ...And number one, I think it makes it more personal to the person; they're not just turning up having not spoken to anybody...Because I think people have to feel very safe in that environment.*

ii) Identify from patients what they value

Following identification of the right patients, many experts mentioned that it might be useful to learn where patients were in their illness journey regarding self-management of their condition or to participate in SM support programmes however, this might require from

professionals communication, discussion and building relationships with the patient to offer them interventions suitable to their needs and wants.

> *EP8:* *What you need to do is maybe take a step back and try, first of all, to just build up a relationship with that person... it takes more time, but we're asking people (professionals) to be really curious about what that person's experience of COPD is and how it's affected them. And then to work with them on seeing what their options are...So you're not just forcing people with our model of what helps, you're actually thinking with them about what do you want in your life, what do you value and what do you want to be able to do with COPD, and how can we get you there?.... try and understand a bit about why people aren't doing what we tell them what to do. .. I think people don't do things if you tell them to do it. We have to present them with options and choices, and say, "What do you want to do?" ..."This is what's available. These might be the benefits, these might be the drawbacks."..."And it's up to you." And if people hear themselves say it, then they're more likely to do that.*

> *EP13:* *So, I guess if you look at it that way, I think you have to tune into the patient and what the patient is really ready for. That's where the clinician's role actually is, you know, to get that feel, and it's about listening to the patient and recognising what their needs are, where they are on their journey really. And then maybe offering ... well, hearing what the patients actually want and then having things on offer that are there for them, that will just fit, you know? So it's not just one thing; I don't think it's just one course, you know, is the answer.*

iii) 'Pre-work'/ 'Intermediate step' to support needs of patients

Some experts felt that some *'pre-work'* was needed or an intermediate step was necessary to support patients prior to their attendance in SM support programmes so they might consider participation. The work could involve: provision of information about the illness, support with accepting their condition, making people aware of SM and encouraging patients to consider SM and participating in the programmes by relaying the benefits of the programmes preferably, in places accessible to patient or within their social environment such as GP surgeries, in the community, libraries, place of work, holding an open day comprising of health professionals and lay professionals. The following persons were suggested for this role, health professionals, people who deliver SM support programmes or previous programme attendees.

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> *EP2:* *I often wonder whether a kind of intermediate step is needed, and in our practice we now have something for pain and whatever you want to call it medically, I'll explain the symptoms, something in-between where you can have a conversation about what is likely to go next before you go on a tailored programme which has some prescriptive elements, like COPD, ...And so far the experiences we have are good in two aspects: (a) for the practice network to know, and (b) for the patients. So I think it's not just something which affects the patients, it's something where the team has to be involved as well...*
>
> *EP1:* *... I don't know whether it's worth having just some very accessible sort of sessions, whether that's in GPs' surgeries, where, you know, sort of doing a "what is self-management?" type of thing. ..for patients. ... a sort of introductory thing running however often in GPs surgeries or ... I mean, you could even do information leaflets, ...Whether you could do something pre to get people thinking about it (SM), to address those things, fears and worries, and expectations and get those more appropriate (for programmes). And then from that, getting people thinking, actually, that might work for me. ...Yeah. So, you know, "Come and find out about free new treatment! Ten minute talk," or whatever...*

In line with the above, one expert, from their experience, mentioned that providing individual support to patients in their homes initially proved successful as it had led some patients to come out and attend group-based PR sessions.

iv) Need enthusiastic referrers

Several experts mentioned various personnel such as GP, nurse, physiotherapist, respiratory personnel in COPD clinics, SM tutors or those who were well known and in touch the most with patients as suitable to refer patients. Self-referrals were also suggested. However, there was some inconsistency among the experts about allowing self-referrals e.g. they may already self-managing well or GPs might not refer patients because they might not be interested or believe in the treatment enough to refer patients.

> *EP3:* *Well, if it's referrals then I would say the best people to refer are pulmonary rehab and physios to be perfectly honest. ...And for people to self-refer because you've got in to them to think that they would benefit.*
>
> *EP12:* *(For a) service (in practice)...I think you need to have enthusiastic referrers. ...So the referrers would have to be clinicians, and the practice nurses ... the practice nurses*

get better attendance rates than GPs...practice nurses who refer patients probably have more belief and more interest in COPD, and more belief in the treatment. ... so I think that that might be to do with relationship that the person has, and to do with their conviction...

EP2: *...I think it would be for these programmes better if only the people who want to, sign up for it. ...But it's an opt-in issue, where people make the first step, instead of being passive recipients of a pathway where the system decides something for them... I don't think I have to do outreach for everybody that they really get access, because our resources are not endless.*

v) Training and support for professionals to support patients

In order to facilitate the above suggestions about improving participation a few experts proposed training for health professionals including lay members such as health trainers or health champions; promotion of programme benefits from evidence; and integration of SM programmes into routine care to help professionals become aware of the programmes and to encourage self-care among their patients based on their action plans that were set up at the programme.

Working with the negative mindset of patients was considered to be a challenge for delivery and lack of evidence of benefit of SM programmes was identified as problematic for the future delivery of the programmes (see section 6.6.2.1 (1)). So, the promotion of the programme benefits from the evidence base mentioned here might help professionals to be more accepting of SM for their patients. In addition, arrangements for training and support for professionals to work with patients prior to them attending the programmes might also be helpful to staff who deliver these programmes as it might make it easier for them to work with patients who already had a better understanding about their condition and the programmes

EP5: *...Whereas if they (SM programmes) were fully integrated into the care pathway, so that your specialist nurses and things were fully aware of who is more suitable to attend, what sort of profile patient, what circumstances, what they need to say to the patient around why they think the course would fit, then we see recruitment issues beginning to disappear...*

EP12: *So it's complicated. ..I think the more that we encourage GPs to listen and understand their patients, and to consider the role of self-management then the more likely you*

> *are to achieve control of chronic diseases. That's a theoretical position, but that's what I think we should do. It's likely to be the case with some diseases on the whole. So what should you do? I think you need to be really clear about where the evidence is about self-management; what is it about self-management that works? What can you say to GPs, that this bit works?*

EP4: *...And quite often sometimes it's the practice nurses that do the referrals, in which case I think maybe they could come to understand it (PR service) a little bit better maybe.*

vi) Improvements to logistics of patient invite to the programme

Alongside, some experts suggested that a personal approach e.g. face-to-face or by phone or a DVD would be beneficial when inviting patients to the programme and that the invitation needs to be pitched at the right level of the patient e.g. an anxious patient might need more support and would need to feel at ease before they can consider participation; in addition, the process of invitation needs to be efficient. Furthermore, it might be useful to identify and discuss patient expectations, logistical or practical difficulties and discuss what benefits they expect to gain from attendance e.g. increase in confidence, improvement in coping skills. There was some inconsistency about allowing patients to bring carers to the programme.

EP14: *No. A letter is good, but when you send the letter, you need to follow it up with a telephone call, because if you get a letter out of the blue and you haven't a clue what people are talking about, then there's no point....if the practice nurses have given information out, then that's the time when people's minds are open; they kind of know it's coming. That's the time to put it in writing, and that's the time to do a telephone call. If you can do all three, then you have a better attendance. We've found whatever we invite patients to, if you phone them, they will respond better. Every single patient, out of the 21 patients who were coming yesterday (to the SM programme), had a telephone call on Tuesday and still we ended up with 13 patients yesterday.*

EP7: *I think ...So this is where the course needs to be not in isolation; it's linked up to all health and social care...That somehow, how do we get that person supported? Is it they come with their carers? ...Is it somebody, part of the delivery team? ...*

EP1: *You get two lines of argument, don't you? Some people will say, "Oh, I found it quite motivating ...!" ...Yeah, and other people will say, "That was scary!" So, I*

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think probably maybe some effort needs to be put in right at the beginning of the course, when you're explaining what the course is and what the expectations are, all these difficult issues addressing them head-on, where they're at, you know? ...I think the introductory, setting things up, is worth investment.

(4B) Programme organisational improvements

i) Improvements to organisational aspects of the SM programme to improve participation

Several experts gave suggestions to improve the structure of the programme such as the programme needs to be flexible - a menu for patients to choose from, e.g. choice of programme, location, day, times; the journey to the programme needs to be convenient and patients need to feel comfortable in the venue; the duration of the sessions should ensure that a patient can concentrate and remain stimulated on a two day course.

EP12: Yeah. It (three hours) is a long time. It is a long time to be talking about these things. You probably need to do it in smaller doses, I suppose. The risk is if you have three hours then people will not come back, if they're not engaged, and if their imagination is not stimulated all the time, the risk is that they will not come back

EP11: So trying to have those courses local to that particular where you've done your mailing is quite important. So if you pick a couple of GPs surgeries and do a mailing from them, you really want that course to be held locally....I never had a problem with the courses actually being held at the GPs surgeries, I think that's a good idea. What you tend to find then is the patients assume it's coming from their GP, it's endorsed by their GP and it's just around the corner, and it's almost like they're happy to do that.

Two other experts mentioned that perhaps there should not be any compulsion for patients to attend all sessions of a one-off structured SM programme; instead, the programme could adopt an informal approach whereby patients could attend sessions of interest to them.

Having a group with mixed severities was mostly a unanimous response amongst the participants.

ii) Improvements to the organisational aspects of the programme to improve retention

Suggestions given to improve patient retention in SM programmes were aimed at the organisational aspects of the programme and they included: more training and practice for

facilitations skills, involvement of HCPs in the programme e.g. to instil confidence in patients, and to show the working together of lay tutors and health professionals. Supporting patients with their psychological and emotional limitations by appropriately trained staff was highlighted as important.

EP11: *...The one area I think they (EPP) could do with more help on is how you talk, because they (EPP) say they're not expecting you to be great speakers, which is fine, but they talk about paraphrasing the material; the reality is what a lot of the tutors do when they go away from the training weekend, they will actually read it out. And if you just read out your text, it is very monotone; it sounds bad, and that, I understand from the feedback, is a very negative point on the courses ....And I really think they could do with helping, give the tutors some form of technique to actually put it across better, without sounding like they're reading it out... So I think that's one thing that lets down the course. ..*

EP1: *Yes, (corrects herself) one on stress and one on anxiety and depression (talks given to patients in PR). ..They (patients) liked the ... recognition that emotions were involved in dealing with their illness and the validation of that. It's (COPD is) quite a difficult one to manage though because, with all honesty, if you're trying to explain the link between emotions and symptoms, you have to be careful that patients don't take away the message that what you're saying is that, in any sense, their symptoms are unreal or psychosomatic...Which people do get worried about as soon as you start making that link, so you have to be sure whoever is facilitating manages it in a way where people don't take away that message...*

EP4: *So I wonder whether sometimes maybe a fully trained health care professional is important because maybe that inspires a bit more confidence in what's being taught. But I definitely think the fact that some of these trainers have COPD is a positive thing, because then these people must surely think, well, they know exactly what I'm going through.*

EP7: *I went to see, at the local (hospital) the respiratory, COPD (team) and they were very interested in what the IAPT (staff) can provide because they're saying that they get lots of patients...(and) ..."Oh, we don't know what to do with them. We're not trained, and we can sense that some people are incredibly anxious and depressed, and we've got nowhere to send them, other than go and see your GP." ......Maybe*

they'd (IAPT staff would) come in and do a session just on anxiety and depression...Depression linked to COPD.

Suggestions for the content of the SM programme were also made such as, add an exercise component to help patients put their set goals into practice in a more guided way as this will increase confidence and reinforce learning; the topic on 'end of life', 'living wills' or 'advanced directive' might not be well placed in the programme and could be handled at the discretion of patients' preference; the section on 'Depression and COPD' was considered important and the section 'What is COPD?' should be discussed with a patient preferably prior to them attending the programme. Retention may improve if patients' are reassured that things important to them will be covered.

EP12: *And these are all elderly people so their attention may well be limited. I would think that what you need to do in something like this is to make sure that exercise is part of it...Because I think the exercise itself is what's going to make them feel better. So if we get the association of feeling better with the learning, then the learning is going to be reinforced. ...Exercise is useful when anyone is symptomatic...*

EP6: *... I have a big, big question mark about living wills. ... but I think that (living wills) should perhaps be an add-on for people....And you can say to people, "If you would like to talk about future plans for your healthcare," which is what it is – living wills and that, then I think perhaps you should you should just say, "We're able to do an add-on session for 25 minutes (or whatever it is) if you're interested. But I'd like to only deliver it to people really interested in it, because I realise that at this point in your treatment, you might not be ready to talk about that kind of thing."*

EP3: *....And that is good (What is COPD?)....Yeah, because people really don't know. And you see, I think they should have learnt that elsewhere!...And also people aren't able to listen to that. .... And I always feel like you should just have a little kind of cup of tea place at the end, where you can sit down, have a cup of tea and then you can actually say to someone, "Well, what does this really mean?"...Or, "Can I come back in a week's time to talk about what this really means to me?"*

<u>Need for further evaluation</u>

Some experts mentioned that not a lot was known on this research topic and hence there was need for further evaluation. Some others expressed the view that improving participation would be a steady process as it would need a cultural shift among patients and health professionals - and the working together of various health sectors. Some evaluations were underway or were being planned on this topic e.g. having a SM prompt to remind health professionals to offer or refer patients to the programme, using previous PR attendees to recruit referred patients to PR, getting patients to interact with their referrals, and training for health professionals. Certain organisational features were also being addressed e.g. changing the current letters that were being sent to patients about the PR service, and introducing a taster session prior to the programme

EP13: *... In my mind, it's not going to be easy, there's not a quick answer. I think it will be a steady process of, well, in a way that's how you do things and how you deliver the service. I think that's part of that changing of culture process, which applies to not just clinicians in the service, but of course the service users as well. ... We always, in the service want it all sorted by tomorrow or today; sorry, but that's totally unrealistic, especially if we're talking about long term processes, very ingrained processes and attitudes and beliefs! ....That's the problem of course, politically you want quick solutions.*

EP2: *It's (SM is) an interesting area (in response to what else can help improve uptake in SM programmes) ... And what are the problems with that approach with a one-off educational intervention, versus a longitudinal relationship. ...And also group dynamics; how do you maintain a continuous involvement? If you involve lay tutors in the community, it rests often on individual people to run a group; they'll move, they change so it's a very fluctuating landscape you're interacting with. And a lot of emails to write and phone calls to have people to speak to...Relationships to build.*

EP15: *we're trying to get a larger grant funded to look at teaching physicians to support patient self-efficacy. ...You know, ways to improve their confidence that they can actually do it and picking a goal that's realistic. So it's really borrowed heavily from this (SM), but again, I don't think it's meant to be replacing this type of thing, but to try to bring the physician into the picture. So again, if you did have a combined programme then the doc would be sort of speaking the same language that the lay preachers are.*

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(5) Supporting patients with their SM in a non-group setting

On exploration, whether a group-based SM programme might be tailored and delivered in an individual setting or how else patients with COPD (with emotional/psychological limitations, socially isolated, difficult to access including the housebound) could be supported with their SM, the responses on this topic were inconsistent. Some experts mentioned there was need for more evaluation and some others stated that delivering a programme at home might not be feasible because it would mean increased cost, more resource intensive and would take time.

i) Use existing health and social care teams trained in SM support skills to provide initial support

The integration of SM into the health and social care services was offered as a sustainable solution by some experts for patients with COPD in general including those who might be anxious or fearful, socially isolated, depressed or recently diagnosed, housebound patients and even those not ready to change behaviour. Experts' suggested the use of existing health and social care teams involved in caring for a COPD patients to build relationships with patients through the provision of SM support skills and this might include visiting patients at home initially until patients felt ready to participate in group-based programmes. The use of health trainers or health champions was also suggested as a useful resource to support patients.

EP16: I think to focus on nurses, actually. In primary care, you definitely need validation from the GPs that this (SM) is a good thing and it's worth spending time on. So it won't work where there's a culture within the practice where the GPs just think that self-management is a load of rubbish, and there are practices like that. So you need that sort of validation that they will support the nursing team and give them the time and space to do those sort of more complex consultations…All nurses have to do … several training courses during the year to … keep up dated, so the system is there to allow that, you've just got to make sure the (training) courses are there for them to go to.

EP2: My first idea would be (for anxious people or those who fear groups) a friendly, sociable person, who knows about the subject, who builds an individual relationship first, visits people at home and so builds a relationship, and then brings them

together....And that's probably easier than also to run the group, just to have different relationships to reconcile and to tailor what the group needs. (On further probing)

EP6: *...Well, in an ideal world, ... as well as a GPs. ... what I'd like to do is go into a COPD clinic within a hospital when people are first diagnosed, or whatever, and have a kind of little drop-in table thing there... the consultant sees the person, breaks the news to them, but then sends them straight to your table, to say, "OK, go and talk to so and so who is sitting out in the waiting room, because they'll be able to tell you ways that you can cope with this a lot better, because I understand that it's a big thing to deal with straight away."...I think that's what's missing in all of that, and I think that's the way to get people interested...*

EP1: *...Or, you see, I've often thought that you'd benefit from a stepped interventional model (in response to patients not ready)...What I mean by that is ... you've got some people who would benefit from just the information and that will be enough. Then you've got some people which you'd then have a one to one session, and you figure out what their beliefs are and then from that (I mean, I'm talking idealistically here, obviously!) work on those cognitions to help them be ready for self-management, or maybe if they're ready for a group programme. So you're not just saying everybody has to, at this point, be ready for this approach; you're actually seeing the individuals as different...Now whether the GP does that, or...there's COPD clinics where they're seen by the nurses and they make some assessment...*

EP14: *A lot of the housebound have to have help to build their confidence because a lot of them have become very isolated. ... They do not believe that they can do things. ...and if you can encourage them and show them a tiny thing that they can achieve, that will inevitably help them onto the next stage... ...So you really need to use the teams that are familiar to them (housebound patients)... we have also worked with social work carers....*

However, a few experts pointed out that one needs to accept that some patients may not be ready to change their behaviour and just reminding patients from time to time about the importance of SM would have to suffice.

EP2: *You can't (change people who are not ready to take responsibility or are scared to make a change)....If it would be so easy to change people's attitudes or lifestyle, then we wouldn't be at the price where we are...Probably accepting that there are people*

> *who simply you don't reach and it's not made for them....And reminding them from time to time, and probably having a less evangelical zeal to get everybody.*

Educating family members who are carers was also suggested as another area to explore to support housebound patients.

Apart from one participant who because of cost considerations, suggested the evaluation of technology such as the internet to provide SM support, several other experts mentioned that technology such as internet, DVD or telehealth on its own might not be the best way to support COPD patients who were housebound because of the assumption that these patients' lacked internet skills, were not interested or there was a perceived lack of evidence of benefit.

EP3: *Well, one way (for housebound people) would be to do it internet wise.....But I wouldn't do it on the internet, because I think in (name of area) you're not going to have many people that use it…*

EP1: *And then you've got whether you do it via face to face, through workbook, like the heart manual, through the internet, which I suspect wouldn't be very appropriate with this group. …Or a telephone. You know, my thoughts are that I'm not sure you can cover things in quite the same way by telephone. ..That probably works quite well for disease management, what you're talking about … where there's a nurse coming in, but I'm not sure self-management would work...From all the different options, I think you can probably rule out internet and telephone. I'm not sure about the manual type of thing.*

EP16: *…I mean the big hope for that (tele-health) is that it's going to make people much more aware of self-management and much more sort of connected in. … you're never quite sure how people actually think about it in their own home. Because I think if people are linked into it, they think they're being much more closely monitored than they actually are, so there's that aspect of it. A lot of people don't like it because they don't want to be closely monitored because they don't think they're ill enough…and if they're told they need it, it makes them feel terrible because everybody wants to think that they're well and managing, everybody does. And to be told that we now think that you need this tele-monitoring, basically they feel it's awful!*

In contrast, one expert felt the use of DVD, phone or tele-health would be a useful way to support COPD patients.

EP5: *DVD, work book based, something they could work through…And then of course you've got telehealth and telemedicine as well, so direct feedback into the home and internet in the home and that sort of thing.*

6.7 Discussion

6.7.1 Summary findings

This study is the first to provide an insight from an expert sample (both HCPs and lay experts) of sufficient size to result in data saturation about: reasons for non-participation and dropping out of COPD SM support programmes by COPD patients; how participation and retention might be improved in these programmes; and how might, patients who do not or cannot participate in these group-based programmes, be supported with their SM. However, need for further research on this topic was called for by several experts as they felt there was yet a lot to learn on this research topic.

Nonetheless, identification of the level of engagement in SM among the experts helped to identify that currently patients with COPD might be able to access SM support only from SM programmes. There was uncertainty about the delivery of SM programmes in the future either because of lack of evidence of benefit or this type of programme was perceived as not being the best way to support patients with their SM. Currently, COPD SM programmes are not being delivered in practice unless they are commissioned although, PR programmes are still very much one of the mainstay treatments for patients with COPD. So, the study findings might prove useful to those considering delivery of group-based SM support programmes for patients with COPD and want to improve patient participation.

(1) Factors that might lead to patient non-participation and dropout

Patient non-participation in SM support programmes might be composed of patient, health system and programme organisational factors and poor retention in the programmes might also be affected by patient factors and programme organisational factors (Figure 6.1).
Specifically, the patient-related factors that could affect patient participation included: patients having accepted their condition but patients might not want to seek help, patients

might have not accepted the condition or might take a long time to accept the condition, patients might not want or might not be ready to self-manage/change behaviour; the symptomatic nature along with psychological and emotional consequences might lead patients to lose confidence to go out of the house particularly, among those who live alone or patients might be reluctant to try anything outside of their usual care; patients might lack understanding about COPD and the programmes including the belief that nothing more can be done. Some practical and physical barriers related to participation were also suggested.

Health system factors that might affect participation included: the lack of support from primary care due to SM support programmes either not being a priority or the lack of integration of SM into the COPD patient care pathway; HCPs might lack understanding about the role of SM or the programmes, the lack of evidence of benefit for SM programmes might make professionals reluctant to support the programmes thus affecting patient referral; inefficient workings of the health system including not recruiting the appropriate patients for the programmes.

Some programme organisational factors were suggested to affect participation such as, the venues for the PR assessment and the programme were not at the same, programme staff were not able to explain the purpose of the programme to patients over the telephone (insufficient information about the programme was reported by patient stakeholders), a three hour duration might not be feasible for patients who might not be able to concentrate for long and absence of a rolling programme.

Some patients might have dropped out of SM support programmes because of the following: unmet expectations or perhaps they lacked understanding about the purpose of the programme, instability of the condition and conversely not perceiving the illness as severe, the group dynamic did not work and physical and practical barriers including the lack of support to get patients to the programme venue.

Specific to the SM programme the dropout reasons included: the scripted first session of the programme or the classroom-setting might have felt inappropriate, inadequate facilitation skills and the 'living wills' section of the programme might have made some patients uncomfortable.

(2) Facilitators to improve patient participation and retention

The need for further research and evaluation on this topic had been suggested by some of the experts. However improvements had been suggested for the health system and programme organisational aspects to help improve patient participation and for the organisational aspects of the programme to help improve patient retention.

The proposed health system improvements were: to identify the right patients e.g. at diagnosis or by using the PAM for the appropriate intervention; to identify from the patients what they want and value through building relationships and if they are ready for SM or participation in the programmes; the latter stage might require carrying out some 'pre-work' prior to patient attendance in the programme e.g. provision of support to help patient accept illness, information about the illness, promotion of the programme benefits; to use enthusiastic (health and non-health) personnel to refer patients to the programme; and the patient invitation and provision of information about the programme would need to be pitched at the right level for the patient including identification of patient expectations from the programme, and any practical or logistical difficulties related to participation. To support these health system improvements several experts had suggested provision of training and support for health professionals alongside promotion of the benefits of SM programmes from evidence and integration of SM into the care pathway.

Specific organisational improvements had been suggested for improving participation and they were: offer flexibility e.g. a menu of several programmes at various times and locations, ensure a convenient journey, a comfortable venue and the programme session should ensure patients remain engaged or stimulated. A different option, to delivery of the structured programme, was having SM workshops to allow patients to choose the session of interest to them and this could result in patients begin to take control of their condition.

The improvements suggested for the SM programme organisational aspects to improve patient retention were: more practice for tutors to improve their facilitation skills, involvement of HCPs in delivery of the programmes and learning about SM support skills and/or psychological skills so professionals could support patients with emotional/psychological limitations was perceived as important. The content of the programme might benefit from inclusion of exercise, the ''living wills' section might not be appropriate, the section on 'depression' should remain and the content 'what is COPD?' should be covered with patients prior to them attending the programme.

Similar to the topic of improving participation, the issue of alternative ways to support patients with their SM in a non-group setting was also recognised as needing further evaluation. The delivery of the SM programme at an individual level was seen as being resource intensive and not cost-effective. However, a solution was proposed, for reaching and supporting patients (with emotional/psychological limitations, socially isolated, difficult to access including the housebound) and that was integration of SM into the care pathway with provision of training and support for all personnel involved in caring for COPD patients in SM support skills. The inclusion of lay personnel and family members to support patients was also suggested. The suggestions for working with this vulnerable group at an individual level matched some of the suggestions that had been given for improving patient participation. They were: building relationships, getting patients interested in SM, changing their cognitions towards SM, demystifying the group process, building confidence and identifying and addressing unrealistic expectations. Support via technology on its own was also not considered appropriate by some experts for housebound patients owing to their lack of skills, lack of interest in technology and the lack of evidence of benefit for technology in COPD.

6.7.2 Comparison with patient stakeholders findings

It is useful here to compare the views given by experts with views of patients in the previous chapter. The commonalities/similarities with regard to factors affecting participation were the patient-related factors. Both experts' and patients' characterised the participants as people with COPD who had accepted their condition, wanted to help themselves or were already engaged with the health services – in other words they were activated patients (discussed in chapter II). While, the non-participants might still be in denial of their condition or resigned to it or were not ready to help themselves or change behaviour as they felt entitled to or were reluctant to try anything else other than usual care. Next, the negative beliefs about the illness or the psychological/emotional limitations due to the symptomatic nature of COPD might lead people with COPD particularly those who live alone, to lose confidence to go out unaccompanied and physical/practical barriers related to participation e.g. competing commitments were suggested by both patients and experts. On exploration of gender differences one male patient said that they had seen more men than women in PR while, a few experts said that the numbers who attended the programme were not too dissimilar

between men and women. However, one main distinction between men and women emerged and that was that men might be too proud or felt uncomfortable to ask for help or men were not joiners or sociable in comparison to women.

One programme organisational factor, insufficient information or explanation given about the programme to patients was reported by both to affect patient participation.

Reasons suggested for dropping out of SM support programmes were illness and lack of perceived benefit. In addition, some patients also suggested poor facilitation skills of programme staff e.g. tutor lacked knowledge about COPD as a dropout reason. This lack of knowledge of COPD or the difficulty to facilitate the COPD elements of the programme had been identified as a challenge by one expert interviewee.

The mention of 'pre-work' that might be needed e.g. supporting patients with accepting their condition or discussion of the programme benefits by several types of personnel in the patient's own environment such as their home or GP practice, to support patients prior to patient attendance was similar to patients' views about provision of motivation and encouragement.

Several organisational improvements were proposed to improve patient participation and/or retention by both patients and experts and they were: the patient invitation should be at the right level for the patient or the patient should believe in the benefits to enable participation; trained staff was important as was the need for improvement in facilitation skills of tutors; invite health professionals to give more talks or involve health professionals in the programme. With regard to the structure of the programme: the duration of the programme needs to ensure patient remains stimulated for the duration, include light exercise/activity, the topic on 'depression and COPD' was important and the topic on 'living wills' might not be appropriate.

With regard to supporting patients with COPD (housebound patients, patient who might be anxious, depressed, socially isolated or not ready to change behaviour) with their SM, an alternative way suggested was supporting patients individually until they felt comfortable to attend a group-based programme as delivery of the SM programme at an individual level for the long term would be costly and hence not sustainable or use existing health and social care teams trained in SM support skills and including family to support patients. Instead of offering SM support via technology a better option proposed was either to have SM

workshops so patients could choose their session of interest or deliver the sessions in monthly Breathe Easy meetings.

Both patients and experts also recognised that despite all efforts some patients might still not want to participate.

One key difference between the patients and experts was that while many patients suggested that if people with COPD might be allowed the opportunity to bring a family member, friend or carer to the programme to encourage participation, some experts were not sure whether involving carers would be useful however, one expert did mention that it could be left to the patients to decide.

The comparison of the findings in this chapter with the previous chapter has been informative because it has highlighted that the patient-related factors that were reported in this chapter were also reported in the previous chapter to affect participation. This suggests that there is a need for further involvement of patients with COPD in their care by health professionals and working with these patients individually through 'pre-work' or provision of 'motivation and encouragement' by trained professionals in SM support might get patients to participate in their care which could help to address some of the patient-related factors and this might further help to improve patient participation in SM support programmes.

6.7.3 Comparison with existing literature

This qualitative study confirmed the findings of quantitative studies[85,109] that the problem of participation and retention in COPD SM support programmes does exist and some experts suggested that this could have contributed to the closing down of some centres that provide the programmes. This could explain why currently COPD SM programmes are only delivered in practice following their commissioning (EPP CIC link, personal communication) and not all CCGs might be commissioning delivery of PR programmes in practice http://www.nice.org.uk/guidance/cmg43/chapter/3-Assessing-service-levels-for-people-with-COPD#benchmark-for-establishing-a-new-pulmonary-rehabilitation-service (accessed 25-8-14). Until now, an explanation for withdrawal of PR services has been the lack of funding[341] and not poor uptake though both factors could possibly be interdependent.

(1) Factors that might lead to patient non-participation and retention

This study identified some new factors that could affect patient participation in SM support programmes and has made a contribution to the limited evidence base.[116,124,218] The patient factors included that patients with COPD might not be ready or might not want to self-manage or change behaviour. This was explained in the previous chapter that it could be because they might have not to come to terms with their illness or because of loss of motivation. In addition, other determinants of behaviour change have been reported as self-efficacy, SM skills, social support, environmental factors and ongoing support,[67] lack of which might affect participation. The experts also suggested that patients might take longer to accept their illness which could affect participation. Taking time to accept COPD can be explained by the slow progressive nature of COPD which may go unnoticed as patients might not experience a life disruption caused by their illness[331,339] or the symptoms may be ignored or 'explained away' in less serious terms.[331] In addition, the lack of perceived benefits from SM support programmes that have been previously reported to affect patient non-attendance (Chapter IV), negative treatment beliefs such as, perceived incurability of the condition or perceptions that the programme is to be about smoking cessation (also reported in Chapter V) and lack of understanding about the condition are also suggested in this study to affect patient participation. The lack of knowledge or understanding about COPD and perceptions of the programme to be about smoking cessation and as a result being angry or reluctant to learn anything was reported as a challenge in delivery of SM support programmes by some experts. This negative mindset has been previously attributed to patients only knowledge of 'incurable' COPD coming from GPs and smoking cessation being demanded of them.[342] Fear of breathlessness and exercise owing to physical and psychological limitations has been reported previously as a reason for non-participation in PR,[100,116] in this study along with fear of breathlessness and other symptoms such as coughing, the fear of the unknown, previous anxiety episodes, and the lack of confidence to go out alone particularly among people who live alone were also given as non-participation reasons. In contrast, results of a survey revealed that patients with high levels of anxiety and depression may be interested to join PR – albeit an inpatient PR programme.[343] It might be useful to explore the needs of patients who might be anxious or depressed with regard to their management. Dislike of a group approach has been reported previously by one patient as a reason not to participate in PR[100] however, this study identified that it might not be the group setting but being referred somewhere that was new or different to the patient's usual care. The fear of making a change due to being

dependent on existing health services has been reported for poor attendance in a COPD SM programme previously.[122] Different to previous reports,[100,114,116,122] some new practical barriers were reported to in relation to affecting participation in this study and they included that the patient might worry about bringing oxygen to the programme venue and comorbidities might make it difficult for patients to sit for the duration of the SM programme. Being on long term oxygen therapy was reported recently to influence completion of PR.[344]

The findings of this study support previously reported findings[116,218] that the limited knowledge of PR and lack of enthusiasm among primary care professionals while informing patients about PR could affect patient referral and thus PR participation. This explains why some patients in previous studies[100,116] included in Chapter V, may have given, insufficient information or inadequate explanation about the programme as a reason for non-participation. Additionally, this study found that an inefficient health system e.g. lack of training among practice nurses to provide the right information about PR, the lack of communication about PR to patients despite being informed to do so, the lack of communication between primary and secondary care might also contribute to non-participation. Results of a recent survey[345] suggested the presence of a significant association between low self-efficacy among primary care providers and their non-adherence to offering PR to patients with COPD which was not identified in this study. This study further identified that the lack of understanding about the role of SM or about the programmes among primary care professionals could affect patient participation and some experts explained that this might be because of the lack of integration of SM and the programmes in the COPD care pathway, SM not being a priority for professionals which could be due to the insufficient evidence of benefit for SM programmes particularly, the lack of translation of patient benefits into cost savings. In addition, some experts were uncertain whether SM programmes could really change patients' beliefs and hence were uncertain about the future delivery of the programmes. These findings can be supported by studies that reported the lack of promotion of exercise behaviour change among patients with COPD due to professionals lacking understanding about the importance of this SM strategy for COPD;[218] and poor recruitment in the national evaluation of the generic SM programme was because GPs were unable to relate to and conceptualise the benefits of the programme;[346] and inadequate conclusions from studies on effectiveness of COPD SM education on health care utilisation.[84] Despite the national roll-out of disease-specific SM programmes in the community for patients with chronic conditions including COPD

http://www.patient.co.uk/support/expert-patients-programme (accessed 21-9-14 and policy focus[47] on the provision of an integrated service for COPD patients where collaborative SM is a key feature, not much seems to have changed concerning the place of SM in COPD care in comparison to other chronic conditions for example diabetes.[347] So, until there is a shift among HCPs in understanding the role and benefits of SM and applying a collaborative approach[348] when considering the care of COPD patients the problem of poor participation in SM support programmes might possibly remain. One other health system factor that was not reported previously to affect patient participation was that the right patients might have not been recruited for SM programmes e.g. too wide or stringent criteria was used. The generic SM programme has previously received much criticism[73] for including a self-selected group of patients in research studies as opposed to patients who might benefit most from the programme such as, those with poor literacy and those belonging to socio-economically deprived groups. In addition, one expert stated that although they received referrals following application of the MRC criteria some patients still did not participate perhaps because they were not asked if they perceived benefits from attending the programme which suggests that identifying the right/appropriate patients solely through use of criteria might not be enough.

Furthermore, the following organisational factors were reported in this study that could have affected participation and had not been reported previously: SM support staff unable to explain the purpose/benefits of the programme to patients over the telephone – till date the lack of information or explanation about the benefits of SM support programmes by health professionals has been reported (shown in Chapter IV). However, the programme staff not being able to explain the purpose and benefits of the programme itself could further increase patient non-participation in SM support; staff that invited patients to programme not being present at the programme – this could impact participation among patients who might already be nervous or fearful of entering a new environment or meeting strangers or who disliked a group setting (Chapter V); and absence of a rolling programme – the lack of flexibility by the programme has been reported previously.[100]

The patient dropout reasons such as unmet expectations, lack of support, instability of the condition, physical and practical barriers that were suggested by experts in this study had also been reported by patients previously for SM support programmes (Chapter IV). In addition, some new dropout reasons suggested in this study were: the lack of understanding about the

SM aspect of the programme or that they might not be ready for SM, the group dynamic not working either because younger patients could not relate to older patients or some patients were disruptive, disliked facilitations skills of the SM tutors and 'living wills' session of the programme might have been off-putting.

(2) Facilitators to improve patient participation and retention

In this study, improvements were aimed at the health system and the programme organisational aspects to improve patient participation. The following improvements to the health system were new findings and they comprised of: identifying the right patients for the programme e.g. at diagnosis or via the patient activation measure (PAM) (and patients might need another form of support at this point); building relationships with patients to see what they want and value and if they might be ready for SM/programmes (and patients might need another form of support at this point); carrying out 'pre-work' which might include supporting patients to accept their condition, addressing treatment beliefs by discussing the programme benefits; using enthusiastic personnel about SM and programmes to refer patients; pitch the programme at the right level of the patient and assess and address patient expectations about the programmes, practical/physical barriers related to participation; and these suggestions might need the provision of training and support for HCPs.

Improving patient referral through improving the information flow was a suggestion given to improve participation in PR previously.[109,218] This study further suggested that patient referral might improve through the provision of positive evidence of SM in COPD among professionals and integration of SM programmes into the patient care pathway to help professionals encourage SM among their patients. Besides improving patient referrals, the remaining proposed suggestions to improve participation in this study have been reported in the literature individually in the context of improving patient self-management and not participation in SM support programmes. The PAM has been recently used in a study[349] among patients with heart failure whereby targeted tailored interventions based upon a patient's activation levels showed potential of improvement in patient activation towards SM. Professional communication and collaboration to build relationships with patients has been considered necessary if they want patients to participate in their own health care.[350] A recent editorial[351] has suggested that HCPs should concentrate more on addressing individual concerns of COPD patients and help to reduce the emotional burden of living with COPD which would be valued more by patients to better manage their illness. Another study[352] has

suggested building relationships with COPD patients and their families through a 'dialogue' whereby the nurse can be responsive to patients' needs and concerns rather than having a prescribed agenda about how to make patients perform health-related behaviours. One more study[205] has emphasized helping patients to understand their illness and its management to help them engage with SM and shared-decision making.

A new improvement to the organisational aspect of the SM programme given in this study that could be added to the existing evidence base[122] to improve patient participation was that throughout the duration of the programme it should ensure that patients with COPD can remain engaged and stimulated.

Improvements to the programme organisational aspects were also proposed for improving retention in this study. The new suggestions were: need for more training for SM tutors to improve their facilitation skills, involving HCPs in delivering certain aspects of the programme which indeed was always the plan or intention for disease-specific programmes (EPP CIC); elicit patient preference prior to discussion of the 'living wills' section and cover 'what is COPD?' with patients prior to their attendance in the programme. One study reported that patients with COPD might be more interested to learn about living and managing with their COPD as opposed to dying with COPD.[93]

There was some consensus among the experts in this study that the provision of training in communication and SM support skills for professionals belonging to various health and social care teams who are already involved in the care of COPD patients might be one way to support patients with COPD who cannot or do not attend SM support programmes. Working in this way initially with patients with COPD could become a starting point for patients to start thinking about SM and then possibly participation in SM support programmes. This option was preferred by several experts as a better way to support patients with COPD in comparison to delivery of a structured COPD programme to patients in an individual setting either face-to-face or through technology. However, some experts had realised that the provision of SM support in routine care might be a slow and steady process. The slow development of integration of SM support into chronic care management among 13 European countries including the UK was reported in a recent study.[348]

This study identified some key strategies, not reported previously, to support patients who do not want to or cannot participate in group-based PR/SM programmes and these suggestions matched those that had been reported by the experts for improving participation for example, anxious patients could be supported by building relationships, patients who might not be ready to self-manage or participate in programmes would need support with changing their negative cognitions towards SM, demystifying the group process. The use of lay experts and involving family members was also suggested to support and encourage housebound patients with their SM. A non-technological alternative given to delivery of a structured programme was to consider delivery of SM workshops in the future to allow patients to participate in the session of their choice and which could be a way for patients to begin to take control of their condition.

6.7.4 Strengths and limitations of the study

The study is the first of its kind to explore from lay and HCPs the reasons why patients might not participate in SM support programmes moving beyond the exploration of barriers to patient referral and facilitators to improve referrals in PR among primary care professionals.[109,218] The study findings have made some contribution in the field of how to support patients with COPD who cannot or do not want to participate in group-based SM support programmes and added to the limited evidence that exists on the topic of understanding COPD patient non-participation in COPD SM support programmes and how participation might be improved in these programmes. However there were some study limitations.

Firstly, the research topic, how patient participation might be improved and how patients could be supported in a non-group setting was relatively new, as was acknowledged by several experts in this study. Thus, the findings should be applied with caution.

Secondly, as the previous chapter, reasons for non-participation were not explored from patients who might have been non-participants in a study of a SM support programme however, the patient-related factors that were suggested to affect patient participation matched those that were reported by the patient stakeholders in the previous chapter and hence can provide validation to the findings to some extent. Plus the factors identified might have been difficult to obtain from the non-participants themselves. Furthermore, this chapter was able to demonstrate that besides patient factors and organisational factors several health system factors could also affect patient participation in SM support programmes.

6.8 Conclusions

Patient participation in SM support programmes could be affected by a number of patient factors e.g. not ready to self-manage, negative consequences of living with COPD; health system factors e.g. lack of understanding about the role of SM; and programme organisational factors e.g. unable to give sufficient information about the programme. Improvements to the health system and programme organisational factors might help to address the patient factors and thus increase the potential of improving patient participation in these programmes. Specifically, following identification of the right patients, patients need to be asked what they value and if they might be ready to self-manage or consider participation in SM support programmes through building relationships and provision of appropriate support so patients feel motivated and confident to better manage their condition which could include participation in SM support programmes. One way of involving and supporting patients in their care would require provision of training and support to professionals involved in the care of a COPD patient in communication and SM support skills alongside the promotion of SM support programmes among HCPs and integration of the SM into the COPD care pathway. The process of improving participation could also be used to support patients who cannot, or do not want to, attend group-based programmes by involving various health and social care teams and those already involved in the care of the COPD patient. This might be a more cost-effective, feasible and sustainable option in the long run in comparison to delivery of a structured SM programme to patients in an individual setting either face-to-face or via technology.

Patient dropout reasons suggested were: unmet expectations from the programme or perhaps patients' did not understand or were not ready for self-management; the group dynamic not working; severity of illness and not ill enough; and, specific to the SM programme patients, might have disliked the facilitation skills of the SM tutors and felt uncomfortable with the 'living wills' section of the programme. Improvement in patient retention could include more practice for SM tutors in facilitation skills, involving HCPs in the programme, asking patients' preferences prior to discussion of the 'living wills' section in the programme and cover 'what is COPD?' with patients prior to their attendance in the programme.

6.9 Implications

The study findings suggested that the delivery of SM programmes might be the only way patients might have been able to access SM support as this study flagged up that perhaps some PR services might still be offering didactic education which has been reported elsewhere;[342] this lack of provision of best practice[30] and the limited implementation of COPD SM programmes routinely could limit patients with COPD from acquiring valuable SM strategies that are necessary for their long term management.

Nonetheless, the findings have helped to gain understanding that patient participation in SM support programmes might be affected by more than just patient factors or organisational factors but also health system factors. In addition, the experts suggested that building relationships with patients and providing appropriate support tailored to their needs might help to improve patient participation. Building or establishing relationships have mostly been suggested as important by patients to help them to participate in their care[138,188] and so this finding suggested by experts highlights that patients and professionals might be moving towards the same goal that is necessary if patients are to take responsibility for their health and which includes participation in SM support programmes. To help health professionals build relationships with patients and to consider SM for their patients they would need to be positive about SM. This might require professionals evaluating their attitudes towards patients with COPD,[351] assessment of their beliefs about patient SM http://www.insigniahealth.com/solutions/clinician-activation-measure (accessed 17-12-13) and training in SM support. This might also help integration of SM more into the COPD care pathway seen for other chronic conditions.[347]

The health system and programme organisational improvements reported in this chapter could be used by others involved in the development and delivery of SM support programmes for patients with COPD to help improve patient participation.

The next chapter describes a non-UK developed model of SM support and its adaptation for the UK.

Chapter VII. Self-management support for COPD patients – the 'CENTREd' Model

- One conclusion from Chapter VI was to offer patients with COPD (including those who do not want to or cannot participate in group-based SM support programmes) SM support by health care professionals trained in communication and SM support skills to help patients start to think/consider SM to better manage their condition.

- One novel model of health SM support referred to as the 'CENTREd' Model, developed in Tasmania, Australia, aimed at patients with chronic disease including COPD was identified during the course of the doctoral study as another method being used to deliver SM support to patients with COPD, other than a group-based SM support programme. The model is described briefly and its adaptation for the UK in this chapter.

7.1 Introduction – The 'CENTREd' Model

The 'CENTREd' Model was developed by Dr Helen Cameron-Tucker (HC-T) (senior physiotherapist at Hobart, Tasmania, Australia and postdoctoral research fellow at Menzies Research Institute, Tasmania, Australia). The training and development programme of this doctoral study enabled me to make a two-week research visit to learn more about the model's development and its evaluation in research studies; to observe its implementation in clinical practice (by HC-T and a colleague) in different clinical scenarios mainly among patients with respiratory disease including COPD (Appendix 7.1); and to undergo the accredited training in order to train HCPs to deliver the model.

The 'CENTREd' Model draws together and adds to core skills of other evidence-based behavioural models www.health.vic.gov.au/pch/downloads/factsheet08.pdf (accessed 14-1-14),[201] including: the Heart Manual;[353] the Flinders Chronic Disease Self-management Programme; http://www.flinders.edu.au/medicine/sites/fhbhru/self-management.cfm (accessed 30-8-14) the Stanford Chronic Disease Self-Management Programme;[70] Motivational Interviewing;[354] and health psychology literature;[355] in particular that relating to health behaviour adoption or maintenance.

The model aims to equip HCPs to support their patients in developing the confidence and capability to take an active role in managing their health, including managing chronic conditions such as COPD. The training provides HCPs with practical steps, skills and tools immediately applicable to clinical practice.

The "'CENTREd' Steps" are strategies that guide HCPs to offer self-management support in a structured format to prevent professionals missing a key 'Step' or activity during consultation with patients. The Steps with their key aims are presented in Box 7.1.

Box 7.1 The 'CENTREd' Steps with aims

The 'CENTREd' Steps	Aims
Commitment	To 'Connect' and agree to work collaboratively
Engagement	To establish a mutually agreed agenda
Negotiation	To mutually define and decide on goals and link these to health behaviours
Taking action	To set a 'SMARTIC' (Specific, Measurable, Achievable, Relevant, Timely, Important, Confidence) action plan to achieve goals
Repeating back	To clarify mutual understanding. Ensure preferences have been met
Establishing follow-up	To mutually agree on time and mode of planned follow-up

The "'CENTREd' Skills" include:

- Communication skills (*I statements, listening skills)*;

- Motivational interviewing skills (*open-ended, affirmation, reflective listening, summarising, looking Back, envisaging possible future, dealing with resistance, dealing with relapse)*;

- Problem solving skills;

- Goal setting skills; and

- Action planning skills.

The expected outcomes following implementation of the above listed skills include: improved health self-management, adoption or maintenance of health-related behaviours, improved satisfaction with the consultation by both patient and health professional and improved/reduced health care utilisation.

Embedded in the 'CENTREd' Model is the 'SNAPPS' Health-Management framework with a holistic focus on health. 'SNAPPS' is a mnemonic referring to the health related behaviours of *Smoking, Nutrition, Alcohol, Physical activity, Psychosocial wellbeing* and *Symptom management*. The 'SNAPPS' Tools can be utilised with patients to engage them and facilitate change in the 'SNAPPS' health behaviours.

An illustration of the 'CENTREd' Model process is shown in Figure 7.1 and Box 7.2 lists the 'SNAPPS' Tool with their function. Appendix 7.2 gives a more detailed description of the 'SNAPPS' Tools.

Figure 7.1 The 'CENTREd' Model process

Steps	Skills and Tools	Examples

Skills and Tools:

Commit and Connect
e.g. use open-ended questions, listening skills

Illicit preferences, expectations, identify motivation, identify agenda through use of SNAPPS Guidelines, develop SNAPPS summary report and patient profile, reflective listening

Affirm positive actions, prioritise agreed goals to address agenda, provision of information, teach skills, use behavioural ruler tool to affirm behaviour and build upon existing behaviour

Set an action plan (SNAPPS Tool, problem solving skills

Examples:

'Tell me what's happening with you?

How does your breathing affect you? (SNAPPS Behaviours)

What are the things you would like to work on?

What are you doing for exercise now? (SNAPPS Behaviours)

What would you like to do about it now? Would you like to build on your existing exercise/physical activity? (SNAPPS Behaviours)

What will you do exactly? How much are you going to do? Is this what you want to do? When will you do it? How important is this plan to you? How confident are you that you can achieve this

Circle diagram labels:

Participant

Partnership

Health Professional

Commitment

Engagement

Negotiation

Taking action

Repeating back

Establish follow-up

Commitment

Left side boxes:

Mutually agree on time and mode of follow up

Given appointment card,
On week 8 we will do a review

Both patient and health professional repeat back what was discussed

Tell me what are you going to do when you get home? Do you want me to show you once more? Would you like me to repeat this information?

Box 7.2 The 'SNAPPS' Tools with its functions

The 'SNAPPS' Tools	Function
(1) "'SNAPPS' Health behaviours Choices and Guidelines'"	Denotes most recent guidelines/recommendation on each of the SNAPPS Health behaviours
(2) "'SNAPPS' Health Behaviours Summary Report'"	Is utilised with a patient to gain an understanding where a patient might be with respect to each of the SNAPPS Health behaviours (Tool 1 is used with the patient to complete this tool)
(3) "'SNAPPS' Health Behaviour Profile'"	A profile of patient is created after completion of Tool 2. This tool affirms what an individual currently does to manage their health and identifies behaviours to address
(4) "'SNAPPS' Agreed Actions'"	Are mutually determined between patient and professional regarding behaviour/s that will be adopted or maintained by the patient following completion of Tool 2 and 3 The above tools 2, 3, and 4 can be utilised with a new patient or a patient being seen at follow up and can be referred to at each consultation to help provide the right support to the patient at the right time
(5) "'SNAPPS' Progress forms'"	Can be utilised to monitor progress in detail of the health behaviour/s the patient may have chosen to address. There is a progress form for each of the 'SNAPPS' Health Behaviours
(6) 'Personal action plan'	A template to set out an action plan with a patient
(7) 'Behavioural ruler'	Used to help patients reaffirm what they are currently doing regarding a health behaviour/s and what they would like to do regarding the health behaviour/s prior to identifying a goal and action plan
(8) 'Steps for Dealing with your concerns'	A visual tool which can be utilised with the patient to identify problem solving steps with a patient

The 'CENTREd' Model has been refined from an approach that has been evaluated in three small studies[340,356] in Tasmania among practice and community nurses trained in SM support (referred to as health mentors) who delivered SM support to patients with COPD by telephone.[357] Recently the 'CENTREd' Model was tested in a feasibility study with nurses in Tasmanian General Practice and was found to positively change nurses' practice.[358]

7.1.1 Refinement/Adaptation of the 'CENTREd' Model for the UK

The intervention was refined following discussion with a UK respiratory nurse consultant (based at St Georges Healthcare NHS Trust and part of the London respiratory team). Specifically, one of the tools of the 'CENTREd' Model, the 'SNAPPS' Health Behaviour Choices and Guidelines' (based on the Australian and Tasmanian government guidelines) (Appendix 7.2) following gaining approval from HC-T was adapted and made relevant for the UK by referring to the Live Well, NHS Choices website http://www.nhs.uk/livewell/Pages/Livewellhub.aspx (accessed 27-12-13). The UK NHS health guidelines were adopted for the following 'SNAPPS' health behaviours: *Smoking, Nutrition, Alcohol, Physical activity and Psychosocial wellbeing* (Appendix 7.3).

The next chapter presents the overall summary and discussion of the study followed by the overall conclusions.

Chapter VIII. Overall discussion and conclusions

In Chapter I, the thesis was introduced and the rationale of the study it's aims and objectives were described. The thesis comprised of four stages to meet its aims and objectives, following steps proposed in the MRC guidance on developing and evaluating complex interventions. These four stages formed Chapters II to VII.

In Stage 1, Chapters II, III and IV *examined existing evidence and applied appropriate theory* to understand patient participation and completion in SM support programmes. Specifically, in Chapter II, the conceptual review explored the origins and meanings of patient participation in health care and identified existing studies that had attempted to utilise behavioural models to explain participation in health care interventions, including SM interventions among patients with chronic disease. Two behavioural models identified in this chapter were applied in Chapter IV to the findings of the included qualitative studies in the qualitative synthesis in order to better understand participation behaviour of patients with COPD in SM support programmes. In Chapter III the quantitative element of the systematic review quantified the actual rates of participation and retention in *studies* of COPD SM support programmes.

In Stage 2, following a new exploration of views from COPD patient stakeholders (Chapter V) and from lay providers and professional stakeholders (Chapter VI), a *theoretical understanding* of participation and non-participation behaviour was further developed. This work included suggestions around how participation in SM support programmes could be improved and how patients, who cannot, or do not want to attend group-based SM support programmes, might be supported in their self-management.

In Stage 3, Chapter VII described a non-UK developed SM support model and its adaptation for the UK after *carrying out refinements*.

This Chapter (VIII) presents a summary of the principal findings followed by discussion of the results in context with other research in the area. The chapter identifies the strengths and limitations of the studies in the thesis. Next, the implications for clinicians and policy makers are presented followed by research recommendations and finally a summary of the overall conclusions are presented.

8.1 Summary of principal findings with discussion

Effective pulmonary rehabilitation[42] and self-management interventions[359] are expected to remain mainstay treatments alongside pharmacological treatments to help patients with COPD to better self-manage their condition and to utilise health resources effectively. The imperative for this comes not just from the Department of Health, or health care professionals (HCPs), but from patients with chronic conditions themselves.[360] To help maximise the reach of SM support treatments to eligible patients, this mixed-methods study broadly attempted to understand the problem of poor participation and retention reported in studies of ~~PR and~~ SM support programmes, including programmes for patients with COPD; understand patient non-participation in SM support programmes and how this could be improved; and to identify better ways patients with COPD might access SM support.

The principal findings of this study are presented under the four stages recommended in the MRC guidance for developing and evaluating complex interventions.[290]

8.1.1 Stage 1: Using existing evidence and application of theory to gain an insight into the participation behaviour of patients with chronic disease including COPD (Chapters I, II and III)

Existing participation and retention rates in studies of COPD SM support programmes (Chapter I)

In contrast to previous reports,[108-112] the quantitative systematic review including 56 studies of SM support programmes found high study participation rates (in 43/56 studies only 19% had a study participation rate of <50%) and low dropout rates (the study dropout rate and intervention dropout rate were <=30% in 93% and 94% of all the studies, respectively) (Table 3.6)).

Based on the participation definitions adopted in this study and on the calculation of the study participation rate (Figure 3.1 and 3.2) endorsed by the extension of the CONSORT statement for reporting pragmatic trials[226] the calculated proportions were the true estimates of participation and retention. Differences between the findings in the systematic review and the individual studies[108,109,123] and other reviews[112] arose from the included studies:

(1) reporting the participant flow data incompletely (16% of studies reported 'potential participants identified', 39% reported 'numbers assessed for eligibility' and 77% of studies reported 'numbers eligible' (Table 3.6));

(2) adopting their own definitions of what constitutes patient participation in both study and the intervention within the study; and

(3) failing to state the definitions used clearly, which made it difficult to identify whether proportions reported referred to the study or to the intervention.

In addition, based on completeness of the data, the chosen characteristics: year of publication, quality score, exercise intervention versus non-exercise intervention and group versus individual programme, did not show any evidence of effect on the study participation rate.

Of the 56 studies only 27 studies supplied reasons for patient non-participation, non-attendance and/or study/intervention dropout. Sixteen studies reported the following reasons (Table 3.8) which were common to both patient non-participation and study or intervention dropout: physical or external factors; patient-related factors e.g. competing demands or priorities, illness, lack of interest; study/intervention factors e.g. inability to contact patients, patients failing to comply with the study or intervention or programmes not suitable. Several of these reasons had been reported previously in other studies of COPD SM support programmes.[25,115,117,118] In addition, 11 studies had reported 'refusal/did not wish to take part' as a reason for study non-participation but did not, or were unable to, elaborate on the reason for refusal.

The incomplete recruitment picture observed among the included studies in the systematic review; and the lack of reporting by studies of reasons for patient non-participation, may compromise the delivery of SM support programmes in practice as the study findings may not be generalisable to the target population; this could lead to exclusion of suitable patients who might want to participate and gain benefits from these programmes.[361] Several studies[113,293,344] have highlighted an acute need for qualitative research to understand the problem of participation and retention in PR among people with COPD.

Using a qualitative approach, this thesis (in Chapter IV, V and VI) helped in understanding why patients with COPD do not attend and/or drop out of SM support programmes; why patients with COPD may not want to participate in a SM support programme or may not be interested in taking part; how participation may be improved and how else patients with

COPD could access or receive SM support - thus making these study findings topical and timely.

Before discussion of the summary findings of the qualitative approach specific to COPD the conceptual review summary findings (Chapter II), which informed the qualitative approach, are presented.

__Definitions of patient participation in health care (Chapter II)__

It is clear from the quantitative review that clarity is needed around the definition of the terms 'patient participation and 'non-participation' in health care. The conceptual review (Chapter II) found that the meanings given in the dictionaries (section 2.3.1.1) most closely matched the definitions adopted by this study (see glossary page). In addition, the conceptual review grouped the various meanings and definitions of 'patient participation' into two areas: one based on the context of the patient/individual and one at the patient-professional interaction level (Figure 2.3).

Patient participation at an individual level meant the individual making the decision to take responsibility for their health; and at a patient-professional interaction level (through patient partnership/patient collaboration, patient-centred care, patient engagement and shared decision-making) it meant involving patients in making decisions about their health and health care. Furthermore several studies, through exploration of the meaning of the terms from perspectives of patients (mostly with chronic disease) and professionals, found that patient participation involved more than just decision-making. Among patients, patient participation had meant being confident in one's self and the HCP, comprehending information about illness and its management, and seeking and maintaining a sense of control. Lack of patient participation meant the reverse of these plus a lack of support from professionals and not being respected or listened to.

Among nurses, patient participation had meant patients receiving information based on the individual needs arising from their condition and non-participation had meant that patients did not acknowledge the provision of information. These potentially very important differences in meaning for patients and professionals have also recently been reported elsewhere.[348] To facilitate patient participation in line with the views of patients,

professionals, in addition to providing information to patients should ensure that the patient has understood the information given. The latter approach performed by the professional may also help them to obtain the acknowledgement they want and see as patient participation.

This difference in meaning was a key indication of a barrier for patients to participate in their care and likely to extend to participation in SM interventions. The importance of professionals changing their practice to work in partnership with the patient at an individual level and within the patient's context (their values, needs, expectations) was a key finding in the qualitative study (Chapters V and VI) to help improve patient participation, and is the premise of the patient-centred SM support model described in this thesis (Chapter VII) (discussed later). Furthermore, the conceptual review showed that not all patients with chronic disease may want to participate in their care and that participation may change with time, and across different phases of the disease and treatment – demonstrating that patient participation is not static but a dynamic process. The dynamic nature of participation was explained by two studies in the conceptual review (Chapter II), first[148] through a taxonomy (Table 2.1) that was developed from the perspectives of patients and professionals and a second study[136] which developed a conceptual model (Figure 2.2) from the perspective of patients and which showed that the process of patient participation was influenced by a mix of patient, professional and contextual factors.

Factors affecting participation in studies of SM support interventions among patients with chronic disease (Chapter II)

The conceptual review, which included 25 studies using 11 theoretical models (a socio-behavioural model/health care utilisation model, attachment/interpersonal theory, social theory and health behaviour theories), also suggested (see Figure 2.11) that the main influences on patients with chronic disease seeking professional care were increased perceived need, or increased perceived severity of symptoms and the need for symptom management. In comparison, and in contrast to patients seeking professional care, participation in ongoing SM services was *not* influenced by perceived severity of symptoms; instead participation was influenced by patients' intentions and action planning, the changing psychology between motivation and action influenced by increased self-efficacy, positive outcome expectations and increased risk perception. Exercise identity was influenced by a person's perceived importance of, and confidence to exercise; the availability of support; and

perceived benefits (social and psychological). And in comparison, and in contrast to patients who were offered ongoing SM services for the maintenance of their SM behaviours, *attendance* at SM interventions (mostly at outpatients) was influenced by their beliefs concerning the intervention and their perceptions of the illness and the intervention in response to their health threat.

Specifically, the Self-Regulation Model (SRM) and/or the Self-Regulation Model Necessity-Concerns Framework (SRM-NCF) model was utilised by studies either prospectively (to predict/explain attendance) among patients admitted in hospital, following discharge and retrospectively (following attendance/non-attendance behaviour), or in a descriptive way to explain patient participation behaviour in SM interventions. The prospective studies reported the following illness and intervention perceptions as most predictive of patient attendance: increased perceived cure, controllability and necessity for the intervention among hospitalised patients; increased perceived disease identity and consequences of the illness among patients discharged but prior to programme attendance. The retrospective studies reported that the perception that the cause of illness was not related to lifestyle, or that the cause was not modifiable, or that the intervention was less necessary, led to patient non-attendance whilst increased perceived personal controllability led to attendance. Studies that utilised the Theory of Planned Behaviour (TPB) and the Attitude-Social influence-Self-efficacy (ASE) model found that patient attendance or intention to participate in a SM intervention was influenced by an individual's positive attitude towards the intervention (perceived benefits), subjective norm (TPB)/social influence (ASE) (i.e. the perceived influence of others such as health professionals, family members or friends on attending) and perceived behavioural control (TPB)/self-efficacy (i.e. reports of fewer external/practical barriers to participation).

Factors affecting participation in studies of SM support interventions among patients with COPD (Chapter IV)

Despite the paucity of theoretical models utilised by studies to explain patient participation behaviour in SM interventions among patients with chronic disease, and there being only one study involving PR,[110] the application of the SRM and the adapted ASE model to six published studies of SM support programmes (Chapter IV) helped to develop understanding of COPD patient participation behaviour (attendance, non-attendance and dropout) (Box 4.1)

in studies of SM support programmes beyond the previously reported socio-demographic and clinical factors.[112,121] The results of the qualitative synthesis (Chapter IV) were consistent with the conceptual review findings: the participation behaviour of COPD patients was influenced by individuals' attitude and social influences; and illness and intervention perceptions/representations. Attitudes of wanting to help oneself, the perceived influence of HCPs, perceptions of the controllability of illness and perceived positive benefits of the COPD support programmes, including positive past experiences, were particularly influential on attendance behaviour. Non-attendance was influenced by negative attitudes including: that improvement in their condition was no longer possible; the perception that the programme would not benefit their condition (including negative prior experiences); perceived physical or practical concerns related to attendance; and the perceived negativity of professionals and family/friends towards the programme. Dropout behaviour was influenced by an individual's attitude and intervention representations that the programme was not beneficial after attending a few sessions and by their perceived severity of symptoms.

8.1.2 Stage 2: Further development of theoretical understanding about non-participation and participation behaviour of patients with COPD from a new qualitative study (Chapters V and VI)

Besides understanding the problem of participation and retention in SM support programmes among COPD patients, exploration and understanding the characteristics of 'refusers' in these programmes has also been described as vital.[322] The findings of the primary qualitative study that explored the perspectives of 22 patient stakeholders and 16 experts (comprising of both lay and HCPs) (Chapter V and VI), helped to gain understanding of (a) patient non-participation in COPD SM support programmes; in addition (b) how participation could be improved in these programmes; and (c) alternative ways patients might be supported with SM other than in a group setting.

a) Reasons for patient non-participation and participation in COPD SM support programmes

The reasons for non-participation in SM support programmes were a combination of patient-related, programme organisational and health system factors (Figure 5.1 and Figure 6.1).

In particular, 'refusers' might be patients who are not ready to help themselves or to change their behaviour; they might have become resigned to their illness; they might be in denial or

just taking a long time to accept the nature of their illness; they may be reluctant to try anything different to usual care, particularly any physical activity; they might hold negative illness beliefs (e.g. condition is incurable), negative treatment beliefs (e.g. exercise perceived as unnecessary, programme preaches about smoking cessation) including perceived increased concerns related to participation e.g. cost of transport, difficulties of carrying oxygen to the venue and experience negative emotional reactions e.g. fear, anxiety that could result in loss of motivation and low self-confidence to go out of the house alone to a programme perceived as new/strange. In addition some experts suggested that patients might lack understanding about their illness and some patient interviewees, beyond personal factors, said that patients might be unaware about the programmes.

Besides cost and lack of perceived benefit from exercise, none of the reasons for non-participation attributed to patients suggested by the interviewees in this thesis were reported in a large qualitative study that explored PR programme non-attendance amongst patients who did not attend or complete PR.[311] In Keating's study, the main reasons reported for non-attendance and non-completion were physical/practical barriers and illness. Furthermore, some interviewees added that unmotivated patients being asked to ring up for a PR assessment or patients having insufficient information about the programme or having inadequate access could lead to non-participation. Some experts had also suggested SM support staff being unable to explain the purpose and benefits of the programme over the telephone; the absence of rolling programmes; and different venues for PR assessment and the programme as reasons for non-participation. Moreover, several expert interviewees highlighted health system factors that could affect patient referral and thus participation beyond poor information flow about the programmes. Particularly, non-participation could be a result of lack of support from primary care due to: the SM programme either not being a priority for HCPs; or the lack of integration of SM into the COPD patient care pathway; or a lack of understanding among professionals about the role of SM and the programmes - possibly owing to insufficient evidence of benefit for SM programmes in COPD. The latter findings were directed mainly towards SM programmes however, these findings could be applicable to PR programmes since inadequate patient referral to PR programmes and a lack of understanding among professionals about how exercise can be beneficial to patients,[218] or about the importance of PR for COPD management[362] have all been reported. Other reasons cited for non-participation were the inefficient working of the health service e.g. a lack of

trained primary care staff to provide the right information about programmes, lack of communication between professionals at various levels, and administrative problems (e.g. referrals getting lost), and failure to target the right patients for SM programmes.

The health system factors cited above could explain why some patients might be unaware about the programmes. These factors, and the programme organisational factors, could not have been foreseen by patient stakeholders. Thus gaining the perspectives from both patients and professionals helped in understanding non-participation beyond understanding the characteristics of 'refusers'.

Dropout reasons included: poor communication and facilitations skills of SM tutors, PR staff not being able to focus much attention on new patients, inappropriate venue; illness; inability to keep up with the exercises and embarrassment to ask for help, and unmet expectations from the programme – this latter finding was also reported in the qualitative synthesis (Chapter IV).

b) Suggestions for improving patient participation in SM support programmes

This thesis, and particularly the qualitative study (Chapter IV and V), has made a contribution to the limited evidence base that exists regarding improving patient participation in SM support programmes for COPD (Figure 5.1 and Figure 6.2) however, several patient interviewees also suggested that despite all efforts to improve participation some patients may still be reluctant to participate, and some experts suggested that this topic would benefit from further research.

The patient interviewees suggested the following to help improve patient participation: provide encouragement, motivation, and support in things patients might be doing well; encourage participation by discussing the programme, or their benefits using a one-to-one approach e.g. through GP, PR staff in a GP practice, invite patients to a trial session, visit patients at home or use a DVD to inform about the programme; help patients accept their condition and build confidence so they feel a "sense of worth"; and allow patients to bring a family member, friend or carer to at least one programme session. In addition, lack of awareness of SM support programmes could be addressed by creating awareness of COPD among the general public – better recognition that COPD is a disabling disease might prompt patients to seek help and support.

The interviewees suggested promotion of SM programmes through adverts in several locations e.g. health website, in GP surgeries, day surgeries (patient admitted and discharged on the same day), hospitals, pharmacies and also suggested using the familiar and trusted staff in these locations to discuss the benefits of the programmes with patients. Using volunteers to promote the programmes was also proposed.

The experts similarly stated that much initial work needed to be done with patients at an individual level to improve participation. Several suggestions were made; professionals should identify the appropriate patients for the programme e.g. at diagnosis, or using the Patient Activation Measure (PAM). The PAM scores could then be used to provide tailored support to individuals – this action was recently reported as a key message within the King's Fund report of 'supporting people to manage their health'.[195] Building relationships with patients was recognised as important to identify what patients' value in their illness journey and exploring their readiness to self-manage and to participate in SM support programmes. This is different to administering the PAM because the measure identifies patients' ability to self-manage and how likely they may be to engage in healthy behaviours.[195] However, only through building relationships would one be able to understand the reasons why a patient may not be ready to self-manage or engage in health behaviours and only then could appropriate and tailored support be provided or offered to the patient. This support could take the form of supporting patients to accept their condition, provision of information about the illness, promoting benefits of the programme and was referred to as 'pre-work' or an intermediate step prior to patients attending SM support programmes. The suggestions given by patient interviewees above e.g. provision of motivation and encouragement to patients could be included within this 'pre-work' stage.

Subsequently, the experts also suggested that, ideally, referral should be made by professionals interested and enthusiastic in SM and SM support programmes; the programmes should be pitched at the right level for the patient; and practical and logistical issues would need to be assessed and addressed. In addition, the experts recognised that for these suggestions to take place there was need for provision of training and support for professionals, integration of SM support into the routine patient care pathway and the promotion of evidence on the benefit of SM in COPD.

This alliance of patients and professionals working together, and the importance of building good relationships, mentioned in the qualitative study was also identified in the conceptual review chapter (Chapter II) as a key aspect of patient-centred care in a clinical setting, i.e. to encourage patient participation or encourage patients to become active by identifying their needs and preferences so they can participate in the management of their health and health care.[55] Activated patients are more likely to engage in healthy behaviours e.g. taking regular exercise.[195] Established relationships with professionals was what patients with chronic disease understood as patient participation in health care.[188] This suggests that the role of SM support programmes to teach patients skills to take greater responsibility for their health[153] might have to be the role of health professionals also, through the process of creating partnerships and building relationships with patients, to help them consider participation in these programmes. However, the latter may require a positive attitude and the acquisition of appropriate skills among professionals.[363]

Moreover, there were several suggestions from both patients and experts to help improve uptake of the novel COPD-specific SM programme previously evaluated by the author.[85] Some of these suggestions could also be applied to improve patient uptake in PR. Patients suggested: where self-referral is not available it should be GPs who refer patients; use of a personal approach to invite and inform about the programme; use of trained staff to facilitate the programme; introduce talks by several experts e.g. smoking cessation experts could educate about the lungs, health psychologists could explain the importance of adopting health behaviours for the long term; the content should continue to include the topic 'depression and COPD' and omit the 'living wills' topic; reduce waiting time between invitation and attendance from two to four weeks; hold the programme outside of the 'rush hour'; keep in mind that the concentration of a patient with COPD mainly lasts an hour or two; include light exercise with music; refer patients to PR or Breathe Easy at the end of the programme.

The experts similarly felt that the programme should ensure patients remain engaged and stimulated; in addition, the programme should be flexible e.g. offer patients several programmes at various times and locations, and the journey to the programme should not be a challenge.

These findings above were not used to refine the existing COPD SM programme in this study because (a) organisational changes within the EPP CIC had led to redundancies including the lay tutor who had agreed to help with refinements of the programme; (b) the EPP CIC had stopped delivering COPD-specific programmes in the community unless they were specifically commissioned (c) and, most importantly, the findings of all the work in the thesis to date suggested that there needed to be radical changes to many aspects of the original programme, including recruitment, content and delivery, in order to improve participation.

c) Other/Better ways patients with COPD could be supported to access SM

Most patient interviewees felt that a group-based programme was still the best way to offer SM support to patients with COPD including housebound patients. This view mostly seemed to originate from their own positive experience of participating in group-based SM support programmes. In addition, apart from one interviewee who suggested use of 'skype,' most interviewees were not keen to see delivery of the programme over the phone, via a manual or technology e.g. DVD, internet - perhaps because of their own disinterest in, or dislike of, such approaches.

The participants did recognise the importance of provision of individual support for housebound patients, who cannot, or do not want to, attend group-based programmes; however, they mentioned that offering the SM programme on an individual basis would be costly and felt it would not be sustainable in the NHS. Instead, some participants suggested that more efforts could be directed to get housebound patients out of the house so they could gain benefits from the programme; the resources e.g. one-to-one/a personalised approach could be focused upon introducing the programme and their benefits to patients and taking care of any practicalities. Few interviewees mentioned the use of existing services e.g. the REDS team to deliver support to housebound patients. The recent British Thoracic Society guidelines[42] made a recommendation that housebound patients should not routinely be offered PR within their home due to insufficient evidence of benefit. Two non-technological options had been offered by other patient interviewees and they included have a person/specialist based in a GP practice that patients could regularly access for COPD-related queries and deliver sections of the COPD SM programme in Breathe Easy meetings.

Several experts were also either unsure or did not think the SM programme would be feasible or cost-effective to deliver to patients in an individual setting. They too felt provision of SM support via technology was not appropriate owing to patients' lack of skills, lack of interest and insufficient evidence of benefit. Experts stated that identifying the best way to support patients with SM in a non-group setting needed further exploration and evaluation and perhaps it could mean spending more resources in the short term to see long term benefits e.g. professionals would need to be trained in communication and SM skills. The suggestions given to support housebound patients were similar to those given for improving patient participation e.g. there is need to ask about patients' needs and beliefs, build relationships with them, get patients interested and relay the importance of SM, build confidence, and address unrealistic expectations about the programmes. A small number of participants also suggested linking SM services with smoking cessation services to sustain SM; and that integration of SM support into both health and social care services was important. Training in communication and SM support skills for all HCPs involved in COPD care and involving family members to support patients with COPD was suggested. This finding can be supported by studies[24,356,364] that reported the majority of patients with COPD might be able to access improved SM support through delivery by their regular HCPs trained in communication and SM support skills.

8.1.3 Stage 3: Adapting a non-UK developed SM support model for the UK (Chapter VII)

A model of SM support, the 'CENTREd' Model was refined by Dr Helen Cameron-Tucker (H-CT) in Tasmania Australia, from an approach that had been evaluated in three studies by Walters[340,356,357] (a colleague of H-CT). The three studies[340,356,357] had evaluated a patient-centred model that provided health mentor training to practice and community nurses that enabled provision of SM support to patients with COPD by telephone. The refinement and the uniqueness of the 'CENTREd' Model was the addition of the 'SNAPPS' Health-Management framework with a holistic focus on health. The delivery of this SM support model in routine clinical practice by H-CT and colleague was observed. Following training, this model was refined and adapted for the UK (Chapter VII). Specifically, the guidance for the 'SNAPPS' behaviours were replaced with the guidance from the Live Well, NHS Choices website

http://www.nhs.uk/livewell/Pages/Livewellhub.aspx (accessed 27-12-13) following discussion with a UK respiratory nurse consultant (based at St Georges Healthcare NHS Trust and part of the London Respiratory Team), and a COPD action plan developed and designed in the UK[365] and recommended for practical use was added to the training manual.

8.2 Strengths and Limitations of this thesis

8.2.1 Strengths

Patient participation in COPD SM support programmes is problematic and there was limited evidence to help understand the reasoning behind the problem and much less evidence on how it might be improved. Application of the MRC framework, to develop and evaluate complex interventions, in this thesis helped to gain further understanding about the problem of poor participation and how it might be improved. The balance of approaches used in this thesis may have been more towards developing a complex intervention (three reviews – Chapter II, III, IV and a primary qualitative study – Chapter V, VI) and not on evaluation of the intervention though, the approaches used were conducted in-depth and helped to inform the aims and objectives of this thesis.

This doctoral thesis is original as it has shed light into an important but easily neglected topic. The conceptual review (Chapter II) led to the meticulous examination of the meaning of the term patient participation from different perspectives and for the first time the meanings have been subsumed broadly into an individual/patient level and a professional-patient interaction level. In addition, the review through use of health behaviour theories, helped understanding of the different behavioural factors that influence participation in ongoing SM services, the maintenance of SM behaviours, and participation in SM interventions (normally held in outpatients) among patients with chronic disease.

A comprehensive quantitative systematic review (Chapter III) identified a 'true' estimate of study participation and completion rates in studies of COPD SM support by adopting definitions of patient participation. This exposed problems with previous work in the area. The definitions helped to clearly delineate the differences between the terms 'participation' and 'attendance'; 'non-participation' and 'non-attendance' and these distinctions were followed where possible throughout this thesis. In addition, the lack of recording or reporting of participant flow data, including reasons for patient refusal, highlighted the scope for further understanding on the topic and this was achieved by the qualitative study (Chapter V and VI) in this thesis.

Use of the 'best fit' thematic 'framework synthesis (Chapter IV) with application of theory (from Chapter II) as a 'lens' to view patient reasons for participation (attendance, non-attendance, dropout behaviour) in the published studies of COPD SM support, suggested for the first time that the participation behaviour of patients with COPD was influenced by their beliefs or perceptions of their illness and treatment – these findings are novel and go beyond previous reports of socio-demographic or clinical factors.

An original qualitative primary study (Chapter V and VI) was conducted to explore the topic of non-participation and how it might be reduced – a topic which has been suggested as a priority[322] but which has received little research attention in terms of increasing understanding. In addition a health behaviour theory and a social theory (discussed in Chapter II) were used to explain some of the findings that were proposed to influence non-participation in COPD SM support programmes (Chapter V). Furthermore, the suggestions given to improve participation went beyond the improvement of information flows about referrals to programmes among HCPs.

The triangulation of findings around patient participation from these different sources led to a comprehensive, thorough, and considered examination of the research topic with extensive recommendations for improvement grounded in the findings of this thesis and support the research literature.

The identification of a novel model of SM support, the 'CENTREd' Model, and its adaptation to the NHS suggest there is merit in conducting a further evaluation in the future with the possibility of implementation in the UK clinical practice.

8.2.2 Limitations

The initial intention of the systematic review (Chapter III) had been to calculate the participation and completion rates in studies of SM support programmes among patients with asthma and heart failure in addition to COPD however, the limited time to complete the review within the wider doctoral study led to the decision to focus only on COPD. In addition, the review calculated the participation proportions from effectiveness studies of COPD SM support programmes. In addition, while the data extraction included, 'numbers of potential participants identified' and 'numbers assessed for eligibility', the letter (Appendix 3.1) sent to the authors of the included studies to obtain further information on the participant flow data had not included these two outcomes which may have contributed to the incompleteness of the data. However, the likelihood of receiving this additional information

was probably low as only 51% of the authors had responded to the request for more information and not all their responses included the participant flow data requested.

Using a less structured approach to conduct a conceptual review (Chapter II) and lack of regular discussion with experts in the methodological/topic area could have led to omission of some key articles. In addition, the review focused mainly on health behaviour theories to help explain patient participation in SM interventions and little attention was given to social theories to help explain the research topic. Furthermore, the included studies had utilised either older or newer versions of the theoretical models and this might have limited the consistency of the findings to explain patient participation.

In the qualitative synthesis (Chapter IV), the contribution of the six studies was unbalanced as none of the studies had individually explored reasons for attendance, non-attendance and dropout and none of the studies were underpinned by theory. The limited verbatim data in some of the included qualitative studies or the data being outside of the remit of the two theories, prevented the mapping of four subthemes onto the 'best fit' theoretical frameworks. Another limitation was that under the 'best fit' framework approach[302] the health behaviour theories (adapted ASE model, the SRM-NCF) applied in the qualitative synthesis was the earlier/ or original version of the model that were used by Lemaigre[184] and Keib[181] in their study. Both these models have been further developed since the 1980s/90s and include several more theoretical constructs.[13,316]

Exploring the topic of non-participation amongst patient stakeholders (Chapter V) mostly with good previous attendance in a SM support programme and with professionals (Chapter VI), instead of with patients who had refused to participate in the programme might limit the transferability of the findings to non-participants in a study of a SM intervention or the intervention itself. In addition, several expert interviewees felt that there was still a lot to learn about the topic of how participation might be improved, or how patients with COPD might be supported to access SM support other than in a group-based setting and voiced the need for further evaluation. Due to the limited evidence on these topics in COPD, efforts should be made to evaluate the suggestions given to improve patient participation in this thesis to build the evidence base.

8.3 Results in context of other studies

Comparison with other literature about patient participation (attendance, non-attendance, dropout) behaviour

Only one other study[366] was identified that applied the MRC framework. This study aimed to improve the low attendance rates reported in studies of cardiac rehabilitation (CR) programmes among coronary heart disease patients (where fewer than 35% of eligible patients take part). Mosleh[367] developed and piloted a theoretically worded patient letter (based on the Self-Regulation (SRM) and the Theory of Planned Behaviour (TPB)) among patients approached in hospital wards. The letter was targeted in response to patient behaviour i.e. patients failing to attend after invitation, and patients' negative illness beliefs. Sixty eight per cent of patients (n=375) were recruited into the study. The study findings demonstrated that the letter significantly increased patient attendance to 84%, in comparison to 74% in a control group receiving a standard letter (odds ratio 2.93, 95% CI 1.56-5.56). The number needed to treat was 9 (95% CI 7-12). The attendance rate was acknowledged as being higher than usual for CR. On assessing the patients' illness perceptions, among the programme attenders, a patient's increased perceived 'identity' (attributing symptoms to the illness) was also significantly associated with attendance. The latter has been reported previously to influence CR attendance among hospitalised patients.[177]

In addition to Mosleh's study, several studies[173,174,177,179,180] have utilised the SRM and the SRM-NCF (Necessity-Concerns Framework) to predict/explain attendance and non-attendance in cardiac rehabilitation among coronary heart disease patients (Chapter II). This thesis, on application of the SRM and the SRM-NCF behaviour change theories in the qualitative synthesis (Chapter IV), consistent with the findings of studies of cardiac rehabilitation in the conceptual review (Chapter II), identified that particular COPD illness perceptions ('perceived controllability', 'perceived consequences', 'perceived identity') and treatment perceptions including 'perceived necessity or concerns' were associated with the full range of participation behaviour (attendance, non-attendance and dropout behaviour) in COPD SM support programmes. And On application of the adapted Attitude-Social influence-External barriers (ASE) model, again in line with Lemaigre's study,[184] participation behaviour was shown to be influenced by a patient's 'attitude' and perceived 'social influences'. As a result, assessment of beliefs/perceptions about the illness and intervention among patients with COPD could prove helpful when predicting attendance at SM support programmes.

However, the time of assessment of patient perceptions in their illness journey may also be important in predicting attendance in SM support interventions. This thesis (in Chapter II)

identified that while illness perceptions predicted attendance in outpatient cardiac rehabilitation programmes offered to patients in hospital or following hospital discharge,[174,177,182] patient perceptions did not predict attendance in maintenance programmes;[170] Sniehotta[170] suggested one explanation for the latter was that patient perceptions may change over time. A recent study[368] also found that patients with coronary heart disease who had been invited to participate in the EPP, a year after their cardiovascular event, refused to participate - perhaps because they were in better physical condition (or perceived fewer 'consequences' from their illness). However, this may not be the same for patients with COPD due to the progressive and deteriorating nature of their condition and regular assessment of perceptions of patients with COPD has been suggested by other studies. [318,319] This thesis further proposes targeting the negative patient perceptions (as they are amenable to change)[13] with a view to improving patient participation. Therefore adaptation of the existing illness and intervention questionnaire[13,180] for COPD might be useful.

In this thesis, exploration of patient stakeholders' reasons for attendance and drop out at SM support programmes (Chapter V) were consistent with reasons reported in previously published qualitative studies[122,304,305,309] (Chapter IV). A novel reason given by one participant for attending the SM programme was to remind oneself of skills they had learned in PR over a year ago and forgotten over time. A recent study reported that COPD patients with a diagnosis of more than five years are at an increased risk of mild cognitive decline[369] and so would benefit from having more regular follow up with regard to their management.[370]

Regarding dropout behaviour, another new reason proposed by a few patient interviewees was poor communication and facilitation skills in those leading the groups. Although having good programme facilitation has been cited previously as important for SM programme *engagement and adherence* by patients with chronic disease.[371] While, a new reason proposed for drop-out from PR in this thesis was staff being too busy to give sufficient individual attention to participants. These participants, according to expert interviewees, could be those who lacked understanding about what the programme entails or might not be ready to self-manage or could not perceive any benefits. Hence, these patients might benefit particularly from individual attention, at least initially, as staff supervision and support has previously been reported as a reason for patient adherence and completion of PR.[305] Another drop-out reason cited in the study (Chapter V and VI) in this thesis was inappropriate PR venues, a

previous study[115] has reported transport difficulties and longer travel time to get to the programme as reasons for PR non-completion.

The new suggestions identified in this thesis mentioned above could also be explained by the SRM, SRM-NCF and the adapted ASE model. The behavioural constructs of the SRM and the TPB (particularly the attitude and subjective norm constructs of the TPB) that were used by Mosleh to create the letter that improved attendance in CR[367] helped to explain both attendance and dropout behaviour among COPD patients in this thesis (Chapter IV). As a result, there may be scope to target the letter (following refinements) to improve patient retention in SM support programmes. For patients with COPD, Mosleh's letter[367] may also need to incorporate the SRM in relation to 'intervention representations' e.g. lack of perceived benefits and the SRM-NCF 'perceived necessity' and 'perceived concerns' constructs e.g. prior commitments or lack of transport because these constructs influenced the attendance and dropout behaviour of COPD patients in this thesis. Physical/practical barriers are recognised problems of attendance among patients with chronic disease including COPD in SM interventions.[220,311] These barriers were included among the reasons that had been suggested in this thesis for non-participation in SM support programmes. Understanding barriers to participation and how it might be improved was also a focus of this thesis and is discussed next.

Comparison with other literature about patient non-participation

Mosleh[367] had a high study participation rate (68%). The participants were approached about the study in hospital wards by nurses/physiotherapists and interested participants were provided with written and oral study information by the research team. This approach is likely to have contributed to the high participation rate; telephone or face-to-face as recruitment has been reported previously to improve participation in behaviour change interventions.[372,373] In comparison, the systematic review in this thesis also found high study participation rates in studies of SM support programmes and in over 40% of the studies (where reported) the mode of invitation had been verbal/face-to-face. However, this may differ in routine care on the ground. Patients with COPD are normally referred to PR by professionals based in secondary or primary care via a letter with, or without, prior discussion when their condition is stable[116] or immediately after hospital discharge following an acute exacerbation.[317] On receiving the letter patients with COPD are requested to ring up for an

appointment to attend PR assessment but many do not even make an assessment appointment[113] and (Timi Ogunlowo. Lead Respiratory Physiotherapist. Personal communication 2013). The requirement to ring up for an assessment was cited in the qualitative study in this thesis as a factor that might predispose to non-participation in a SM support programme.

Mosleh's[367] theoretically constructed invitation letter could be used to recruit patients in COPD SM support programmes and for some individuals the letter (without any prior discussion) may be enough to address negative beliefs, reassure and motivate them to consider participation. However for some the letter on its own may not be enough to boost participation.

One explanation for potential differences in response between patients with coronary heart disease and those with COPD is the socio-demographic differences between patients with these two conditions, for example, in Mosleh's study,[367] the mean age of the study participants was 62.5 years; 69% were male; 72% had suffered a myocardial infarction and only 10% lived in the most deprived areas. The CR programme attenders were younger, employed and less likely to have hypertension. In comparison, COPD tends to be a disease of the elderly[374] with low socio-economic status[375] and widely reported to have poor literacy and health literacy.[376] Secondly, the patient non-participation reasons in COPD SM support programmes cited by both patient and expert stakeholders in this thesis suggest that these individuals might benefit more from interaction and discussion with a HCP rather than receiving a (theoretically constructed) letter. Key patient-related reasons for non-participation identified in this thesis included: patient not ready to help themselves, self-manage or change behaviour; in denial of their illness or just resigned to living with the illness; reluctance to try anything different to usual care or feel entitled to be a burden; prolonged inactivity due to the nature of the condition and hence reluctance to try anything new; negative illness beliefs, including negative emotional reactions, result in loss of motivation to do anything particularly any physical activity and loss of confidence to venture out alone to a programme considered new/strange; negative treatment beliefs or lacked understanding about COPD and its treatments – all of which may not be easily addressed by a letter alone.

Before discussing how non-participation could be addressed it was useful to compare the above non-participation findings with patient reasons cited for non-participation in previous

studies of SM support programmes. Sanders[338] explored barriers to participation in a study of tele-health services among patients with chronic disease including COPD. Non-participation reasons included many patients being uncomfortable, or not knowing how, to use the technology and the finding that some would have preferred to speak to someone in person supports the findings of this thesis. Bower[377] explored refusal to participate in a study of the EPP, the reasons given comprised of: not wanting to receive the intervention; having received it previously; and the intervention being unsuitable or inconvenient. Reasons for refusing to participate in a study of PR[114] included lack of perceived benefits of exercise, and physical and practical barriers. In addition, two studies[224,377] also explored reasons for participation in studies of SM support programmes and altruism was the dominant theme in both studies. The latter has been reported as a major reason why people take part in research.[378] Willis[224] explained that some patients with COPD participated in the study of SM support because although they believed they could not make their own life better they wanted to help others. Hence, the same author suggested that potential participants should be encouraged to believe that participation would be not only of direct benefit to them but also future generations. Discussion about the benefits of SM support programmes was suggested in this thesis to help improve participation or address non-participation in SM support programmes. Some studies have suggested that patient recruitment for SM interventions may benefit if recruitment is conducted face-to-face in routine consultations by HCPs.[85,368]

Comparison with other literature about improving patient participation

In this thesis the findings around improving participation include suggestions on what could be done *now* to boost patient participation. To avoid duplication, these practical suggestions are compared with other relevant literature, and denoted by an arrow symbol, in this section rather than being discussed in the implications section of this chapter (section 8.5).

Both patient and professional participants in this study suggested methods or processes to help improve patient participation aimed at HCPs. These involved: identification of the right patients e.g. through use of the PAM or at the right time e.g. at diagnosis; building relationships with eligible patients, identifying what they value and exploring whether they are ready for SM or ready to participate in SM support programmes in their illness journey; carrying out 'pre-work' among patients not yet ready e.g. supporting patients to accept their condition, providing information about their illness; building confidence, motivating and

encouraging participation in programmes by discussion of programme benefits e.g. via professionals, peers, home visits, DVD, or by invitation to a trial session.

→ In a recent report[195] assessing the activation level of patients via the PAM measure it has been suggested that this measure helps identify patients who might or might not be receptive to SM, or even to shared decision-making.[195] The PAM score could then be used to provide individualised and appropriate support[195], for example, a patient with a low activation score (less than level 2, see page 93) may not want to/may not be ready to participate in a SM support programme - in this case the health professional may have to work with the patient one-to-one on an issue important to the patient and provide support and follow up until goal achievement before moving to the next step.

According to a recent study[152] 'SM is a process of continuing learning within the life context of a patient living with chronic disease'.

→ This might require all HCPs to support patients holistically to address how patients live and reduce limitations as a result of living with the chronic condition.[152]

One study[214] reported that patients with chronic disease are most keen to learn about their condition and its management, and are receptive to SM education soon after diagnosis. Similarly, in COPD, it has been suggested[30] that patients may be more receptive to 'teachable moments' and accept SM education, PR and smoking cessation strategies soon after suffering an acute exacerbation. In the qualitative study in this thesis one recently diagnosed patient was very keen to participate in a COPD SM programme despite having completed PR previously and would have liked to receive the SM programme soon after diagnosis. This eagerness/interest to learn about the condition and management soon after diagnosis has been explained by patients becoming overwhelmed by the many changes that they be asked to make soon after diagnosis.[214] Another study[53] has proposed three patient characteristics which make them suitable for referral to SM programmes: low health-related quality of life, active engagement in life (e.g. plans to do enjoyable things) and low self-efficacy, as an improvement in health-related quality of life and self-efficacy were seen among these patients following completion of the programme.[53] However the same author acknowledged that people who are disempowered, have worse health and fewer resources were more likely be less engaged and not referring these patients could increase health or social inequalities.

→ This suggests that perhaps more efforts might need to be made with less engaged patients prior to programme attendance through building relationships.

Building relationships with patients,[350] concentrating on the individual concerns of patients with COPD,[351] and being responsive to patient-family needs[352] have so far been suggested in studies to engage patients in self-management per se, but have not previously been proposed for promoting engagement in SM *interventions*. However, one aspect of patient self-management may include making the decision to participate in SM interventions.[198]

To improve participation, patients' concerns or needs might need to be addressed which could take the form of professionals' 'pre-work':
→ prioritising discussion of COPD and its treatment with patients[379] prior to patient referral,[379] or when considering patient referral, during consultation with the patient;
→ supporting patients to accept their condition which may involve helping patients to understand their limitations or losses as a result of their condition and adjusting their expectations of what is realistic and achievable;[380] and/or
→ motivating and building confidence which might involve using a holistic approach to identify what is important to patients, helping them set realistic/specific goals using goal-setting skills and developing action plans by using action planning and problem solving skills to achieve the set goals (premise of the 'CENTREd' Model, Chapter VII).

Motivating patients to encourage participation with pamphlets or during home visits has been suggested to improve participation in CR[220] and the use of lay health workers to support patients following patient referral has been suggested for PR[100] while in this thesis,
→ the opportunity to bring a friend, family member, informal or formal carer to at least the first session of the programme was also suggested as an avenue to encourage participation. The latter might be particularly helpful to patients who are fearful, nervous, lack confidence to leave the house on their own, or might be uncomfortable to go into a new environment and meet strangers.[122]

Actions which might be useful to conduct prior to, or during patient referral to improve patient participation are discussed above, however it remains necessary for HCPs to:

$\rightarrow$ consider referring eligible people to COPD SM support programmes in the first place.

Lack of referral to SM interventions has been identified as a problem in the literature[367] and was also cited as one of the health system factors influencing patient participation in this thesis. Factors that could affect patient referral identified in this thesis were:

(1) lack of enthusiasm/support for SM among HCPs including lack of integration of SM into the COPD patient care pathway;

(2) lack of understanding about the role of SM and programmes e.g. due to insufficient evidence for SM in COPD;

(3) lack of communication between professionals in primary and secondary care and between programme staff and professionals; and

(4) organisational/administrative problems.

Some of these findings are consistent with findings from other studies[116,218] that explored the barriers to PR referral among primary care professionals. In summary, the barriers identified by these other studies were: limited knowledge of PR; lack of understanding about how promotion of exercise can be beneficial or the importance of PR for COPD management; and lack of enthusiasm while informing patients about PR.[116,218,362] Compared to PR, the usefulness or importance of SM programmes for COPD has been given little regard, or even rejected, in primary care.[368] In particular, reports of inconclusive evidence of benefit for COPD SM programmes,[84] reported by several expert interviewees in this study, and a study suggesting harm[50] based on negative findings of two studies[105,381] presumed to be of SM programmes (but in actuality disease management interventions[51]) could have created further disinterest among primary care professionals. Furthermore, some experts in this thesis (Chapter VI) cited that programme staff find it difficult to discuss the benefits of SM support programmes with patients over the telephone which could also lead to patient non-participation.

$\rightarrow$ To increase patient referrals to SM support programmes, particularly from primary care this thesis suggested utilising professionals interested in and enthusiastic about SM; pitching the programme at the appropriate patient level and assessing patients, and trying to address any practical and logistical difficulties that might impact attendance. Other suggestions included: provision of information about the

programme benefits to professionals and training for professionals to improve referrals; SM needs to be integrated into the patient care pathway; and evidence of benefit for SM in COPD needs to be promoted. Previous studies[116,218] have proposed improving information flow about referrals and services and a recent Australian study suggested making PR part of standard care through financial incentives to enhance PR referrals.[218]

PR has been reported to be one of the least implemented guideline recommendations for COPD management in primary care.[382] In the UK, PR is considered a mainstay treatment for patients with COPD in health policy guidelines[42,43] and research studies[100] but it is principally recognised as standard care for patients with COPD by secondary care professionals rather than by primary care professionals.[30,218,311] The Quality and Outcomes Framework (QOF) includes a COPD indicator that records *"The percentage of patients with COPD with a record of FEV$_1$ in the previous 15 months (COPD 10)"*, to help GPs identify potential patients who could benefit from PR. There was a plan in 2013/2014 to have a new indictor for direct recording of percentage of PR referrals by primary care; however, this plan has now been deferred for another year http://www.nhsemployers.org/your-workforce/primary-care-contacts/general-medical-services/quality-and-outcomes-framework/changes-to-qof-201415 (accessed 13-5-14). This could further impact patient participation in PR with already poor patient referral to PR observed in primary care (Stephanie Taylor, Personal Communication, 2014).

→ Instead, perhaps the following support among professionals could help to address some of the referral problems cited above: education to create awareness about the importance of SM in COPD;[85] promote the recent evidence of benefit for SM in COPD;[359] reiterate the positive evidence of PR to help professionals become aware of its benefits[218]; recognise the importance of PR in COPD;[30] and stress that patients who do participate in SM support programmes do attend and complete these programmes.[361]

→ One study participant also cited that professionals need to 'believe' in the benefits of SM support programmes so they can positively influence patients to participate in the programmes which could help to improve patient participation. This may be achieved if professional peers or local commissioners championed the benefits of SM in COPD through discussion, education and perhaps even drafting suitable local

policies. Using local commissioners to stress PR referrals in primary care has been suggested previously.[100]

→ It is important to note that stressing the benefits of programmes to improve patient referrals may be futile if HCPs remain unaware of service provision.[341] A survey[341] examined the extent of PR programmes across the UK and revealed that about 58% of acute units had access to PR for eligible patients. The units lacked access due to several funding and organisational issues (e.g. no funding, unit not being aware of a PR service, programmes not running due to lack of staff, PR not available for all postcodes, patients get PR if referred from hospital but not from GP). If all professionals involved in patient referral could be provided with a list of all locally-based SM support programmes, and if they are made aware of any changes to availability (e.g. services closing down) this could help to improve the information flow about referrals and services for both primary and secondary care. In addition, involving the referring health professional in the programme may increase understanding about patient eligibility and lead to confidence in wider referral to the programme[85,220] and could also help to improve communication between programme staff and HCPs as the latter was identified as a barrier to participation in this thesis.

→ Moreover, that the venue of SM support programmes needs to be local to the patient cannot be emphasised enough. The cost of transport was cited as a concern by some of the patient interviewees. The burdensome journey to PR previously reported[100,114] was also identified in this thesis (Chapter V and VI).

→ Wider awareness of COPD SM support programmes among the general public was also suggested by several patient interviewees so that more people with COPD could consider seeking help and possibly participate in these programmes. The interviewees proposed for example, putting posters in hospitals and GP surgeries, using a health website, TV and also involving people in places that patients with COPD normally frequent and trust such as, GP surgeries, hospital, day centres and pharmacies. To date, the lack of awareness about COPD and PR programmes has only been reported by professionals[116,218] as a barrier to communication about the benefits of the programmes. Johnston[218] suggested media e.g. YouTube to promote awareness of COPD and PR. A recent editorial[374] also suggested directing patients to the British Lung Foundation website to find out more about PR.

→ The qualitative section of this thesis also recommends several components to help improve patient attendance and retention to the existing COPD SM programmes as (section 8.1.2; Chapter V, Chapter VI) additions to previously proposed suggestions.[122]

Comparison with other literature about supporting patients with their SM other than in a group-based setting

Despite all efforts to improve participation, both expert and patient interviewees acknowledged that some patients with COPD might still not want to participate in group-based programmes. Both patients and experts felt it was important to support housebound patients at home however, delivery of the SM programme at an individual level either through technology e.g. internet, DVD, telehealth, video or face-to-face was not the answer according to most interviewees because it would be costly to the NHS and hence would not be sustainable.

In comparison, Beswick[220] reported that home-based programmes should only be aimed at patients who are motivated and unable to access group-based programmes; these programmes should not be a substitute for patients with low motivation or who lack interest. Hopkinson[374] advised caution in relying too much on internet-based strategies as these may exclude many patients with COPD due to lack of use/access. Jaglal,[383] on evaluation of a tele-chronic disease SM programme among patients in rural and remote communities, found improvements in self-efficacy, health behaviours and health status similar to the traditional group-based programme and thus advocated this approach for patients unable to access group-based programmes. Fairbrother[384] suggested that professionals saw SM only as patient compliance in the context of telemonitoring and the study called this 'compliant self-management'. Dinesen's study [385] of tele-rehabilitation among patients with advanced COPD identified that although patients had initially committed to learn about the new technology and perform exercises at home, the performance of exercises varied as a result of the physical and emotional limitations felt daily due to changes in their illness As a result, Dinesen suggested that these patients would benefit from regular assessment to help identify the right intervention or support and also who will most benefit from tele-rehabilitation. Perhaps patients with advanced COPD might benefit from, or would be more suited to, receiving one-to-one support.

→ Both patients (from their positive experience of SM support programmes) and professional interviewees in this thesis suggested that a better use of resources might be to support housebound patients individually initially so appropriate support could be provided, or until they felt comfortable or ready to self-manage and, that at this point they might even consider participation in group-based SM support programmes.

This view of working with patients individually to improve participation has been discussed in the earlier section and could be applied to housebound patients as well. Some experts in this thesis further suggested that, instead of offering a one-off group-based programme to support patients with their SM (also reported elsewhere,[85,386]):

→ SM needs to be integrated into the existing health and social care services to *"make every contact count"*. Others felt that integration of SM into existing services might be a slow and gradual process, and costly in the first instance, as this would require professionals to work with patients more intensely, in particular with those who might be anxious, disinterested or not ready, recently diagnosed or housebound.

In addition, a few experts mentioned that provision of training in patient engagement, communication, and SM support for all professionals who care for patients' with COPD would be a sustainable option in the long-term.

Currently, the provision of SM support for patients with COPD other than in a group-setting is aimed at or is the responsibility of nurses within chronic disease management.[16,152,387]

→ However, the role of facilitating SM and being supportive[152] can be difficult for nurses without appropriate training.[387,388]

Very limited evidence exists on interventions at the level of HCP[220,367] to improve patient participation in SM interventions. Mosleh[367] identified health system factors to affect participation in CR however, they chose to improve patient attendance by placing focus on patient-related factors and devised a simple and inexpensive intervention (theoretically-constructed letter). Based on the findings of this thesis, the letter would have not have been sufficient to improve patient participation in COPD SM support programmes. In contrast this thesis suggests intervening at the level of HCPs particularly by exploring the acceptability and feasibility of the 'CENTREd' Model of SM support among both UK respiratory nurses and patients with COPD. Reasons being, the evaluation of the 'CENTREd' approach in study by Walters[356] showed that primary care professionals recognised that the model was about involving patients in decision-making, identifying patient agenda through effective

communication and prioritising patient choice and this approach of partnership working and supporting patients with COPD is a key suggestion given in this thesis to improve patient participation in COPD SM support programmes. However, recognising the importance of partnership working might not be enough for its routine implementation because this thesis also identified several health system factors e.g. the lack of integration of SM into the COPD patient care pathway that would need to be addressed, also reported elsewhere,[389] to facilitate the partnership style of working, to help improve participation in SM support programmes. This might require:

→ creating a wider, general awareness of principles of chronic disease management[390] that includes SM support among different levels of the health system.

→ The practice culture may also need to recognise that change takes time[391] for example, allowances need to be made initially for the new style of working between patient and professional or until the delivery of SM support becomes routine.

8.4 Overall conclusions

Poor participation and retention rates in PR programmes have been well documented in the literature however, this doctoral study arose as a result of poor study participation rates in a study of COPD-specific SM programme. Thus, understanding the problem of participation in COPD SM support programmes with a view to improving participation in these programmes and identifying other suitable ways patients with COPD could access SM support was the focus of this thesis. Key findings from each chapter have been drawn together to produce an explanatory model of barriers to participation and how it might be improved (Figure 8.1).

In conclusion, non-participation and other related aspects of participation (attendance, non-attendance and dropout behaviour) in COPD SM support programmes could be influenced by:

- socio-behavioural patient factors e.g. resignation to illness, negative illness beliefs which may change over time due to changes within the illness journey of a patient;
- organisational issues e.g. provision of insufficient information about the programme, poor facilitator skills, an inaccessible location; and
- health system factors e.g. lack of support from primary care/lack of integration of SM in to the patient care pathway, lack of understanding about the role of SM/programmes among professionals

Patient participation in COPD SM support programmes could be improved by addressing the patient socio-behavioural factors through carrying out improvements in the health system and the programme organisation. Addressing health system factors would help patients to participate in their care (become 'activated' or 'engaged') which could include making a decision to participate in a SM support programme.

Specifically, at the level of the patient-professional interaction this would involve:

- identifying the right/eligible patients for the programmes;

- building relationships with patients to identify what they value or need and to assess if they might be ready to participate in their care including participation in a SM support programme or another type of intervention;

- carrying out 'pre-work', among patients who might not be ready to self-manage or participate in the programme, to help them get ready to participate in their care and in a SM support programme. Here the 'pre-work' could involve supporting patients to accept their illness, providing more information about the illness, encouraging participation by motivation, building patient confidence and discussing the benefits of SM and the programme. This stage would also be useful for patients who cannot or do not want to access SM support in a group-setting.

- making appropriate referrals to the programme which could involve pitching information about the programme at the right patient level, addressing any unrealistic expectations about the programme and assessing and addressing any practical or logistical difficulties. Referrals would likely improve if they were made by professionals who were aware of the benefits of SM and the programmes for their patients.

To facilitate the above patient-professional interaction wider health system improvements would need to made such as:

- provision of training to change the practice style of professionals to include communication and SM support skills (through the 'CENTREd' Model) to help with patient engagement, negotiation and carrying out 'pre-work' in accordance with patients' needs. Plus provision of follow up support for trained professionals to enable the implementation of the learnt skills in routine care with confidence;

- better communication to HCPs about the availability of the programmes and the referral process involved;

- better communication between various professionals at different levels of the health system including with programme staff; and

- wider promotion of SM support programmes and their benefits among HCPs and integration of SM into the patient care pathway

- wider awareness of COPD among the general public including the medical profession

Figure 8.1 Explanatory model of barriers to patient participation and how it might be improved

Key: Barrier to participation | Facilitator to participation

Record and report the participant flow data to calculate participation and completion rates

Wide health system improvements PLUS Wider awareness of COPD among the public and professionals

Facilitation of a partnership/patient-centred approach with inclusion of SM support

At the level of patient-professional interaction

To improve patient participation

Provision of training and ongoing support for professionals to facilitate partnership approach

Integration of SM into the COPD patient care pathway

Promotion of SM and their benefits for patients with COPD

Better communication between professionals including programme staff

Wider awareness of COPD

Identify the right/eligible patients e.g. at diagnosis

Build relationships to identify patients' values, wants and needs and if they are ready to participate in SM and programmes

Carry out 'pre-work' to support patients with their SM **so patients consider participation in care** including in the SM support programme

Professionals enthusiastic about SM to refer patients

Pitch patient invitation at the right level of patient, assess and address programme expectations, practical/logistical difficulties, and offer patient to bring a family member or carer to the programme

Best way to support patients with their SM other than in a group setting through use of trained staff

Participation (attendance, non-attendance, dropout) can be influenced by patients':
- attitude and social influence
- illness and intervention perceptions

- Programme organisational factors e.g. inadequate facilitation skills insufficient support

Illustration of patient participation definitions

Non-attenders

Study dropouts

STUDY

Intervention dropouts

Eligible patients

Study participants

Attenders

Intervention completers

Study completers

INTERVENTION

Study non-participants

Can result in patient participating in their care

Non-participation could be influenced by patients':
- resignation of illness and in denial of illness;
- negative illness and treatment beliefs including negative emotional reactions
- health system factors
- programme organisational issues

Programme organisational improvements e.g. structure, content, trained staff

But patients' beliefs or perceptions may change over time due to changes in the illness journey

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8.5 Implications for clinicians and policymakers

8.5.1 Implications for clinicians

Understanding the reasoning behind the participation and non-participation behaviour of patients with COPD in SM support programmes has important clinical implications. In addition, this thesis provides HCPs with insights into the process that is needed to support patients with COPD to improve their participation behaviour. This process has been discussed at length in section 8.3 (denoted by the arrow symbol).

Based on these findings, to improve participation, patients with COPD need to be supported in coming to terms with their illness, they need to understand that their condition can be controlled and managed and that they can still achieve things important to them. They need to understand the importance of and the benefits of SM support programmes for the management of their condition. Alongside, practical/logistical difficulties related to attendance need to be addressed where possible.

To achieve this, clinicians should promote patient-centred care or encourage patients with COPD to participate in their care by showing commitment and engaging patients (through use of communication/motivational interviewing techniques and listening skills) and identifying what patients' value, want or need to better manage their condition and overall health and assess if they might be ready to manage their condition or to participate in a SM support programme (the patient activation measure could be used to assess if patients might be ready to self-manage). Health care professionals should relate patients' wants and needs to target key health or SM behaviours and discuss with them where they are with these behaviours and what if any they would like to address or build upon.

If a patient is ready to participate in the SM support programme, information about the programme should be pitched at the right level of the patient and assess and address, where possible, practical or logistical difficulties (e.g. if anxious reassure and make patient feel comfortable, allow them to bring a family member, friend or carer to at least the first session of the programme) and make appropriate referrals. If a patient is *not* ready to self-manage or to participate in a SM programme, identify the reasons, address the negative beliefs towards the illness and the programme, negotiate and support the patient (through use of motivational techniques and SM support skills) with their SM by linking to things that is important to the patient and that they would like to and realistically could achieve. This should be followed

until the patient feels ready to participate in the SM support programme and make appropriate referrals.

In addition, clinicians should recognise that patients' perceptions of their illness including treatments may change over time owing to the progressive nature of their condition and its impact which might affect day-to-day management. As a result, these patients might benefit from regular assessment so the appropriate support can be provided which may include referral to a SM support programme or another intervention.

To enable HCPs to provide patient-centred care including SM support, provision of training, ongoing supervision and support should be made available. To ensure smooth patient referrals to SM support programmes there needs to be wider promotion of benefits of SM and SM support programmes, integration of SM into the patient care pathway and better communication between clinicians working at different levels of the health system including programme staff.

Lastly, the SM support programme would need to be available and accessible to patients with COPD and be delivered by trained staff.

Regarding improvement of participation rates in clinical services – for example, a study[113] that evaluated the effectiveness of a clinical PR service, 27% of eligible patients failed to attend (declined/did not attend) a PR assessment, nearly half (47%) of patients assessed for PR did not attend PR and 60% of those referred failed to complete the treatment. Clinical and socio-demographics factors could only explain a small proportion of the variance in attendance and completion. The study highlighted the need to gain patients' perspective and explore how patients were prepared for PR.

Based on the findings of this thesis, understanding the reasons why eligible patients might decline or not attend a PR assessment and then addressing those reasons through professional innovations and indeed the wider health system making changes towards a patient-centred care approach with inclusion of SM support could begin to make a difference in the participation and completion rates of the PR service. However, this can only be assessed in a future evaluation.

8.5.2 Implications for policy makers

Policy makers may be encouraged that HCPs have begun to recognise the importance of patient-centred care and provision of SM support for patients with COPD. However, policy makers need to be aware that without health system improvements suggested in this study the routine implementation of patient-centred care including SM support may remain the exception rather than the rule[348] Supporting professionals to support patients is essential as this study has shown that patient participation in their care can be influenced by a variety of patient, professional and health system factors.

While the recent BTS guidelines[42] for PR have recommended clinical PR services to calculate patient uptake, adherence and completion rates, the guidelines could further recommend adoption of patient participation definitions to help calculation of the participation rates. The clinical services could either adopt their own definitions or the ones used in this thesis.

The adoption of rigorous definitions and application of quantitative methods helped to identify high study participation and completion rates in studies of SM support in this thesis – this encouraging finding should be helpful in continuing the commissioning of SM support programmes for COPD patients.[361]

Commissioners involved in setting up local polices could help improve patient referral to COPD SM support programmes by altering health professional beliefs towards SM, stress the importance of SM and SM support programmes for their patients through education and clinical guidance; setting up decision and reminder prompts to refer eligible patients; and motivating professionals through evaluative feedback and comparing individual GP practice performance relative to peers also based locally. This approach was proved successful for increasing appropriate prescribing and reducing inappropriate prescribing among GPs in a recent study.[392] Financial incentives could also be used to support and improve patient referrals.[392]

8.6 Future research recommendations

Future research studies should provide clear and rigorous definitions when reporting patient participation, enabling a 'true' estimate of patient 'participation rates' and avoiding confusion amongst readers. To calculate 'participation rates', it is important for research studies of SM support programmes to record and report detailed participant flow data. It is essential for studies to report these data to help HCPs interpret the study results and to decide if the results

could be applied to their patients.[285,286] A recent study[393] has also recommended research studies have an *a priori* definition of a programme completer with explanation for the number of sessions chosen as a pre-determined dose to help clinical services that might be developing or delivering exercise-based programmes for patients with COPD.

Studies, until now, have only used psychological/behavioural theories to understand participation behaviour in SM interventions however, as participation can be also be affected by a person's external environment[167] future research should include exploring and understanding this behaviour from a societal or sociological perspective[204,213] to help improve this behaviour.

In COPD, application of health behaviour theories in this thesis was useful to understand participation behaviour and hence, assessment of patient perceptions towards their illness and treatment may help to predict attendance in COPD SM support programmes;[110] in addition, the negative perceptions identified would need to be understood and acknowledged by HCPs and could be targeted by behaviour change interventions,[177,180,318] and the practical aspects related to attendance could be considered in the design of the programmes.[320] This thesis proposes adaptation of the illness[13] and the intervention perception questionnaire, targeted at patients with coronary heart disease,[180] for COPD. This thesis has made a start towards the development of an intervention (namely, for the PR programme) perception questionnaire. Using the Necessity-Concerns Framework as a conceptual guide, the findings of the qualitative approach in this thesis (from Chapter IV, V and VI) helped to generate a list of draft statements (Appendix 8.1). These statements have undergone face validity assessment among experts (three clinicians, ST (principal study supervisor), PW and RF; and three health psychologists, AC, EE and LS). The responses from experts were generally positive and that the questionnaire largely had face validity. In a future study, efforts will be made to continue the development of the draft questionnaire by following the recommendations suggested by Streiner and Norman[394] for developing a screening instrument and piloting it among patients with COPD.

Additionally, this thesis proposes an evaluation of the feasibility and acceptability of the 'CENTREd' Model of SM support among patients with COPD and UK respiratory nurse specialists working in the field of COPD management. Rationale being, respiratory nurses have insufficient knowledge of evidence-based strategies to help promote SM among patients with COPD and mostly owing to lack of training in specific communication techniques;[395] the nurses would benefit from training and education to manage patients with respiratory

disease;[396] and training for professionals in communication and SM support skills was identified as one strategy to better support patients with their self-management which in turn could help to improve participation in SM support programmes. The aims of the feasibility study will assess:

1) the acceptability of the training in the 'CENTREd' Model among health professionals

2) the feasibility of delivery of the newly learnt skills among patients with COPD in routine practice by the trained professionals

3) the acceptability to patients with COPD of receiving SM support in routine practice and the potential to adopt SM health-related behaviours including participation in SM support interventions

The research objectives will comprise:

1) Identification, recruitment and training of health professionals in the 'CENTREd' Model and the assessment of acceptability and feasibility of the training.

2) Assessment of the trained professionals' adoption of the 'CENTREd' Steps, Skills and Tools and their implementation in routine practice among patients with COPD over a study period of 4 months.

3) Among patients with COPD, assessment of the acceptability of receiving SM support in routine practice and their potential in the context of this support to improve or maintain lifestyle/health-related behaviours including participation in SM support interventions.

The proposed methodology will include a before-after study design with qualitative methodology (through video recording of clinical consultations and post-consultation interviews). This methodology can be supported by a similar methodology that was proposed in a recent study[397] within a wider pragmatic cluster RCT design whereby the implementation of a complex intervention (focus on osteoarthritis consultation between patient and nurse) was to be documented through interviews and observation (unspecified how) of clinics and feedback meetings.

Lastly, researchers need to recognise that reasons for participation in a SM intervention might be different to a study of a SM intervention. Chapter II and Chapter IV helped to understand patient participation behaviour in studies of SM interventions and Chapter V and VI helped to understand participation and non-participation behaviour in SM support interventions. So,

patient participation in the proposed feasibility study or another study of SM support might improve by: keeping the patient reasons in mind when developing the study eligibility criteria; inviting and informing eligible patients about the study using a one-to-one or personalised approach preferably by health professionals and passing details of the interested patients to the study researcher; the study researcher ensuring that the interested eligible patients have understood the purpose of the study and the intervention, assessing patient expectations, practical or physical barriers related to participation and addressing where possible any unrealistic expectations, practical or physical barriers. It might also be useful to assess if the eligible patients are ready or capable of self-management. Finally, the study should record and report reasons for study non-participation, intervention non-attendance non-completion and study non-completion.

Appendices

The appendices from every chapter have been saved in a CD enclosed with this thesis.

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